



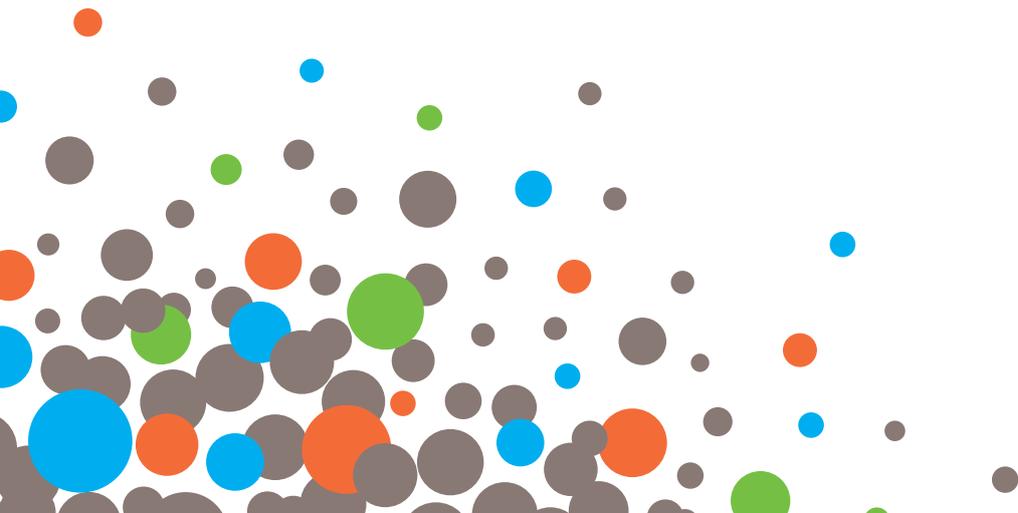
The National Centre of Excellence  
in Youth Mental Health

## Nip it in the bud

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Intervening early for young people with eating disorders

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# Our Partner

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This paper was led by Orygen, The National Centre of Excellence in Youth Mental Health in partnership with the Butterfly Foundation which represents all people affected by eating disorders and negative body image. Butterfly is committed to collaboration across the eating disorders sector and co-ordinates the National Eating Disorders Collaboration (NEDC) for the Australian Government Department of Health.



**Butterfly**  
Foundation for Eating Disorders

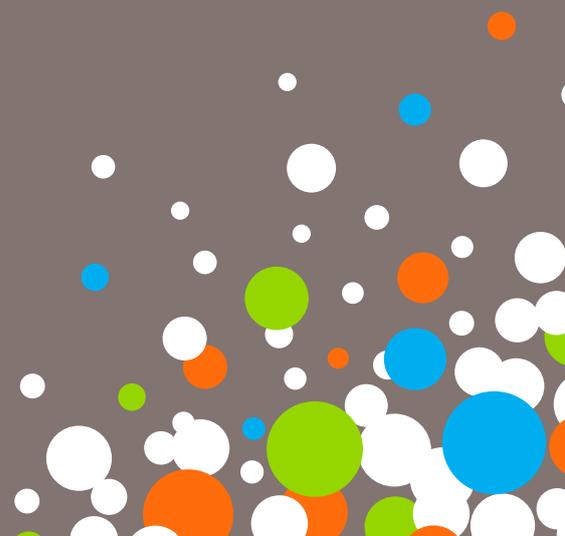


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Intervening early for young people with eating disorders

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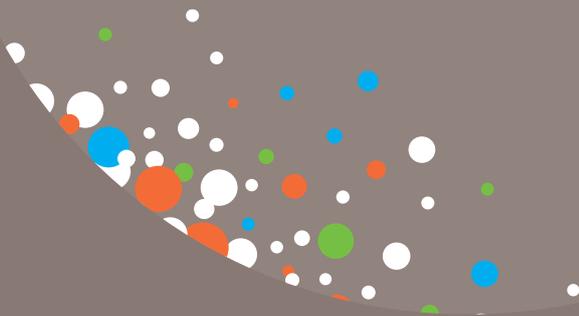
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## Abbreviations

<b>ABS</b>	Australian Bureau of Statistics
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>AN</b>	Anorexia Nervosa
<b>BED</b>	Binge Eating Disorder
<b>BMI</b>	Body Mass Index
<b>BN</b>	Bulimia Nervosa
<b>BoD</b>	burden of disease
<b>CBT</b>	Cognitive Behavioural Therapy
<b>CBT-E</b>	Cognitive Behavioural Therapy Extended
<b>CAMHS/ CYMHS</b>	Child and Adolescent/ Youth Mental Health Service
<b>DSM-V</b>	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
<b>ED(s)</b>	eating disorder(s)
<b>QoL</b>	Quality of life
<b>GP</b>	general practitioner
<b>MBS</b>	Medicare Benefits Schedule
<b>NEDC</b>	National Eating Disorders Collaboration
<b>OSFED</b>	Other Specified Feeding and Eating Disorder
<b>TAU</b>	treatment as usual
<b>USFED</b>	Unspecified Feeding and Eating Disorder

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Eating disorders are not one, but a set of complex and serious illnesses that can have a significant and often long-term impact on the life of a young person, as well as his or her family, peers and community.



# Executive Summary

Eating disorders are serious, complex, prevalent yet treatable illnesses with a high rate of onset in adolescence.

Eating disorders are **serious** as they have a devastating impact on young people, their families and the broader community. Not a 'phase' or a 'lifestyle choice', eating disorders are serious illnesses with a high risk of recurrence and chronicity and they can affect the health and the quality of an individual's life and contribution for the whole life span (Deloitte Access Economics, 2015). Eating disorders are related to significantly higher rates in mortality, either through the devastating impact they have on nearly all organ systems or through suicide. (Steinhausen, 2009) The financial and emotional costs of supporting treatment and bearing witness to the impacts of the illness also place considerable strain on families and loved one (National Eating Disorders Collaboration, 2010). Consequently, the socio-economic cost of eating disorders in 2012 was estimated to be \$69.7 billion, with \$99.9 million in health system costs; \$15.1 billion in productivity costs and \$52.6 billion in burden of disease costs (Deloitte Access Economics, 2012).

Eating disorders are **complex** as they are not one diagnosable illness but a set of neuropsychiatric illnesses, with biological, psychological and socio-cultural risk factors. They include anorexia nervosa, bulimia nervosa, binge eating disorder and a number of other specified or unspecified feeding and eating disorders. Often a young person diagnosed with one form of eating disorder will move into another, and possibly back again (Uher and Rutter, 2012). Other young people will experience eating disorders alongside comorbid

conditions such as anxiety, depression, drug and alcohol disorders and obesity. Treating eating disorders effectively requires a complex response to all related presentations of physical and mental ill-health. Recovering from an eating disorder requires the provision of medical, psychological and nutritional treatments which, particularly for young people, also require participation and a significant commitment from the entire family.

Eating disorders are **prevalent**, with estimates that approximately 9% of the population in Australia have an eating disorder (National Eating Disorders Collaboration, 2012b). A significant proportion will be affected by binge eating disorder and other or unspecified feeding and eating disorders, and there is data to indicate that the prevalence of binge eating disorder, in particular, may continue to rise (Deloitte Access Economics, 2012). Conservative estimates of disordered eating behaviours (similar to eating disorders but less severe) indicate almost 20% of females are affected (Hay et al., 2008). Even more concerning, is that 90 per cent of 12-17 year old girls and 68 per cent of 12-17 year old boys report having been on a diet of some form (Tucci, 2007).

Eating disorders are **treatable**. There is a significant body of evidence for effective intervention models and treatments for eating disorders if provided early into the illness. Cognitive Behavioural Therapy (CBT-E) for bulimia nervosa and binge eating disorder (Hay, 2013) and Family-based Therapy (FBT) for anorexia nervosa in young people under 18 years (Le Grange, 2005). Treatment for eating disorders is intensive and extended with a long period of recovery. However, there is a good likelihood of recovery.

The critical element of best practice interventions for eating disorders is a 'continuum of care' model, provided across prevention, early intervention, treatment and recovery/relapse intervention. Optimal care for the stage of illness (including pre-risk and at risk) should be accessible at the point in time it is needed, moved through in either direction depending on circumstances and, where appropriate, delivered with the involvement of family members (Deloitte Access Economics, 2015).

There is also evidence for a number of prevention programs which can build both, healthier body image and eating behaviours in all young people, but also possibly 'nip in the bud' potential pathways into an eating disorder for particularly vulnerable young people (National Eating Disorders Collaboration, 2012c).

However, at present young people are not seeking help and treatment or if they do, struggle to access these interventions via a systematic, guaranteed pathway of medical, psychiatric and nutritional care as would be provided if they were experiencing another form of serious, life threatening illness. Studies suggesting that only 22% of people with eating disorders access specialist treatment (National Eating Disorders Collaboration, 2013). Barriers to accessing evidence-based early intervention and treatment for eating disorders include:

- Low rates of identification and ineffective referral processes from first-line responders, such as GPs and other primary care practitioners, school staff, and youth and community mental health services;
- A lack of clinicians and services with the knowledge, resources and willingness to treat eating disorders;
- The inadequate level of mental health funding to provide for the duration and dosage of evidence-based treatment required for eating disorders;
- A significant gap across Australia in locally-based service systems that can provide the multidisciplinary continuum of care required for responding to the psychological, medical and ongoing support required to provide for a successful recovery. Meanwhile, entire jurisdictions in Australia, along with rural and regional areas, have no access to eating disorder specialist services.
- Stigma and low mental health literacy in the community regarding all eating disorders and disordered eating; and
- Social and cultural norms reinforcing disordered eating behaviours and body dissatisfaction;

These are significant barriers which, at present, are the reason why so many young people with the early warnings of an eating disorder or early onset of the illness are unable to access services and treatment that would provide them with the best possible chance of intervening early and achieving recovery.

However, through national and jurisdictional leadership providing for coordination, long-term commitment and urgent investment (with clear dividends into the future) there are opportunities to remove these barriers and provide an eating disorders system that responds, early and effectively. Young people with an eating disorder now and in the future should be able to access evidence-based early interventions (including prevention programs for those at risk), provided by a workforce with the skills and capacity to deliver these to a high degree of fidelity.

This paper presents a number of future directions (summarised below) which would, if acted upon, go a long way to ensure that in Australia we are able to provide the optimal care and treatment for young people, their families and indeed anyone who will experience an eating disorder.

### Increase access to evidence-based early interventions for eating disorders

- Increase the number of Better Access MBS sessions for a person with a diagnosed eating disorder to match the evidence base for the treatment dosage and duration required over one year. For example: 20 sessions of CBT-E for bulimia nervosa and binge eating disorder plus ten more sessions for those with comorbid conditions (subject to review points at ten sessions and again at 20 sessions) and 30 sessions of FBT for anorexia nervosa.
- Improve access to coordinated care by clarifying with GPs and other primary health care professionals that eating disorders are eligible to be coordinated through the Chronic Disease Management Plan.
- Invest in a trial of an innovative early treatment response for young people with binge eating disorders and bulimia nervosa in four headspace centres in cities or regional centres where there is currently limited access to any eating disorder support services.

- Service mapping should be tasked to each Primary Health Network to: develop an eating disorders service map and gap analysis in catchment areas; develop locally relevant service information for young people with an eating disorder or disordered eating behaviours, their families and primary care professionals; and identify opportunities to respond to gaps in local treatment pathways. This should be prioritised in those PHNs tasked with developing regional service pathways for young people with persistent mental ill health, comorbid substance misuse and increased risk of physical ill health.
- COAG, in partnership with existing specialist eating disorder services, should consider how investment could be best targeted to address the gaps in the continuum of stepped-care for young people with anorexia nervosa and/or severe presentations of other eating disorders which require a rapid referral and an intensive treatment response.

### **Increase the capacity of the workforce to deliver evidence-based early interventions**

- All staff in youth mental health and youth health organisations should be trained in basic eating disorder responses while a subset of staff should be trained in advanced practice to deliver evidence-based treatments. National coordination is required to align national and jurisdictional workforce development activities including the development of an online platform to improve access to training, tools and resources across the country.
- Resource a project to investigate and support the involvement of young people with a lived experience of an eating disorder in the development and delivery of effective interventions, including prevention programs, online and offline treatment responses.

### **Increase access to evidence-based prevention programs for young people at risk**

- Include requirements in funding agreements with deliverers of school-based mental health and wellbeing programs to deliver evidence-based eating disorder prevention activities within their program.

- Support the NEDC and the National Centre of Excellence in Youth Mental Health to build sector partnerships to develop and trial innovative prevention programs which address eating disorders along with comorbid conditions.

### **Provide national coordination and leadership**

- A national commitment to eating disorder prevention and early intervention responses should also be prioritised through the COAG mental health reform processes. Responding to gaps in eating disorder service provision should be prioritised. This could include that all government funded youth mental health services be required to identify an early intervention response to eating disorders and disordered eating as part of their core business.
- As a part of this process the Australian Government should continue to resource the NEDC at sufficient levels to provide ongoing national collaboration and coordination.

### **Build awareness of all eating disorders and reduce stigma in the community**

- Develop online and offline awareness-raising information and resources for young people and their families, to improve understanding of the dangers of dieting, disordered eating, all eating disorders (including a focus on binge eating disorder) and over-exercise. These should be developed in partnership with young people (including those who do not identify as having an eating disorder) and their families

### **Address gaps in research and data**

- Research gaps need to be addressed including understanding the nature, risks and effective interventions for young men and Aboriginal and Torres Strait Islanders with eating disorders or disordered eating. These gaps could be considered and prioritised by the National Health and Medical Research Council or through targeted funding.
- Improve data collection on the community prevalence of eating disorders through the inclusion of eating disorder questions in ABS and AIHW population surveys on health, wellbeing and mental health. Considerations should also be given to the harmonisation of current diagnostic data collection occurring across jurisdictions

# Introduction

Eating disorders are estimated to affect 9% of the population, with onset most often occurring in adolescence and young adulthood (National Eating Disorders Collaboration, 2012b). They are not one, but a set of illnesses with unique diagnostic criteria, including anorexia nervosa, bulimia nervosa, binge eating disorder and other specified feeding and eating disorders which may be clinically significant but do not meet a full diagnostic category. Binge eating disorder is the most prevalent and rates appear to be rising (Hay et al., 2008).

Eating disorders are complex neuropsychiatric and behavioural disorders with genetic underpinnings. No single cause has been identified and they may develop in vulnerable individuals through a combination of any number of biological, psychological, socio-cultural and environmental factors. Eating disorders also share a number of characteristics and the condition can often be exacerbated in a significant proportion of people who move from one eating disorder to another and/or those who also experience comorbid conditions such as depression, anxiety, obesity and/or drug and alcohol disorders.

Many people with eating disorders are either not diagnosed or only access treatment after an extended period of illness. At present, a young person with the onset of an eating disorder may potentially not seek treatment for 4-10 years (Gilbert et al., 2012). While evidence-based treatment provided within two-three years of diagnosis has been shown to be successful, the costs of delayed, or no treatment, are devastating for young people experiencing the illness, their family and the community. Indeed Deloitte Access

Economics in 2012 estimated the total socio-economic cost of eating disorders in that year was \$69.7 billion (Deloitte Access Economics, 2012).

Drawing from international data and research where needed, this paper will discuss evidence-based prevention interventions for disordered eating behaviours, body dissatisfaction and other links in the chain of events that may lead to a young person, with underlying vulnerabilities, to develop an eating disorder. These programs, while currently available, are funded and delivered in a piecemeal fashion and require a far more systematic and committed approach so they can be embedded in school and community-based mental health and wellbeing programs.

This paper will highlight the issues young people and their families experience early on in accessing treatment for eating disorders. In the development of this paper a number of people were consulted including: young people with a lived experience of an eating disorder, parents of young people who had experienced an eating disorder as well as clinicians, academics, practitioners and researchers. Most identified that critical opportunities to identify eating disorders early and facilitate help-seeking through appropriate and effective referrals were regularly missed. For example, while training and tools for key professionals (such as GPs) which provide early identification for eating disorders are available, many are still either failing to diagnose the illness or are responding with the damaging 'watchful waiting' response to the medical aspects of the illness while the psychological treatment needs remain unaddressed and the illness exacerbates.

There are also ongoing gaps in eating disorder early intervention and treatment, with many youth mental health services, as yet, not able to provide a nationally consistent, embedded eating disorder response within their service model. With adequate resourcing, opportunities exist to address this gap as well as build on, and improve, young person friendly and accessible online and technology based eating disorder information and service responses.

This paper will outline the strong evidence for treatment approaches for eating disorders (Deloitte Access Economics, 2015) delivered within two to three years of onset. These include Cognitive Behavioural Therapy Extended (CBT-E) for bulimia nervosa and binge eating disorder (Hay, 2013) and FBT for anorexia nervosa in young people under 18 years (Le Grange, 2005). There is also evidence for both the effectiveness for cost and outcomes for providing intensive and often family focused, evidence-based treatment course provided as soon as possible after diagnosis. The best practice continuum of stepped-care, if available and implemented, is most likely to achieve successful, long-term recovery. However, there is a significant disconnect between this model and what is currently resourced in the eating disorder service system.

While this paper will focus on interventions for young people (12-25 years) experiencing an eating disorder, it is important to note that:

- Parents and other family members with disordered eating or a history of eating disorder also require specialist support, and if necessary treatment, in order to be able to provide a

recovery environment for the young person. Without this, the treatment for the young person is likely to be less effective.

- There is strong evidence that for those who do not receive effective early intervention the course of illness is likely to be a long one with a high risk of recurrence in the late twenties and thirties. All early intervention and treatment responses for young people, therefore, need to be seen in the wider picture of access to treatment at all stages of life.

Over the last five years the Butterfly Foundation and the members of the NEDC have made a significant contribution to raising awareness about eating disorders, their impact, evidence-based practice and the economic and social case for investing in early intervention and optimal care. This paper acknowledges this substantial body of work and concludes that there are a number of identified key opportunities that can address the unmet needs of young people at risk of, or experiencing, the devastating physical, psychological, social and financial costs of eating disorders.

These opportunities highlight that leading and investing in a system of care to deliver early and effective responses to eating disorders will improve (and potentially save) the lives of young people in Australia who may be affected by eating disorders now and into the future.

## Section 1

# Young people and eating disorders

## What are eating disorders?

Eating disorders are not one, but a set of complex and serious illnesses that can have a significant and often long-term impact on the life of a young person, as well as his or her family, peers and community. Eating disorders have both biological and psychological causes and present in an individual as highly disturbed eating behaviours and/or weight regulation. They are often characterised by a distorted body image and severe distress or concern about body weight or shape, which can disproportionately impact an individual's self-worth.

Current diagnostic categories recognised in the most recent Diagnostic and Statistical Manual of Mental Disorders (DSM 5) include anorexia nervosa, bulimia nervosa, binge eating disorder and other specified or unspecified feeding and eating disorders (OSFED & UFED). These are described in more detail in Box 1.

### KEY POINTS

ALL eating disorders are serious mental illnesses.

ALL require appropriate medical and psychological responses specific to the type of eating disorder.

Treatment within two to three years of onset significantly increases chance of recovery.

## BOX 1

**Eating disorder descriptions****(sources: Eating Disorders Victoria website and NEDC website)**

**Anorexia nervosa** involves a persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory and physical health). It involves either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though the person already has significantly low body weight). It also includes disturbances in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or a persistent lack of recognition of the seriousness of current low body weight.

**Bulimia nervosa** involves recurrent episodes of binge eating. An episode is characterised by:

- Eating, in a discrete period of time (e.g. within any two hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances;
- A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); and
- Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise.

The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months.

**Binge eating disorder** is defined as recurring episodes of eating significantly more food in a short period of time than most people would eat under similar circumstances, with episodes marked by feelings of lack of control. A person will be distressed and may have feelings of guilt, embarrassment, or disgust. This disordered binge eating behaviour occurs, on average, at least once a week over three months.

**Other specified feeding and eating disorder (OSFED)** refers to situations where a person has clinically significant feeding and eating disorder symptoms but does not meet the full criteria for another diagnostic category. An examples of this category may include atypical anorexia nervosa (e.g. weight is within normal range).

**Unspecified feeding and eating disorders (UFED)** are clinically significant feeding or eating disorders that do not meet the criteria for another eating or feeding disorder.

Most people with an eating disorder do not seek help, with only 17–31% of individuals in the community with a diagnosable eating disorder seeking eating disorder specific treatment (Hart et al., 2011). If help is sought, it is often after an extended period of illness, in some cases between 4 to 10+ years (Gilbert et al., 2012). Even then, the treatment is often not appropriate or evidence-based (Mond et al., 2009).

As such, many adolescents who develop an eating disorder will experience the illness well into adulthood, by which time the condition has become chronic, physically and psychologically disabling with substantial long-term personal and societal costs (Herpertz-Dahlmann, 2015).

Early intervention is critical. People who have had an eating disorder for less than two years are likely to respond more rapidly to treatment and experience fewer physical health consequences (Deloitte Access Economics, 2015). Young people under the age of 18 are more likely to experience good outcomes from intervention (Ackard et al., 2014) and family therapy delivered within three years of the onset has repeatedly been found to be the most effective approach for young people with anorexia nervosa (Le Grange, 2005).

## Who do eating disorders affect?

Eating disorders affect approximately 9% of the total population (National Eating Disorders Collaboration, 2012b). A report by Deloitte Access Economics estimated more than 913,000 Australians had an eating disorder in 2012, although it was acknowledged that this figure could be a conservative estimate (Deloitte Access Economics, 2012), possibly due to under-reporting and under-diagnosis.

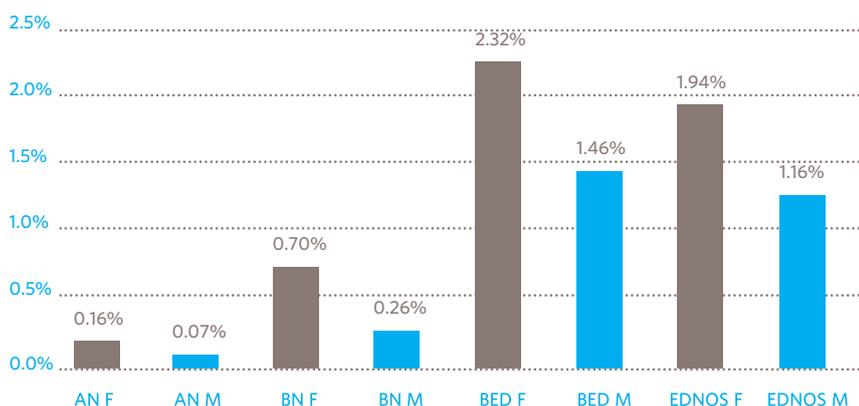
As with many other experiences of mental ill-health, eating disorders most frequently start in childhood and youth—the peak period for onset of eating disorders is between the ages of 12–25 years, with a median age of around 18 years (Hart et al., 2011). Studies show a peak onset usually in early to mid-adolescence for anorexia nervosa, and in later adolescence and young adulthood for bulimia nervosa and binge eating disorder (Stice et al., 2013).

In a recent three-month prevalence study in Australia, the most common eating disorder diagnoses according to the DSM 5 criteria were binge eating disorder (6%) and subthreshold binge eating disorder (low frequency or limited duration), or other specific feeding and eating disorder type (7%) (Hay et al., 2015).

Meanwhile, Figure 1 presented below from the Deloitte (2012) *Paying the Price* report provides a similar picture through Australian one-year prevalence estimates for all eating disorders across both genders, but which reflects the previous DSM IV criteria, including the type eating disorders not otherwise specified (EDNOS).

**Figure 1**  
**Estimated Australian eating disorder one-year prevalence, by disease and gender, 2012**

Source: Deloitte Access Economics (2012)



There is also evidence to indicate that the rate of eating disorders in the Australian population is increasing (Hay et al., 2008), most notably for diagnoses of bulimia nervosa and binge eating disorder, paralleled by a comparative increase in childhood obesity (O'Dea, 2005). The rate of anorexia nervosa, on the other hand, has been generally stable.

The Deloitte Access Economics (2012) report suggested the prevalence of binge eating disorder will continue to increase in both males and females in the next 30 years. These disorders are considered to be as serious as anorexia nervosa and bulimia nervosa (Hay et al., 2010), and are associated with a higher mortality rate and increased risk of suicide compared to these in the general population (Crow et al., 2009b).

There are a number of shared characteristics across different eating disorders, and longitudinal studies of anorexia nervosa and bulimia nervosa have found that a significant proportion of people with one eating disorder will move into another (Uher and Rutter, 2012). This mostly occurs from anorexia to bulimia nervosa: in one study, one-third of individuals with an initial diagnosis of anorexia nervosa developed bulimia nervosa during a five to ten-year follow-up period. In comparison, only 10–15% of those with an initial diagnosis of bulimia nervosa developed anorexia. These figures are even greater for transitions from bulimia nervosa to binge eating disorder (Castellini et al., 2011). One young person described her transition from anorexia through to bulimia nervosa in the Deloitte Access Economics (2015) *Investing in Need* report:

'It (hospital admission for anorexia nervosa) was horrific. I can't tell you how bad it was. Admission scared me. I was so determined not to end up there again. I reverted back to bulimia and became a functional bulimic.' (Deloitte Access Economics, 2015, p.40)

### Young women

Being female is the most commonly identified risk factor for the development of an eating disorder (Jacobi and Fittig, 2010), and rates among women and girls are 2.5 times greater than among men and boys (National Institute of Mental Health). This is demonstrated through the prevalence rates shown in Figure 2. Approximately 90% of people diagnosed with anorexia nervosa and bulimia nervosa are female, although instances of binge eating disorder appear to be evenly represented across both genders (Deloitte Access Economics, 2012). For young females, eating disorders represent the second leading cause of disability due to mental disorder (Bailey et al., 2014) and the third most common chronic illness after obesity and asthma (Yeo and Hughes, 2011).

**Figure 2**  
**Estimated age-gender prevalence of total eating disorders in Australia**

Source: Deloitte Access Economics (2012)



## Young men

There has been an increase in reports of body dissatisfaction and eating problems in young males, including weight control and weight gain behaviours (O'Dea, 2005). Up to 50% of boys have reported wanting to change their body size (Bean et al., 2005), while approximately 25% of children diagnosed with anorexia nervosa are male (Madden et al., 2009). As disordered eating behaviour and excessive exercise adopted by young men can often result in increased muscularity and physical bulk, the signals for a potential eating disorder often go unnoticed (The National Eating Disorders Collaboration, 2012c).

## Prevalence in Aboriginal and Torres Strait Islander young people

There is a lack of research and data regarding the prevalence of eating disorders in Aboriginal and Torres Strait Islander young people. One study by Hay and Carriage (2012) indicated binge eating disorders are at least as common, if not more common, in Aboriginal and Torres Strait Islanders. In addition, they found weight and/or shape concern to be as high if not higher in these populations, while rates of restrictive dieting and other compensatory weight control behaviours were similar to those in non Aboriginal and Torres Strait Islander populations.

Some Aboriginal and Torres Strait Islander adolescents have body image concerns related to a desired muscular shape (Flaxman, 2012, Cinelli and O'Dea, 2009), with higher levels of body dissatisfaction and a desire to build up muscle reported among Aboriginal and Torres Strait Islander males (Mellor et al., 2004).

### A note on data

Deloitte Access Economics (2012) identified a lack of official national data for eating disorders. With the exception of state-based research studies, including those by Wade et al. (2006), Hay et al. (2015) and a national study on early onset of eating disorders in 5-13 year olds (Madden et al., 2009), there is limited available Australian data beyond hospital separations where an eating disorder is diagnosed.

The Australian Bureau of Statistics (ABS) has not collected data on eating disorders, while the Australian Institute of Health and Welfare (AIHW) published applied prevalence figures from a Swedish study for anorexia nervosa in males and females and bulimia nervosa in females only (Deloitte Access Economics, 2012). It is a significant concern that no national data is available for the two most prevalent eating disorders: binge eating disorders or OSFEDs.

## Why do young people develop eating disorders?

Eating disorders are complex neuropsychiatric and behavioural disorders with genetic underpinnings. No single cause has been identified and they may develop in vulnerable individuals through a combination of any number of biological, psychological, socio-cultural and environmental factors.

**Biological/genetic factors:** There are a number of studies underway that are attempting to unlock the genetic blueprint that might exist for eating disorders. The Anorexia Nervosa Genetics Initiative is a global effort to identify the genes that may contribute to eating disorders. Other studies have been investigating early genetic markers such as anxiety (Goddard and Treasure, 2013) and perfectionism, both commonly regarded risk factors for development of an eating disorder (Wade, 2010). It is important to note that there is no 'eating disorder gene', but rather, a number of genes within biological systems that relate to food intake, appetite, metabolism, mood and reward-pleasure responses may be involved (NEDC, Website: *Eating disorder risk factors*).

**Psychological factors:** A number of personality traits may be associated with eating disorders, including perfectionism, obsessive compulsiveness, impulsivity, body dissatisfaction, neuroticism and core low self-esteem (NEDC, Website: *Eating disorder risk factors*).

**Socio-cultural influences:** There is evidence that socio-cultural influences play a part in the development of eating disorders, particularly in Western cultures, which promote a thin 'body ideal'. This ideal may be delivered through media, family, friends and sporting cultures (Keel and Klump, 2003).

Jacobi and Fittig (2010) provide an additional analysis of psychosocial risk factors across eating disorder types and found the most potent risk factors for bulimia nervosa and anorexia nervosa were gender, weight and shape concerns and a number of other variables around negative thoughts, neuroticism and general psychiatric morbidity. While studies specifically looking at risk factors for binge eating disorder are few, those that are available identified family neglect, low self-esteem and low perceived social support as contributing factors (Jacobi and Fittig, 2010).

## Comorbidity

Eating disorders are often experienced alongside other symptoms of mental ill-health in a young person. These include anxiety disorders (e.g., obsessive compulsive disorder) and depression; some personality disorders, such as borderline personality disorder (18+ years); alcohol and drug disorders and self-harming behaviour (Hay et al., 2014).

### Depression

There are particularly strong associations between eating disorders and depressive disorders, with lifelong comorbidity estimates of 40% for anorexia nervosa and 50% for bulimia nervosa (Surgenor and Maguire, 2013, Rodgers and Paxton, 2014). A study in 2011 found that teenage girls who feel depressed are twice as likely to start binge eating as other girls, while girls who engage in regular binge eating have double the risk of experiencing depression (Skinner et al., 2012).

There has been debate around the sequencing of these comorbidities, with some suggesting that there can be an over-diagnosis of depression, which is actually secondary to the state of malnutrition (Surgenor and Maguire, 2013). The relationship between the disorders presents additional challenges for recovery and effective treatment in that should one disorder be ignored in the treating of the other, the chances of successful recovery are diminished (Rodgers and Paxton, 2014).

### Anxiety

There are also very strong associations between all anxiety disorders and the eating disorders, with approximately 65% of patients with eating disorders meeting the criteria for at least one anxiety disorder (Deboer and Smits, 2013). The most common were social phobia (42%), followed by post-traumatic stress disorder (26%) and generalised anxiety disorder (23%) (Swinbourne et al., 2012). Anxiety and eating disorders share a number of common psychological risk factors, including eating pathology, perfectionism (Egan et al., 2013) and negative self-evaluation (Deboer et al., 2013). As one young person consulted for this paper identified:

“ In reality it was the anxiety, [low] self-esteem and depression that I really needed help with as the eating disorder was a strategy I used to cope with these feelings.

## Obesity

The increasing rates of binge eating disorder are currently mirrored by increasing rates of obesity, with strong evidence that obesity is a common comorbid condition for both binge eating disorder and bulimia nervosa (Hay et al., 2015). The two share common risks in body dissatisfaction, low self-esteem, childhood or parental obesity and dieting. Obesity can be both an outcome of an eating disorder and pathway into an eating disorder. Among girls who diet, the risk of obesity is greater than for non-dieters (Daele et al., 2002, O'Dea, 2005), and many medical complications of binge eating disorder are those associated with obesity such as type II diabetes, high blood pressure, menstrual problems and gastrointestinal problems (National Eating Disorders Collaboration, 2010).

Government, community and family messages of weight control and management can, despite the best intentions, contribute to disordered eating behaviours and body dissatisfaction in young people and, contrary to their intent, potentially contribute to an increase in both obesity and eating disorders (National Eating Disorders Collaboration, Website: *The boomerang effect*). As described by one young person consulted for this paper:

“ I find it really hard when there is any diet or exercise (public health campaign) going on, when I first started getting sick at uni, there was “why don't you walk instead of getting on a bus?” signage and...if you aren't doing that well, you take it on board.

## Alcohol and other drug use

Research findings have demonstrated (with some variability) co-occurrence of eating disorders and substance misuse, in particular in bulimia nervosa (Bulik, 2004). Further associations between dieting and eating problems and substance use in younger populations have been documented, and increasing severity of dieting and problems associated with eating disorders were associated with increased rates of alcohol, cigarette and other drug use (Krahn et al., 1992).

Serious problems with alcohol are not uncommon for people with anorexia nervosa or bulimia nervosa, and the risk of developing an alcohol problem continues over time (Franko et al., 2005). Tobacco and other drug use is also significantly higher for people with an eating disorder (Krug et al., 2008), as is laxative abuse, a toxic drug that is associated with poor eating pathology, general psychopathy and elevated risk of self-harm (Tozzi et al., 2006).

While alcohol and other drug comorbidity is well documented in eating disorder research, currently there is little evidence for effective interventions for eating disorders that also address co-occurring drug and alcohol use. There is, however, existing evidence for early intervention programs for treating the co-occurrence of other mental ill-health and alcohol and other drug use of young people. This is explored further in the policy paper recently prepared by Orygen, the National Centre of Excellence in Youth Mental Health titled *Two at a time: alcohol and other drug use by young people with a mental illness*.

**IMPLICATIONS**

All eating disorders are complex and serious neuropsychiatric illnesses and have high rates of onset in adolescence. Binge eating disorder and OSFEDs are the most prevalent and appear to be increasing in the community. Effective interventions for young people with early onset of an eating disorder need to acknowledge and understand all types of eating disorders.

To effectively inform policy and program responses and interventions, improved national data collection is required to collect and aggregate prevalence and demographical data of clinical and community presentations of all eating disorders (including bulimia nervosa and binge eating disorder).

There remain gaps in the research regarding the prevalence and impact of eating disorders on young people in Aboriginal and Torres Strait Islander communities and young men.

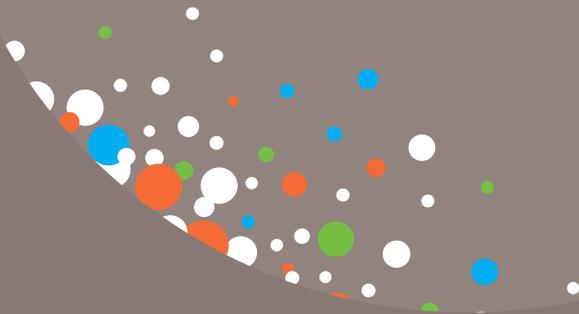
A public health approach is required that integrates prevention and early intervention activities for both eating disorders and obesity. At the core of this approach is a mutual agenda targeting young people that promotes nutrition, healthy relationships with food, realistic physical activity and positive self-identity.

There is a strong connection between eating disorders and the mood, affective and anxiety disorders. There is a need for youth mental health services responding to symptoms of either one of these illnesses to screen for the other. Early interventions need to be developed to respond effectively to both eating disorders and comorbid mental ill-health.

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In 2012 the socio-economic  
cost of eating disorders in  
Australia was estimated  
to be \$69.7 billion.

*Deloitte Access Economics (2012)*



## Section 2

# The impact

Eating disorders can have a devastating and long-lasting impact on a young person's physical and mental health. They can make it difficult to study and work and they can impact on relationships with family, friends and partners (The National Eating Disorders Collaboration, 2010).

For a young person, the experience of an eating disorder can significantly disrupt education, impact on identity formation, self-esteem and physical development. Not surprisingly, the quality of life for people with eating disorders is very low compared to the general population (DeJong et al., 2013, Hay et al., 2010).

Eating disorders also impact on the health and wellbeing of all family members, resulting in their own experiences of mental ill-health, increased social isolation, relationship break-ups and sibling ill-health (Deloitte Access Economics, 2012). The lengthy period spent navigating through service systems and treatment pathways requires the participation and commitment of family members and impacts on their own workforce participation. The financial impacts are then further exacerbated by the difficulties accessing publicly funded treatment pathways, with 60% of the health system costs for eating disorders being borne by individuals and their families (Deloitte Access Economics, 2012).

## On the young person

### Physical health and mortality

With a high risk of recurrence and chronicity, eating disorders can affect the health and the quality of an individual's life and contribution for the whole life span (Deloitte Access Economics, 2015). Sadly, for people with *all* types of eating disorders life expectancy can be significantly shortened: young people with eating disorders are over ten times more likely to die prematurely than their peers without an eating disorder. In anorexia nervosa there is an almost 18-fold increase in mortality (Steinhausen, 2009). The rate of suicide and self-harm is high among people with eating disorders (Kostro et al., 2014), with half of all deaths in anorexia nervosa related to suicide (Steinhausen, 2009), and more than a third of young people with bulimia nervosa reporting suicide attempts (Swanson et al., 2011).

Starvation and purging behaviours also have a disastrous impact on nearly all organ systems. Starvation occurring through anorexia can result in heart failure, osteoporosis, amenorrhoea, fertility issues and kidney damage, along with arrested growth and development in children and young people. Purging behaviours can result in dental decay, mouth sores, gastrointestinal bleeding and heart failure, while repeated bingeing can result in gastrointestinal problems, obesity, type 2 diabetes and menstrual problems (The National Eating Disorders Collaboration, 2010).

### Self-esteem / social functioning

Eating disorders are associated with specific personality traits, most notably low self-esteem (Hay et al., 2014). Low self-worth and low self-esteem can be very common for people with eating disorders. Controlling weight and food intake can provide a sense of control and self-determination for a young person, particularly in contexts where they may be experiencing other vulnerabilities and self-doubt.

However, the secretive nature of eating disorders and disordered eating can often result in a young person isolating themselves from positive and reaffirming interpersonal relationships, ultimately exacerbating social anxiety, negative self-image and eroding protective factors. In eating disorders the quality of life in the psychological and social domains seems to be particularly compromised (DeJong et al., 2013). In one study nearly all of those with anorexia (88.9%) reported social impairment, of which 19.6% reported severe social impairment associated with their eating disorder. Adolescents with bulimia and binge eating disorder also reported that their eating problems impaired their social and family relationships (Swanson et al., 2011).

### Study and career pathways

Mental illness can have devastating impacts on the educational and career pathways of young people, highlighted through employment statistics illustrating low labour market participation and high unemployment (Orygen Youth Health Research Centre, 2014).

Eating disorders can lead to difficulties concentrating on study and work. The state of starvation has been shown to decrease cognitive functioning and be responsible for neurological damage, such as impaired memory (Herpertz-Dahlmann, 2015), while the preoccupation with food and weight can become all-encompassing and make it difficult for a young person to function at school or work.

Deloitte Access Economics (2015) estimated the average lost weekly earnings in 2014 for a young person with an eating disorder aged 20–24 years was \$103.56 per week for females and \$137.88 for males. Moreover, the impact can last beyond the duration of the illness: in an 18-year follow-up study of 31 adolescents with anorexia nervosa, one in four did not have paid employment due to their consequences of their illness (Wentz et al., 2009).

### On their families

Eating disorders can impact on every member of a family and come at a significant cost to siblings, parents, grandparents and other significant carers. They take their toll on the emotional health, mental health, educational and occupational outcomes of all involved.

“ Significant effects have been demonstrated on carers in the areas of levels of distress and burn-out; extreme emotional strain (including anxiety, confusion, guilt, shame, hopelessness and doubt) and complex practical challenges, such as providing meal support and meeting financial costs’ (National Eating Disorders Collaboration, 2010, p.53).

In consultation for this paper one parent described the impact an eating disorder had on the confidence of family members, likening the experience of living with her child before diagnosis and treatment to feeling bullied particularly around shopping and meal preparations.

Eating disorders also impact on the workforce participation and career pathways of care-givers, particularly due to the need for intensive support from family and friends once the illness is diagnosed (The National Eating Disorders Collaboration, 2010). Meeting financial costs, as well as maintaining positive family relationships, can be particularly difficult when best practice intervention for an eating disorder can involve direct and intensive participation in long-term treatment, often provided a considerable distance from home and work.

Eating disorders also can have a terrible impact on siblings. As this quote from the Deloitte Access Economics report into the Social and Economic Costs of Eating Disorders (2012) describes:

“ The emotional toll on our whole family has been huge. Our other two children (now adults—31 years and 35 years) have also suffered greatly having to live with the daily stresses of life with an ED sufferer. The illness consumes the whole family and has resulted in all of us needing counselling to cope with the stresses’ (Deloitte Access Economics, 2012, p.82).

## Social and economic impacts

The *‘Paying the Price’* report, released in 2012, revealed the socio-economic cost of eating disorders in Australia in 2012 was \$69.7 billion. This consisted of \$99.9 million in health system costs; \$15.1 billion in productivity costs and \$52.6 billion in burden of disease costs (comparable to the estimated value of the burden of disease for anxiety and depression of \$41.2 billion, and for obesity at \$52.9 billion) (Deloitte Access Economics, 2012). The report noted that these are conservative estimates of the cost of eating disorders. The estimates utilised lower prevalence rates than those found in Australian studies and the limited data available regarding the costs of treatment.

In 2015, Deloitte Access Economics updated the 2012 figures and estimated:

- The annual cost of lost earnings due to reduced employment participation from eating disorders was estimated at \$6.92 billion in 2014 and the total productivity loss for people with eating disorders (including absenteeism and presenteeism and premature death) over \$17 billion.
- The total health expenditure on eating disorders was estimated to be approximately \$81.9 million for children and young people aged 10–24 years, and across all age groups the Federal Government bore 42.4% of these costs, the State and Territory jurisdictions 27.3%.

In comparison to these substantial costs, in 2012 Australia only spent \$109 for each person with an eating disorder (Deloitte Access Economics, 2012) equating to \$145 million for treating eating disorders over the next ten years that were diagnosed in 2014 (Deloitte Access Economics, 2015).

**IMPLICATIONS**

Eating disorders have a devastating impact on young people, their families and the broader community. They significantly reduce the quality of life for people who experience an eating disorder, and that of their families and loved ones. Two reports provided by Deloitte Access Economics in 2012 and 2015 quantify the impact of eating disorders through the direct costs borne by individuals and governments.

There is an undeniable need for investment in prevention and early intervention prior to, and at the point of peak onset (adolescence—young adulthood) given:

- The increased rates of mortality and physical and mental health complications that will be experienced by a young person who develops an eating disorder.
- The long-lasting impacts of eating disorders on young people, their families and the community if the illness is not identified early and is allowed to continue into young adulthood and adulthood untreated. These impacts can include a significant reduction of participation in economic and community life and overall poor quality of life.
- The strong evidence for recovery if eating disorders are identified and treated early (within two to three years of onset).

## Section 3

# Early warnings

### Body dissatisfaction and disordered eating

There are significant numbers of young people, particularly females, who are dissatisfied with their bodies. Preoccupation with weight and shape (typically thinness) has been found to be one of the most potent and replicated risk factors for bulimia and anorexia nervosa (Jacobi and Fittig, 2010).

Intense dissatisfaction with body size and shape can result in disordered eating behaviours, which are similar to eating disorder symptoms but less frequent and severe (e.g., use of extreme weight loss strategies, fasting, use of laxatives, self-induced vomiting and binge eating). While disordered eating does not always result in, or meet the clinical criteria for, an eating disorder, it nonetheless constitutes both a serious health problem (The National Eating Disorders Collaboration, 2012c) and the most common indicator of risk for the development of an eating disorder.

Hay et al. (2008) found that the rate of disordered eating behaviour had doubled in the years to 2005 and is now estimated to affect 20% of females, although it is likely these estimates may be understated due to the secretive nature of the behaviours (O'Dea, 2005, The National Eating Disorders Collaboration, 2013).

Research has found that dieting and disordered eating behaviours that commenced in middle adolescence are likely to continue into young adulthood, a trend consistent for both girls and boys (Neumark-Sztainer et al., 2011). Another Australian study found that adolescent girls who diet at a severe level over 12 months had a one in five chance of developing an eating disorder (Patton et al., 1999). In some adolescents with particular vulnerabilities, dieting and disordered eating can escalate into an eating disorder very quickly.

What is particularly concerning is that disordered eating and body dissatisfaction are now such common occurrences, especially in adolescence (Russell-Mayhew et al., 2007), that they are considered by young people in Australia as a normal and an accepted part of life and growing up (NEDC, Website: *Target Audiences*). Ninety per cent of 12-17 year old girls and 68% of 12-17 year old boys report having been on a diet of some form (Tucci, 2007).

### Triggers

There are a number of psychological, biological, socio-cultural and environmental factors that may trigger a vulnerable young person into a cycle of disordered eating. The trigger may appear to be quite minor, or it may not have the same impact on other young people.

### Body image concerns

The pressure for an unrealistic beauty ideal is thought to be one significant factor in the high levels of body dissatisfaction and eating disturbances among young women in Western societies (Rodgers et al., 2014, Yamamiya et al., 2005). Research suggests that weight concern, body dissatisfaction and dietary restraint constitute early stages in the development of eating disorders (Stice et al., 2010). Food restriction and disordered eating are both risk factors for an eating disorder and prevalent behaviours legitimised in Western society in the pursuit of the 'ideal' body shape and size. This combination could be one of the reasons it is difficult to identify the onset of an eating disorder early.

Body image concerns and weight ideals can also be exacerbated for young people who participate in activities and sports where there is an emphasis on having a low body weight or being extremely thin. These include (but are not limited to) dancing, gymnastics and modelling, and may be further exacerbated at elite levels through the constant monitoring of body measurements, impacting on both young elite and aspiring athletes. As such, coaches and other health professionals involved in, or supporting, the sport industry have a significant role in the prevention and early identification of eating disorders and disordered eating.

### Peer environment

The peer environment has been shown to impact on disordered eating and body dissatisfaction. Young female peer group processes can develop an unhealthy focus on body image, dieting and extreme weight loss and perceived friendship group attitudes towards dieting and weight are strong predictors of weight control behaviour (Eisenberg and Neumark-Sztainer, 2010, Paxton et al., 1999). Peer appearance conversations and peer teasing and victimisation have been identified as particular risk factors for body image concerns (Lunde and Frisen, 2011, Helfert and Warschburger, 2011).

While research has demonstrated stronger negative influences in peer competition than in media or social media for body dissatisfaction and eating disorder symptoms (Ferguson et al., 2014), social networking sites are now significant peer environments. A study of 1,087 girls in Years 8 and 9 in South Australia found that Facebook users were significantly more concerned about body image than non-Facebook users (Tiggemann and Slater, 2013).

On the other hand, peer influence can work as a significant mediator against harmful eating practices among young women and body dissatisfaction in adolescents (Webb and Zimmer-Gembeck, 2014). Interventions that assist young adolescent girls to understand and change peer interactions have been shown to reduce body dissatisfaction and other risk factors for disordered eating over a three-month period (Richardson and Paxton, 2010), while peer-led interventions have been shown to be effective at delivering a cognitive dissonance based program, the Body Project (described in more detail in Box 3) (Stice et al., 2013).

### Familial influences

Family members have a significant role in shaping feelings about body shape, weight and eating behaviours. Parents have been shown to be a strong influence on body image disturbance and disordered eating behaviours (Rodgers et al., 2009). Direct messaging from family members on body shape and eating habits (even ones that are overly supportive and encouraging, yet still pressured) can be strong predictors of body dissatisfaction (Helfert and Warschburger, 2011).

Given the prevalence of dieting in this culture, many young people are also exposed to restrictive eating practices through prepared family meals, either where everyone is eating as per a diet or a significant adult is modelling disordered eating behaviour (Sharpe et al., 2013). Box 2 highlights quotes from young people interviewed for a research study into adolescent's experiences of body dissatisfaction and dieting.

## BOX 2

## Familial influences

*'We've got a friend who's going on a low carb diet at the moment because her family are, like her family's doing it, so it's easier if her and her sisters go along'—Student 3, aged 14.*

*'So if you see your parents going on Atkins Diet or something then you're going to be thinking 'oh should I be having carbs? Like is it not good to have carbs?' So then you just think it's normal to just cut things out of your diet'—Student 16, aged 13.*

Source: Sharpe et al. 2013, p.136

## Emotional/psychological stress

Disordered eating can present as a behavioural response to a number of other underlying emotional, psychological and physical health issues experienced by the young person. These might be exacerbated by significant points of change or stress, such as puberty, relationship problems, bullying, moving out of home and into independent living, starting a new school, TAFE or University, onset of a physical illness, trauma such as the death of a loved one, or being victim of a crime or assault.

Stressful life events and negative affect have been shown to be positively associated with extreme weight control behaviours, binge eating and bulimic symptoms in both male and females (Loth et al., 2008, Rodgers et al., 2014). In a predisposed personality, or where there is psychiatric comorbidity, chronic or serious life stresses can precede the onset of eating disorders, including anorexia nervosa and bulimia nervosa (Schmidt et al., 1997, Sassaroli and Ruggiero, 2005) and binge eating (Freeman and Gil, 2004).

“ I think if I had learnt some anxiety management strategies from a young age I may have not developed an eating disorder as a coping strategy.

This response to underlying emotional distress may be like other forms of self-harm in young people; indeed, in young people who have a diagnosed or sub-clinical eating disorder, the behaviour of restricting food to the point of starvation or bingeing and purging has been considered by some to be self-harming behaviour (Muehlenkamp et al., 2012). This point was raised in the consultation for this paper by a young person, who said:

“ It (an eating disorder) is a form of self-harm even though it is so much more complex than that... you are hurting yourself.

## Evidence-based responses

For disordered eating and body dissatisfaction there are a number of responses positioned within a continuum of prevention activities delivered to young people, often in educational settings. They include:

**Universal prevention initiatives** typically involve a focus on developing healthy lifestyles and a healthy relationship with food, providing clear messages about the risks of dieting, developing media literacy skills and respect for their own body and body diversity. There has been some evidence to suggest that universal initiatives, such as media literacy programs in schools, are effective at reducing risk factors for adolescent girls (McLean et al., 2013), particularly with 12–14 year olds. Media Smart is one such program in Australia that has demonstrated benefits when delivered by health professionals and promising early results when delivered by teachers (Wilksch, 2015).

Given the significant shifts in the platforms of media consumption over the past decade, it is important that media literacy programs ensure they respond to the emerging new media being used by young people.

**Selective prevention initiatives** target higher risk groups, often adolescent and pre-adolescent girls, and assist them to understand their own influence with their peers and provide them with strategies to change these interactions. This has been shown to reduce risk factors for eating disorders and have positive body image outcomes (Richardson and Paxton, 2010, Bird et al., 2013).

**Indicated prevention initiatives** target young people with early symptoms (e.g., body dissatisfaction and disordered eating) and are delivered to selected or self-identified older adolescents at higher risk of developing an eating disorder. Dissonance-based education programs draw a young person's attention to the disconnect between their behaviours (e.g., disordered eating) and their own beliefs as to what a healthy relationship with food is, and have been shown to be effective (Stice et al., 2013). Two indicated prevention programs are described in more detail in Box 3.

### BOX 3

#### Indicated Prevention Programs

**The Body Project:** The Body Project is a two-part group intervention program for adolescent girls and young women at risk of developing eating disorders. Using a cognitive dissonance approach, in the first part of the program participants learn skills to increase body satisfaction, decrease unhealthy weight control behaviours and prevent eating disorder symptoms. In the second part participants learn to make gradual lifestyle changes to achieve a healthy body weight (NEDC 2012). The program, originally designed to be delivered by school counsellors, nurses and teachers, has been shown to be effective at reducing risk factors and eating disorder symptoms and has also been effectively delivered by peer leaders and online (Stice et al., 2013).

**My Body My Life: Body Image Program:** An Australian program consisting of a guided self-help manual supported through six internet-based group sessions (delivered weekly). The weekly group sessions include four to eight participants, last 90 minutes and are facilitated by a trained therapist. Girls complete self-help activities in preparation for group internet sessions, during which they discuss their concerns and learn strategies to improve their eating behaviours and enhance their body image. Sessions are delivered through a secure online chat room and message boards. The program was delivered to 73 girls aged 12-18 years who self-identified as having body image or eating problems and improved body image and aspects of disordered eating (Heinicke et al., 2007).

Teaching young people about eating disorders and their risks through psycho-education has also demonstrated some reduction of risk for development of eating disorders in older adolescents aged 15–25 years, although not for younger groups (Wilksch and Wade, 2009). These programs encourage young people to learn about and discuss cultural and social pressures, their own body development, the dangers of dieting, healthy relationships with food and symptoms of disordered eating and how to seek help. Box 4 describes in more detail *Student Bodies*, an evidence-based psycho-educational program for late high-school and tertiary students.

#### BOX 4 **Student Bodies**

For older self-selecting female students in upper high school and tertiary education, *Student Bodies* is an online psycho-educational intervention program designed to help women establish and maintain a positive body image and to engage in healthy eating behaviours. The program was designed as an 8-week, internet-based, structured intervention program with scope for booster sessions. *Student Bodies* focuses on four areas: eating disorders, healthy weight regulation, nutrition and exercise (Beintner et al., 2012).

Source: NEDC (2012c)

There are very few economic evaluations of eating disorder prevention programs in schools. Economic modelling studies in the United States have reported results that indicate that school-based obesity prevention programs are likely to be cost-effective in preventing obesity and bulimia nervosa (Wang et al., 2011), while school-based eating disorder screening became likely to be cost-effective at the higher end of the range of 'willingness to pay' thresholds in the United States (Wright et al., 2014).

Body image programs, media literacy and eating disorder prevention activities are delivered in schools in a piecemeal fashion, dependent on available funding and school priorities. At present the Australian Government funds general mental health strategies in schools. For example, *MindMatters* (<http://www.mindmatters.edu.au>) provides resources and professional development programs to support secondary schools promote mental health and suicide prevention. *MindMatters* currently does not include a focus on eating disorders prevention and no eating disorder outcomes have been evaluated. However, there is an opportunity to link the evidence-based programs described above into this and similar government funded mental health program platforms and resources.

**IMPLICATIONS**

Disordered eating and body dissatisfaction are early warnings for the potential development of an eating disorder and are disturbingly prevalent and normalised in younger age groups.

Some prevention activities for body image and disordered eating have been shown to be effective at reducing risk and eating disorder symptoms. There is a continued need for the development and funding of evidence-based prevention activities to be delivered to young people in educational settings, potentially incorporated into other government funded youth mental health education programs.

There is significant evidence to suggest the need to consider the role of peer environments within all prevention, early intervention and treatment responses for eating disorders and disordered eating in young people.

Public information and awareness-raising needs to focus on disordered eating in addition to eating disorders, highlighting that despite social acceptance, for some people, dieting can be very dangerous.

It is important that eating disorders are both considered and screened for in a young person presenting with anxiety, stress or other emotional and psychological distress. It is important that when providing a response to disordered eating that underlying psychological stress is identified and responded to, along with issues around eating.

There is a need for prevention programs that also address comorbid conditions and shared risks, such as obesity and anxiety, to be developed and evaluated.

.....

I think it (the eating disorder) being not talked about made it more shameful and embarrassing for me...if there was more awareness and knowing it does happen to lots of people... that it shouldn't be an embarrassing thing, you should be able to reach out for help.

Young Person



## Section 4

# Early identification and help-seeking

As identified earlier in this paper, help-seeking for eating disorders is low, with estimates that only one quarter of individuals with an eating disorder seek evidence-based responses and treatments (Hart et al., 2011, Mond et al., 2010). This gap in time between onset and accessing treatment can be the difference between recovery and a lifetime experience of the disorder. Early intervention that addresses the current gaps in early identification and barriers to help-seeking is required.

## Barriers to help-seeking

Eating disorders, like other mental illnesses, are stigmatised in our community. (McLean et al., 2014). Studies suggest that only 22% of people with eating disorders access specialist treatment for their eating disorder, and identification of people with bulimia nervosa and binge eating disorder may be as low as 10% of actual cases (National Eating Disorders Collaboration, 2013).

There is a range of reasons why young people with eating disorders may not seek help early in their illness, including perceived or actual stigma, feelings of shame, low mental health literacy, fear of change and cost, as well as other socio-economic and geographical barriers.

Often families, who are in a position to identify signs of an eating disorder, also experience these barriers to help-seeking. When young people and their families do seek help, it is only when the symptoms have become severe (Hepworth and Paxton, 2007).

## Stigma and shame

Young people with eating disorders and their families report experiencing, or perceiving, stigma, often through teasing or criticism by others or the withdrawal of friends and social networks. As one young person consulted for this paper described:

“ I became quite isolated as my peers did not understand. It would have been great if I could have directed them to some information that helped explain what I was going through and what they could do to support me. I lost a lot of friendships because it was hard for them.

Low self-esteem or fear of rejection can also contribute to perceived stigma within the context of dominant cultural ideals and pressures (National Eating Disorders Collaboration, 2012a). Some young people participating in a discussion group at Orygen believed that this stigma, perceived or real, and the silence surrounding the topic results in feelings of shame and embarrassment.

In particular, stigma and misconceptions exist among young people and the broader community in regard to disordered eating, bulimia nervosa and binge eating disorder, which lead to feelings of shame and self-blame, and as a result, low help-seeking. (McLean et al., 2014, Rodgers et al., 2015).

### Low mental health literacy

As with other aspects of mental ill-health, such as depression and anxiety, a lack of knowledge of mental health symptoms is associated with poor problem recognition and delays in help-seeking (Hepworth and Paxton, 2007). A recent consultation run by the NEDC and ReachOut also found that participants demonstrated a low level of literacy around eating disorders and that while they had heard of bulimia and anorexia, many were unaware of binge eating disorder or could not identify issues relating to disordered eating (National Eating Disorders Collaboration, 2014).

In consultation for this paper, one parent also identified a limited understanding among parents of what eating disorders were at the onset of the illness:

“ Sometimes the parent does not have all the language to describe the behaviours they are seeing...and then there is an genuine issue that people don't think eating disorders are that serious...out of the five families [in one parent group] the shortest period of time from when a parent had initial concerns and when they got treatment was six months.

Even if young people and their families are able to identify the symptoms, they may not be aware of services available to support them (if such services are available). In a discussion at Orygen with young people who had a recent lived experience of an eating disorder (and were connected into clinical services), participants indicated they would not be able to identify where to direct a friend for support if they thought he/she might be at risk of, or in the early stages of an eating disorder.

Many young people are looking for that service knowledge and support within the settings or services they are already engaged in. This includes their families, educational settings and GPs (discussed in further detail in Section 4). A university student population survey by B-EAT (a United Kingdom charity supporting anyone affected by eating disorders) found that 59% of respondents who have an eating disorder believed that the university was not doing enough to support students with eating disorders or identify those at risk to assist them.<sup>1</sup> While in general

Australian universities and tertiary institutions offer counselling and health services to students, a report in 2007 found that fewer than 19% of Australian university counsellors had specialist mental health training and students reported a lack of access to mainstream mental health services (Urbis, 2007). Further investigation of this situation in 2015 is required.

### Socio-economic and geographic

There is a range of other factors that impact on help-seeking for young people with disordered eating and eating disorders. This can include living in rural and remote areas of Australia, where services are not available, are sparsely available, or are not appropriate for the young person (i.e., where they are not accessible after school hours, or are affected by the 'small town factor', which creates concerns around confidentiality). Other factors can include lower education and literacy levels; language and cultural barriers; lack of means to pay for services (Hepworth and Paxton, 2007); and gender—men are less likely to seek help for eating disorders than women (Tillman and Sell, 2013).

“ There were no services to help me. Any low-cost/free services are during the day, which means if you're trying to get your life in order/make a living to pay bills, you can't go. You have to be at the absolute worst point mentally to be able to receive any help, because there isn't anything except crisis support for those on a normal to moderate income. Effective services are priced prohibitively.

<sup>1</sup> <http://www.bbc.com/news/education-24622909>.

### The valued nature of anorexia nervosa

Anorexia nervosa is often described as ego-syntonic, in that the behaviours and values of those experiencing the illness are in alignment (DeJong et al., 2013). As a result, many people with anorexia will respond ambivalently, even negatively, to suggestions from others that they are unwell and that they need treatment (Schmidt and Treasure, 2006). They may find that treatment that intervenes in their ongoing goal of weight loss will be extremely traumatic and they may deliberately avoid or resist seeking help. In this instance family plays an important and difficult role of facilitating help-seeking and maintaining the young person's engagement in evidence-based treatments such as FBT.

### When and where young people seek help

Young people and their families are more likely to seek out and receive help for weight loss or for other comorbid presentations such as obesity, depression and anxiety than they are for an eating disorder (Evans et al., 2011).

When seeking help specifically for an eating disorder, the early experiences of clinical and health professionals set the course for future help-seeking. That is, if the first help-seeking is a positive experience (i.e. non-judgemental, knowledgeable and helpful), then the person is more likely to continue to engage successfully with future treatment and referral pathways (Schoen et al., 2012).

### General Practitioners

For many young people and their families, their General Practitioner (GP) is a first point of contact, either due to concerns about disordered eating behaviours or to seek treatment for the physical impacts of those behaviours, such as weight loss, weight gain, blood pressure, dizziness and general feelings of ill-health.

GPs are key gatekeepers into care for an eating disorder and play a critical role in both identifying possible eating disorders and facilitating access to appropriate treatment and affordable publicly funded care through the Access to Allied Psychological Services (ATAPS) or Better Access to Mental Health program described later in this paper. GPs can also play a crucial role in providing accurate and helpful information to young people and their parents about eating disorders and disordered eating which can empower them and start them off on a positive path of help-seeking.

Unfortunately, an Australian study of women with bulimia suggested there appeared to be a perception among some doctors that unless a patient was emaciated, their eating disorder is not serious. This study also found that many women felt GPs lacked sufficient time to respond to their issues in the consultation time available. (Evans et al., 2011)

It has been identified in consultations with young people and their parents that many GPs are not adequately screening for possible eating disorders, or if they are, then treat the illness with a purely medical approach, i.e., managing the symptoms and watching for the illness to become severe, rather than addressing the psychological underpinnings, motivating action and providing appropriate referrals early on. This experience is highlighted in Box 5. The failure of some key health professionals to identify eating disorder symptoms and appropriate treatment responses remain a significant problem.

### BOX 5 Experience with GPs

Many young people with symptoms of an eating disorder will often present to a GP, but for other health concerns. A study suggested that while many women would be reluctant to raise concerns of an eating disorder with a health professional in these sessions, they would welcome screening questions and well-informed confident advice (Evans et al., 2011).

This was supported by feedback from a group of young people consulted in the development of this paper who all related experiences with GPs and identified the important role they can play in early help-seeking and appropriate referral:

**P1:** 'I'd probably call my GP and they would be able to point me in the right direction'

**P2:** 'But sometimes they don't even know. Like at the beginning I had so much trouble with my GP'

**P3:** 'They just monitored my weight'

**P2:** 'Yeah mine too—you'd better watch that, and then take bloods and only act on it when they wanted me to go to emergency'

### Physical and mental health services

If professional help is sought, it is often not for the eating disorder itself. The NEDC *Gap Analysis* (2013) reported that 'when people with eating disorders do contact health professionals they rarely talk about or identify an eating disorder. It is estimated that 30% of people seeking weight loss treatment have binge eating disorder' (Hill, 2007) and that between 30–70% of people with eating disorders will actually seek help from a health professional or weight loss centre for help with their weight (rather than the eating disorder)(Hart et al., 2011).

Studies have found the majority of adolescents with eating disorders (72.6–88.2%) contacted services for emotional problems (Swanson et al., 2011) and 35% of participants with bulimia nervosa and binge eating disorder initially confided in a health professional about problems

related to depression and anxiety rather than eating concerns (Hepworth and Paxton, 2007).

Young people participating in a consultation for this paper described headspace as a place they could go to for support with anxiety and depression, but not for their eating disorder. The group identified that they had not seen any eating disorder awareness-raising resources from headspace and as such assumed they did not provide a service response. Indeed, at present, many headspace centres are not resourced to respond to eating disorders with the necessary evidence-based treatments and the duration of care needed for such a complex illness. As one young person described:

“ They (headspace) told me what I was dealing with was “too complex” especially with the trauma history I was dealing with, that complicated matters, and that they wouldn't be able to help me.

### Online

The internet is now among the top sources of information, advice or support that young people, both with and without a probable serious mental illness, are comfortable going to (Ivancic et al., 2014).

There are a number of reputable online sources for information on eating disorders available for example, through the NEDC, Butterfly Foundation, headspace and ReachOut. However, a recent NEDC and ReachOut consultation with young people identified Google Answers and Yahoo Answers as places they would go to for help on the internet (National Eating Disorders Collaboration, 2014). That young people are seeking answers to their questions on eating disorders from these web sources, when there is so much reputable information available online from highly regarded eating disorder services, indicates a possible disconnect in the promotion, search optimisation and/or presentation of these resources.

Informed by the aforementioned consultation and the resultant report, *Eating Disorders and Online Resources for Young People: User Experience Guidelines for Prevention and Early Intervention of Eating Disorders*, the NEDC has recently launched a new online resource for young people to engage young people who are either at risk of, or

experiencing, an eating disorder, or are seeking help for a friend or family member. This resource is available at <http://eatingdisordersinfo.org.au>.

While social media platforms such as Facebook and Instagram do not cause eating disorders, it is possible they can trigger feelings of body dissatisfaction, anxiety and depression and potentially kick-start a cycle of disordered eating behaviours. The existence of 'pro-ana' and 'thinspiration' networks has been widely reported and young people participating in consultation for this paper noted that linking up with other young people with eating disorders may also heighten the risk of triggering unhealthy eating behaviours:

“ My doctor told me to get rid of Facebook because people you know who have eating disorders, or even if they don't have eating disorders, you can't control what comes through your news feed but you know, someone will say I've lost x amount of weight and that will just trigger you.

The rise in use of social media among young people is significant and as such there remains a need to acknowledge young people's use of social media sites, and to continue to develop an understanding of the impacts of social media and online communities on eating disorders and direct young people to positive, supportive online environments.

### Role of family and friends

Research into young people's help-seeking for mental health concerns (Rickwood et al., 2007) found young people tend not to seek help from professional sources and that they are more likely to seek help from informal sources (family and friends). This is also true of eating disorders, where family members play an important role in identifying disordered eating and other early risk signs for eating disorders. Frequently, they may suspect a problem but not know how they should react or assist the person seek help (Hart et al., 2012).

In many instances it is parents who facilitate early help-seeking, expending significant time and resources into navigating the service system, and are subsequently required to play a large role in ensuring the young person remains engaged in services and treatments. As one parent consulted for this paper stated:

“ If a parent presents with concerns for their child regarding their eating behaviours, it is a very strong predictor of a potential eating disorder.

Reflecting the ego-syntonic nature of anorexia nervosa, as described earlier, many parents also find themselves needing to take a particularly assertive and challenging role in leading help-seeking and maintaining engagement in treatment, often in direct opposition to the wishes of the young person. Therefore it is important that eating disorder information and resources are developed for parents as well as young people and provided as early as possible in help-seeking.

### Evidence-based responses

In order to have the best chance of recovery from a diagnosed eating disorder, it is imperative that at the first point of identified symptoms, young people are enabled and empowered to access appropriate services for their location, cultural identity, gender, age and type of eating disorder as soon as possible. There is an excellent chance of recovery when eating disorders are identified and treated with appropriate evidence-based care within two to three years of onset.

### Awareness-raising and mental health literacy

Interventions that aim to improve mental health literacy and understanding of eating disorders for both young people and their core support network (family and peers) are a promising approach to improving help-seeking. In particular, family and friends play an important role in recognising risk and symptoms, reducing stigma (perceived and real), motivating help-seeking, facilitating engagement with treatment and providing hope and optimism for recovery. As such, building the mental health literacy of these networks is likely to be more effective at facilitating help-seeking than increasing the knowledge of individuals with eating disorders alone (Hart et al., 2012).

## Key gatekeepers

Given the low rates of help-seeking, and issues in self-identifying eating disorders and disordered eating, it is essential that key professionals who regularly interact with young people are skilled as gatekeepers. These could include school staff (teachers, school welfare staff), primary care, health and community service providers (GPs, nutritionists, dieticians, community health services, youth services) and staff at sporting organisations (coaches, physiotherapists).

Gatekeeper programs for eating disorders require that these important points of contact understand eating disorders and disordered eating, recognise early warning signs, reduce stigma and promote and support effective help-seeking. Hart et al. (2012) identified preliminary evidence for the use of training in mental health first aid as a suitable intervention for increasing community knowledge of eating disorders and supporting people with eating disorders to seek appropriate help, although the impact lasted only a short duration.

## Screening

Screening questions (such as the SCOFF; see Box 6) can be utilised by the professional gatekeepers listed above and have been shown to help initiate disclosure and talk about body dissatisfaction or disordered eating, leading to earlier access to treatment (Hautala et al., 2009).

A number of other screening tools exist, including the Eating Disorder Screening for Primary Care, the Compulsive Exercise Test and the Anorectic Behavior Observation Scale. One study (Cotton et al., 2003) found two individual screening questions were the most effective at identifying risk of an eating disorder:

- Does your weight affect the way you feel about yourself?
- Are you satisfied with your eating patterns?

### BOX 6 SCOFF

**S**—Do you make yourself **S**ick because you feel uncomfortably full?

**C**—Do you worry you have lost **C**ontrol over how much you eat?

**O**—Have you recently lost more than 6.35 kg in a three month period?

**F**—Do you believe yourself to be **F**at when others say you are too thin?

**F**—Would you say **F**ood dominates your life?

An answer of 'yes' to two or more questions indicates the need for a more comprehensive assessment. A further two questions have been shown to indicate a high sensitivity and specificity for bulimia nervosa:

1. Are you satisfied with your eating patterns?
2. Do you ever eat in secret?

## Referral pathways

The early stages of the treatment journey for people with an eating disorder are critical. At present a lack of referral options and pathways for eating disorders remains a significant issue for early intervention and a barrier to achieving positive health outcomes (Butterfly Foundation, Submission to the NSW Mental Health Commission).

## CASE STUDY

I first got help at the age of 13 or 14. Although I didn't want any help and wouldn't yet admit there was a problem, my mother took me along to a GP who then referred me to a psychiatrist. The psychiatrist didn't seem to know much about eating disorders and some of the things she said or recommended were laughable when I look back at them now. I was prescribed antidepressants and told to simply eat more. At that stage I was still fairly adamant that there was no real problem and I have a feeling she sent me further down the wrong track. When things got steadily worse and being a day patient at a clinic didn't help, she recommended to my mum that she take me to emergency. I was already on the waiting list to be assessed for the eating disorder program at the hospital but still had several months to wait. On arrival at the hospital I was admitted as my pulse was low and the difference between my sitting and standing blood pressure and pulse was dangerously high. In hindsight my experience could have been a lot better. If I had been able to get help directly through the hospital when the problem arose I feel that things would have been much less stressful and much more effective early on. The services for early intervention and information were not there and the time spent visiting health professionals who didn't know much about eating disorders was both a waste of money and time and as a whole, I think it left me worse off.

**Young female, 23 years**

As described by the National Eating Disorders Collaboration (2012) one of the most difficult aspects of seeking treatment for an eating disorder is finding the appropriate entry point into care. Both young people and parents involved in consultation for this paper referred to the confusing and ad hoc nature of referral for eating disorders, reflecting the complex treatment responses required. Where one initial referral may be made to a nutritionist, another is made to a psychiatrist, dependent on the knowledge of the service provider making the referral, the services available in the area, and the young person's (and their family's) access to means to finance the possibility of private health services.

Families are often left to navigate this complex service system without clear referral and care pathways promoted to them. As one parent described,

“ Many families find themselves just rattling around the system.

The emotional and psychological stress this causes for families, along with the impact of delays in accessing appropriate treatment for young people with an eating disorder, are significant issues.

## IMPLICATIONS

To improve help-seeking in young people with symptoms of disordered eating and eating disorders there is a need to:

- Reduce stigma surrounding ALL eating disorders;
- Improve mental health literacy in young people and the broader community for ALL types of eating disorders and disordered eating behaviours;
- Raise awareness of young person appropriate, accessible and reputable help sources both online and in their community for eating disorder information; and
- Ensure help-seeking services are available and affordable.

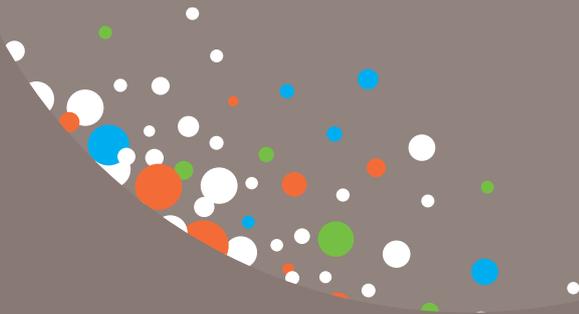
All funded youth mental health services should be able to provide early support to young people at risk of, or with early symptoms of, an eating disorder.

Early screening for risk of eating disorders can be, in many instances, provided effectively via a small number of questions. There is a need to improve the response from GPs and other health professionals to eating disorder management, led by greater knowledge, ability to screen and understanding of youth mental health and eating disorders. The current approach of 'watchful waiting' is not appropriate.

Referral pathways across the sector and within individual communities need to be developed and promoted. This requires funding and leadership both nationally and within communities.

.....

Early intervention is critical.  
People who have had an eating  
disorder for less than two years  
are likely to respond more rapidly  
to treatment and experience fewer  
physical health consequences.



## Section 5

# Early intervention and treatment

Upon early identification of an eating disorder a young person should be referred to an adequately skilled mental health specialist who can assess for all eating disorders and refer or provide the optimal treatment course. There is strong evidence for treatment approaches for eating disorders (Deloitte Access Economics, 2015) delivered within two to three years of onset, including Cognitive Behavioural Therapy Extended (CBT-E) for bulimia nervosa and binge eating disorder and FBT for anorexia nervosa in young people under 18 years.

## Evidence-based appropriate, accessible treatment

### Anorexia nervosa

For anorexia nervosa in adolescents, there is strong evidence for the success of FBT (Maudsley approach) delivered in an outpatient setting within three years of the onset of illness. In most instances 20 sessions is required however this could be extended to 30 depending on the complexity or presence of comorbid conditions (Wallis et al., 2007)

Five-year follow-up studies demonstrate that success rates for adolescents in early stages of illness are between 50 per cent and 90 per cent (Le Grange, 2005). Clearly for anorexia nervosa, good-quality treatment with well-implemented psychotherapy, family involvement and an emphasis on nutritional rehabilitation will always be more effective than treatment as usual. However, high fidelity in the delivery of family-based therapies is required to ensure these outcomes are achieved. Fidelity can depend on the

skills of the facilitator, the organisational support and commitment to the process and the network of supporting services available.

There are also instances where, families may not respond well to family-based treatment or, due to a family breakdown or dysfunction, family-based therapy is not the most appropriate or realistic intervention for a young person. More research is required into alternative evidence-based interventions for this group.

As family-based therapy is an adolescent focused intervention which emphasises the involvement of parents in treatment, there is limited evidence for the application of this model in young people over 18 years. Some clinicians report adapting the principles and interventions of FBT when working with young people transitioning out of adolescence (18-25 years), taking into account that young adults may: have had the illness for a longer period of time; have greater autonomy; and increased resistance to parental control. There is an opportunity to improve the understanding of how family-based therapy could be effectively adapted for this age group. (Dimitropoulos et al., 2015) .

For young people over 18 years a combination of CBT-E with other therapies, medical monitoring, and use of antidepressants or anti-anxiety medication is often applied (New South Wales Government, 2013). Given the delays in the markers of adulthood, resulting in young people remaining in the family home into their 20s (Arnett et al., 2014), there may be a need to further trial the efficacy of integrating elements of FBT into treatment for young people over the age of 18 years.

### Spotlight: Sydney Children's Hospital Network—Butterfly Day Program

A community-based pilot child and adolescent day program model has been developed by the Sydney Children's Hospital Network in partnership with the Butterfly Foundation (an eating disorder advocacy NGO). The program uses a family-based therapy approach and focuses on young people who are most effectively treated out of the hospital environment. The program provides options that reflect the levels of need, including more intensive early intervention, and builds further capacity to support child and adolescent eating disorder care through local health divisions.

The new service operates five days a week as a state-wide (with a focus on rural and regional areas) tertiary eating disorders day program for people aged 10–18 and their families. The model includes family, individual and group work clinical interventions, meal support, maintenance of developmentally appropriate education and psychosocial wraparound support.

(NSW Eating Disorder Service Plan, 2013)

### Bulimia nervosa and binge eating disorder

As outlined by the Butterfly Foundation (2015) and by the Royal Australian and New Zealand College of Psychiatrists (Hay et al., 2014) the best practice treatment for bulimia nervosa and binge eating disorder is 20 sessions of CBT-E, in either individual or in group settings. This is best delivered in community and outpatient settings by psychologists and psychiatrists and is effective for approximately 40–60% of individuals receiving treatment (Hay, 2013).

CBT-E is a particular version of the therapy shown to be effective across these eating disorder diagnoses and is delivered in four stages over 20 weeks. The first stage involves psychotherapy, monitoring of key behaviours and establishment of regular meals and snacks. The second stage provides the opportunity to reflect on the changes and make modifications. The third stage addresses

the main mechanisms maintaining the eating disorder and the final stage prepares for the future and relapse prevention (Hay et al., 2014).

There is also evidence to support the observation that guided self-help based on CBT, both through books and online applications, has some effectiveness as a first step intervention for bulimia nervosa and binge eating (Zandberg and Wilson, 2013, Perkins et al., 2006, Leung et al., 2013) although not for anorexia nervosa (Zandberg and Wilson, 2013). Further, a United States trial found that CBT guided self-help was a cost-effective addition to treatment as usual for recurrent binge eating (Lynch et al., 2010). Another trial in the United Kingdom comparing family therapy with CBT guided self-care for adolescents with bulimia nervosa concluded that CBT guided self-care had a slight advantage in terms of acceptability and cost-effectiveness (Schmidt et al., 2007).

As highlighted by the Government in response to the National Mental Health Commission Review there is strong evidence for the efficacy of digital mental health interventions, particularly for depression and anxiety (Department of Health, 2015). There is evidence to support online interventions for eating disorders. For example, there are a number of online self-help programs available, including Overcoming Bulimia Online (UK) and the Body Esteem project in Western Australia. The Centre for Eating and Dieting Disorders in New South Wales is also currently developing an Online Avatar Therapy Program for binge eating and bulimia nervosa which is based on CBT. For young people who find geographic, economic or service barriers to accessing face-to-face CBT for eating disorders these programs could be an effective means of delivering accessible early treatment. A United States trial reported that telemedicine-delivered (such as e-mental health technologies) CBT had the potential to be more cost-effective than face-to-face CBT for bulimia, on the basis of producing similar clinical results for a lower cost (Crow et al., 2009a).

There has been some evidence to suggest that online self-guided help tools, for example myCompass ([www.mycompass.org.au](http://www.mycompass.org.au)), are also effective interventions for a range of mood disorders and stress (Clarke et al., 2014). While these tools do not directly treat eating disorders, they may be effective at responding to comorbid conditions.

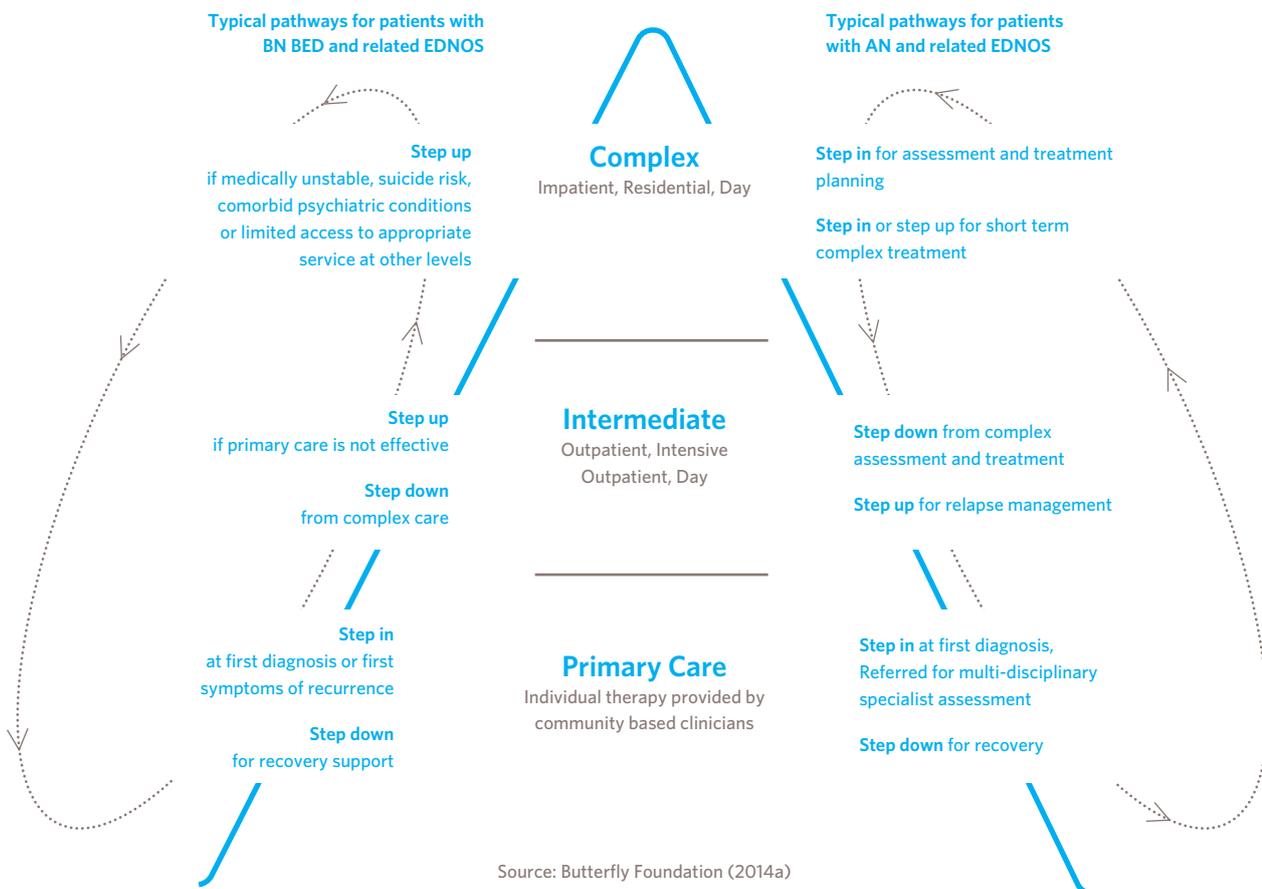
## Best practice and cost-effective standards of care

Once an eating disorder is diagnosed, Deloitte Access Economics (2015) identified that best practice in treatment of an eating disorder occurs across a number of levels of care delivered by a range of programs and across settings. The levels of care needed (including inpatient, outpatient, day programs and residential programs) depends on the severity of the illness, with the pathways between each needing to be both stepped up and stepped down, depending on the complexity of needs and the type of eating disorder. This report concluded the net benefit of delivering best practice interventions for eating disorders over treatment as usual would be \$12.3 billion.

A report by KPMG for the National Mental Health Commission in 2014, however, found that delivering optimal care for a 14 year old female with severe anorexia nervosa untreated for two years is relatively cost ineffective (primarily due to the difficulty in treating severe anorexia and the level of resources required for optimal care) (KPMG, 2014). As such, there is a need for further economic modelling to test for cost-effectiveness of optimal care across diagnoses, stages of illness and ages.

The critical element of best practice interventions for eating disorders is a 'continuum of care' model, provided across prevention, early intervention, treatment and recovery/relapse interventions (Deloitte Access Economics, 2015, Harrison, 2011). Optimal care for the stage of illness (including pre-risk and at risk) should

**Figure 3**  
Optimal care for the stage of eating disorder



be accessible at the point in time it is needed, stepped through in either direction depending on circumstances and, where appropriate, delivered with the involvement of family members (as shown in Figure 3 on page 41).

While there is evidence to suggest that stepped-care models of intervention do show promise, more research is required into their application and effectiveness in younger age groups (Bailey et al., 2014). The BETRS program in Melbourne has published promising data that shows that a CBT-based approach, supported by a day program, can assist young people who are severely underweight to achieve weight gain and psychological recovery across a range of measures (Newton et al., 2013).

What we do know is that for young people, the settings for the provision of these treatment responses need to be accessible, age appropriate and preferably delivered within their community setting. Further, for anyone with a diagnosed eating disorder, care needs to account for the psychological and medical nature of the illness. It should be provided by a multidisciplinary team that works across physical and mental health, can address comorbid conditions, is from a range of specialist disciplines and interacts with the other domains of life for a young person, including their family, their living situation and their engagement in study and employment. Services can include a mix of public and private sector settings.

In the United Kingdom, a 2010 trial comparing psychiatric inpatient and specialist outpatient treatment for young people with anorexia nervosa found little support for lengthy inpatient care on either clinical or health economic grounds, concluding that inpatient care should be targeted at outpatient non-responders (Gowers et al., 2010). An earlier trial from 2007 comparing psychiatric inpatient, specialist outpatient and general outpatient treatment options for this same group concluded specialist outpatient treatment had the highest probability of being cost-effective (Byford et al., 2007).

A number of trials across the general population have shown that stepped-care treatment for bulimia nervosa is likely to be more cost-effective than no treatment (Pohjolainen et al., 2010) and CBT on its own (Crow et al., 2013), while another modelling study in the United States also concluded that comprehensive, multicomponent

care for anorexia nervosa was a reasonably cost-effective alternative to less intensive usual care (Crow, 2014).

Finally, for all services delivering interventions and treatment for young people with eating disorders there needs to be an emphasis on evidence-based care and best practice, which require:

- Services to name eating disorders as core business in service and work plans;
- Support for staff to deliver effective interventions to a level of competency;
- Networking care across the spectrum of treatment and recovery that involves youth, adult and family service systems (reflecting the need for an approach for 12-25year olds); and
- Delivering community-based programs at a level of intensity consistent with their usual service delivery (i.e., not delivering services outside the scope of their usual practice).

While this section identified the elements of best practice evidence-based care for eating disorders, as identified by the NEDC (2013) most people are only able to access only one part of the continuum of care, and in the majority of communities across Australia there appears to be no evidence of geographic planning for a full continuum of care.

### Supporting families

Families often play a particularly strong role in the treatment of eating disorders and also require support for their role across these settings. Most people with eating disorders are not treated in inpatient settings and the burden of care falls on the family to be responsible at all times through managing and monitoring eating disorder symptoms, meal preparation and supervision and emotional support. Given this significant responsibility of care, it is important that any model of treatment for a young person with an eating disorder also builds the knowledge and confidence of parents and families to provide support and make the decisions when treatment needs to be stepped up. As one young person consulted for this paper stated:

“ I feel that a singular person doesn't have an eating disorder...the whole family system has the disorder, so they all need to be informed...the degree to which they can help their loved one is huge.

Parent support groups, education and skill-based support programs and online forums all provide much-needed assistance for families, and parent-to-parent consultation has been shown to improve the effectiveness of FBT (Rhodes et al., 2009). The 'Restore' group parent program at the Central Coast Eating Disorder Outpatient Service is a six-week educational program for parents of young people under 18 with an eating disorder adapted from the 'Nourish' Program at Westmead Children's Hospital. To date, the program has been shown to be effective at increasing the confidence of parents to support complete recovery of their child at home, along with improving progress to weight goals and reducing binge/purge behaviours. As a result, the program has reduced waiting lists for eating disorder treatment (Henry, 2014).

In consultation for this paper, parent raised the need for more support such as 24-hour helplines to raise concerns and seek advice 'without raising the bells and whistles' as well as longer term support, which could include occasional respite through a home nursing program.

### Peer support

While there is some concern about the potential risks of involving young people with a lived experience of an eating disorder in intervention and treatment programs, there has been emerging evidence to suggest a role for peer support models across treatment, including inpatient and recovery care. For many people who have recovered from an eating disorder there is a strong wish to show others that you can get better and that there is hope. As described by one young person, what would be helpful includes *'support from other young people in a recovery-focused environment that is not focused on living with their eating disorder, rather learning and rediscovering together how to live without the eating disorder.'* An example, the Child and Adolescent Health Service Eating Disorders Program (EDP) at the Princess Margaret Hospital for Children (PMH) in Perth, Western Australia, is described below (Box 7).

#### BOX 7

### Involving peers in treatment. The Child and Adolescent Health Service Eating Disorders Program (EDP), Princess Margaret Hospital for Children, Western Australia.

Over the past ten years, as people who were previously patients of the service made contact to offer help and hope to people currently experiencing eating disorders, the EDP developed consumer participation, including a youth advisory group called FACES (Freedom, Advocacy, Change, Empowerment, Support).

One objective of this group was to develop a peer mentoring program, and this was enabled through a collaboration between the EDP and the Body Esteem Program receiving a Mental Health Commission grant to develop and pilot peer support, which became the *Reaching Out of Hope Project*. The program combines the Body Esteem Program's staff expertise in peer support, with the EDP's staff expertise in adolescent eating disorders, alongside the lived experience of young people.

The project funded the development of a training program for peer mentors and the implementation of the first 18 months of group-based peer support. The project is also an ongoing co-produced research project, with formal ethics approval and evaluation of the experience of clinicians, mentors and mentees. The groups meet on two occasions and involve sharing stories of hope and recovery as well as support. The groups aim to reduce stigma, and increase hope and support for current participants of the EDP program. Participants experience a range of positive changes and the peer groups rapidly became popular and well attended.

'It was inspiring, motivating and made recovery a possibility (more real), as opposed to just imaginative hope.' Participant

## Recovery

There is no quick fix for eating disorders. They can continue for extended periods (Wade et al., 2006), and rates of relapse range from 22% to 51% across studies of anorexia nervosa and bulimia nervosa (Keel et al., 2005).

Long-term recovery support remains one of the significant challenges for early intervention in youth mental health and for eating disorders. It is important that once treatment ends, a long-term plan for recovery support is developed and the young person is linked in with ongoing support. This includes the need for follow-up for the physical health complications of eating disorders, including fertility and bone density issues.

Resourcing that support, particularly within communities and through mechanisms that enable easy access could potentially be achieved through the development of online post-recovery support tools, including peer-to-peer networking. Internet-based relapse prevention (CBT intervention) has shown promise for anorexia nervosa (Fichter et al., 2013). Online tools such as this can assist to reduce geographic, language and cultural barriers and provide young people with support throughout the day as well as enable unobtrusive ways for clinical support teams to monitor recovery and intervene as early as possible in relapse. Box 8 provides two examples of online recovery support programs, one of which is currently funded by the Australian Government.

### BOX 8

#### Online recovery support

**ED HOPE Teleweb—online peer support groups:** The Butterfly Foundation's online support groups provide the space for people with eating disorders and body image issues to connect in a safe, recovery-focused environment. The support groups are facilitated and led by experienced and compassionate counsellors who allow participants to receive guidance, support and information during the group. There are four monthly online support groups as part of its National ED HOPE Service for those suffering from an eating disorder, for parents and adult carers, and for siblings and young carers.

**B-EAT UK online support groups:** Complementing the organisation's face-to-face local support groups, these groups provide instant messaging services with people who have recovered from eating disorders and carers. They include the Recovery Club for under-18s, focusing on recovery and what it means to them, as well as open chats and themed discussions with guest speakers.

**IMPLICATIONS**

The Deloitte Access Economics 2015 report concluded the net benefit of delivering best practice interventions for eating disorders over treatment as usual would be \$12.3 billion.

There is strong evidence for effective eating disorder interventions. This includes 20 sessions of CBT-E for bulimia nervosa and binge eating disorder and FBT over 20–30+ sessions for anorexia nervosa in young people under 18 years old.

There is also some evidence to support the delivery of self-help both online and offline for the treatment of bulimia nervosa and binge eating disorder. Given the Government's commitment to digital health service delivery and the evidence available for online self-help interventions for eating disorders, this is an area recommended for development and investment.

There is, however, a lack of evidence for effective interventions for both eating disorders and comorbid presentations such as depression, anxiety and drug and alcohol disorders. More investigation and research is required urgently in this area.

Parents and families often play a significant role in treatment and relapse prevention for eating disorders, and their skills and confidence need to be developed as part of any treatment response.

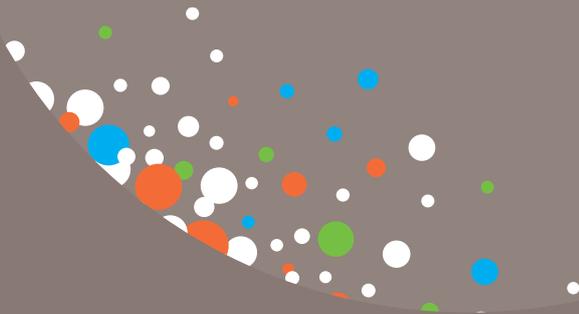
The best practice standard of care for eating disorders involves multidisciplinary teams across a continuum of care that allows a young person to step up and step down to appropriate services when they are required. In most communities this continuum of care is not available.

It is possible to recover from an eating disorder if treatment is provided early and care is provided within the community and over a suitable period of time, acknowledging the long recovery times and potential for ongoing physical health complications.

Peer support programs may provide an opportunity to enhance both treatment and recovery outcomes and are worthy of further trial and evaluation.

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All first point of call youth mental health services should have the capacity to identify risk and provide early intervention treatment for a young person with an eating disorder.



## Section 6

# The current system

In Australia we are fortunate that there are a number of highly skilled professionals, including clinicians, researchers, trainers and advocates, who provide leadership and extensive knowledge in ongoing research, prevention and treatment of eating disorders.

However, at present, there are significant gaps in available services for eating disorders across the spectrum of interventions from prevention through to treatment and recovery. There are not enough specialist services for people with eating disorders, and significant differences exist across the States and Territories in the provision of, and pathways through, eating disorder treatment responses (National Eating Disorders Collaboration, 2013). As identified in the *Victorian Government Eating Disorders Strategy (2014)* 'there is service variability, high service demand and high thresholds for entry into services in both public and private treatment.' (p29)

The service gaps are even more pronounced in those States and Territories (TAS, NT and WA) where there are no specialist eating disorder inpatient services for adults (including young people over the age of 18 years) and in rural areas where there is an absence of health practitioners with the expertise or training for appropriate assessment, diagnosis and treatment for eating disorders (New South Wales Government, 2013).

The public hospital system has limited beds available. The NEDC Gap Analysis in 2013 identified 32 hospitals across Australia for people over the age of 18 years, with no public beds in the ACT, WA and NT, and hospitals are often required to respond to urgent medical needs such as re-nutrition/hydration and monitoring. There

are also limited child and adolescent beds for eating disorders, with long waiting times. As such, most treatment for eating disorders is provided through the private sector and private hospitals. That evidence-based interventions for eating disorders are not reflected in Medicare benefits and other funding initiatives leads to difficulties in accessing treatment, particularly for people who are reliant on public health services (Deloitte Access Economics, 2015).

While private hospitals provide approximately 80 extra beds for adults (in some cases for young people aged 16 years and over) across the country, there is still a high demand for services (National Eating Disorders Collaboration, 2013). For example, in New South Wales, waiting lists for eating disorder programs in the two private hospitals that offer them can be 4-12 weeks long.

### Difficulties navigating the service system

Through the State and Territory mental health service systems, clinical responses for young people with an eating disorder are divided into the child and youth/adolescent mental health services (CAMHS/CYMHS) for 0-18 years and adult mental health services for 18 years and over. (Note: in Victoria a CYMHS service in the eastern suburbs of Melbourne provides a specialist mental health service for 0-25 year olds).

CAMHS/CYMHS services are a crucial component of eating disorder treatment service provision and central to the achievement of early treatment. Given this important role, all CAMHS/CYMHS need a service policy for eating disorders that includes an endorsement of eating disorders as core business, clear service pathways, triage and clinician training in identification and evidence-based treatment with ongoing supervision and support. Evidence-based treatment in CAMHS/CYMHS also requires effective multidisciplinary team relationships with medical professionals, inpatient back-up and access to dietetic input. At present, in many CAMHS/CYMHS this response to eating disorders is not occurring.

Further, transition between the child and adolescent and adult mental health service systems is often difficult to navigate and can result in dangerous gaps in treatment and periods of high risk (New South Wales Government, 2013). This typical age demarcation in the current system also fails to respond and adapt to the new life stages of emerging adulthood (between 18 to 29 years) and the impact of this delay to independence on young people's mental health and wellbeing and their family and home contexts. (Arnett et al., 2014)

There are many challenges in entering and navigating the eating disorder service system, which involves a myriad of services that are often not properly coordinated. For young people and their families it can be incredibly difficult negotiating between public and private services, hospital and community services, travelling to metropolitan-based services as there is nothing available regionally, and moving between the youth and adult mental health systems (State Government of Victoria, 2014).

In Queensland the Eating Disorders Outreach Service (EDOS) has been successful in facilitating patient access to local general medical and psychiatric facilities. EDOS also plays a significant leadership role in the development of effective state-wide networking forums for clinicians and key stakeholders, in in-service delivery and in the provision of evidence-based educational opportunities, each of which has contributed to improved access to services for eating disorder patients. EDOS has established decision tools, practice guidelines and training resources that may be transferrable to other State and Territory contexts (Painter et al., 2010).

The Australian Government recently announced the roll-out of 31 Primary Health Networks (PHN) across the country from 1 July 2015, with a focus on working with GPs, other primary health care providers, specialist service and local hospital networks to provide better care and improve service access and coordination. In response to the National Mental Health Commission Review (Department of Health, 2015), the Australian Government has now tasked these networks with developing and delivering a regional approach to mental health service planning and delivery. The PHNs will be responsible for service mapping, gap analyses, service integration and service commissioning that will meet identified local needs.

This response paves the way for improvements to be made within each of PHN network boundaries to respond to eating disorders so that service access is improved, treatment coordinated and local stepped-care pathways developed. Early on it is important that all eating disorders are included in the service mapping tasked to each PHN. This will require the PHNs to work with existing stakeholders and eating disorder service providers and identify opportunities to: a) respond to gaps in local treatment pathways, and b) develop locally relevant information and referral options (including online) for young people, their families and primary care professionals.

Further, the Government in its response (Department of Health, 2015) committed to "develop innovative funding and delivery models for coordinated service provision for people with complex needs and physical comorbidities" (p18). A number of PHNs have been tasked with developing regional service pathways for young people with persistent mental ill health, concurrent substance misuse and increased risk to physical ill health. This approach will be highly relevant for all people with an eating disorder, including young people.

### Lack of specialist services and trained clinicians

There is an urgent need to address a shortage in eating disorder specialist services across Australia. The NEDC (2013) identified that 85% of people seeking treatment for an eating disorder experience difficulty accessing treatment and 60% of health clinicians have difficulty referring clients for eating disorder treatment.

For many young people and their families easy access into appropriate early intervention and treatment for eating disorders is a near impossible task. There are too few psychologists and psychiatrists who are trained to treat eating disorders, or willing to be involved, given the complex and lengthy nature of treatment and the limitations on funding described below. It is important to note that there are no specialist eating disorder services in regional areas and generally most services, even in urban areas, do not provide the full range of professionals necessary to treat an eating disorder effectively.

### Funding for service access

The Australian Government has endeavoured to improve access to mental health treatment through the ATAPS program introduced in 2001 and Better Access to Psychiatrists, Psychologists and GPs through the MBS introduced in 2006. Both programs require referral from a GP and it is at the GP's discretion to determine the capacity of their patient to cover the costs of treatment.

The ATAPS program provides access to low-cost treatment for people with mild to moderate mental disorders at no cost or a low cost. The program is designed to provide access for people experiencing additional economic barriers, for example, those who are homeless, at risk of homelessness, living in rural and remote areas, or from culturally diverse backgrounds. A range of mental health professionals, including psychologists, social workers, mental health nurses, occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications are involved in the program.

The Better Access program added new mental health items to the MBS. The number of sessions a person is eligible for is capped and people may still have to pay the fee gap if the service does not bulk bill. The Better Access program provides six sessions, plus a further four on referral from a GP or psychiatrist in a calendar year. In exceptional circumstances a further ten group therapy sessions per calendar year can be provided, but it does not guarantee access to 20 sessions for each individual. In some cases, including in regional and rural areas and for young people with a diagnosis of anorexia nervosa, group therapy may not be an appropriate or an available option.

As such, neither ATAPS nor Better Access provide for the eating disorder first point treatment course that the evidence clearly indicates is required, which is 20 sessions for bulimia nervosa and binge eating disorder and up to 30 sessions for anorexia nervosa.

This initial limit of ten Medicare-funded individual sessions puts significant pressure on mental health services to deliver eating disorder interventions that require at least 20 sessions to be effective. Many services, psychiatrists and psychologists are aware that they cannot provide the level of treatment necessary, and as such do not a) access training to deliver eating disorder evidence-based eating disorder treatments, or b) accept referrals for eating disorders.

While eating disorders are not listed as an example of an eligible condition for a *Chronic Disease Management Plan* and *Team Care Arrangements*, the multidisciplinary needs of these illnesses and the length of treatment and recovery mean that they could be considered by GPs for these Medicare items. This could be one way to enable GPs to plan and coordinate the care required although anecdotal feedback from some in the eating disorders sector suggests that the labelling of an eating disorder as a 'chronic disease' is not well received.

## Early intervention

“ The services for early intervention and information were not there and the time spent visiting health professionals who didn't know much about eating disorders was both a waste of money and time and as a whole, I think it left me worse off.

The primary care and community health system is, at present, ill-equipped to respond to the growing numbers of young people who may be presenting with symptoms of eating disorders or disordered eating behaviours. Many services and primary care professionals, including GPs, do not have adequate skills and resources to screen for all eating disorders and/or recommend referral pathways in the community should they suspect risk or onset of an eating disorder (NEDC, 2013).

In 2016-17 there will be 100 headspace centres nation-wide (along with e-headspace), which provide health advice, information and support to people aged 12–25 years in general health, mental health, employment and alcohol and other drug issues. The range of services provided by each headspace centre varies depending on the a number of contextual issues, including local issues, the capacity and scale of the workforce and the funding available. Some headspace centres offer specific eating disorder responses; for example, the Eastern Melbourne Medicare Local (headspace) PEACH program and the Edinburgh North Centacare PACE program for relatives and friends of a person with an eating disorder.

However, as identified earlier, headspace centres are generally only able to offer treatment for mild to moderate mental illness, including milder presentations of eating disorders, and many centres would not be able to accept a young person presenting with a more serious eating disorder. The National Mental Health Commission Review (2014) recommended that a coordinated response to eating disorders should be included as a priority within the existing headspace model. While the Government did not respond to that recommendation directly, it did state a commitment in response to the review to: a) explore ways to provide early intervention to a broader group of young people with early signs of severe mental illness or at risk of a lifetime of severe mental illnesses, and b) provide innovative funding models for care of severe and complex

mental health conditions (Department of Health, 2015). It is hoped that eating disorders would be included in this remit.

This paper would assert that all first point of call youth mental health services, such as headspace, should have the capacity to identify risk and provide early intervention treatment for a young person with an eating disorder, and to see it as their role to do so. It should be noted that headspace centres are not able to provide a response to more serious eating disorders due to a lack of core funding and are also hampered by inadequate numbers of funded sessions through the Medicare Benefits Schedule (MBS) and a shortage of access to and funding for clinicians able to provide expert consultation for eating disorder diagnoses and follow-up with the appropriate treatment type and course, resulting in a significant shortfall for effective early intervention.

Most treatment options for eating disorders are provided through private, often costly, outpatient practices, which frequently leads to access difficulties, particularly for the many young people who are reliant on public health services.

## Prevention programs

While there are a number of evidence-based prevention programs for use in schools and other educational and community settings, there is no consistency in their funding or delivery across States and Territories, and more evidence is required to determine the length of their effect and the times at which new interventions should be delivered. Programs are generally delivered on an ad hoc basis, dependent on schools' priorities and interests, and this lack of consistent implementation can contribute to an overall negation of their impact.

Further, there is a gap in knowledge around what prevention programs are appropriate and effective in responding to body dissatisfaction and disordered eating among males and Aboriginal and Torres Strait Islander young people.

The Australian Government flagged in its response to the National Mental Health Commission Review (Department of Health, 2015) that it will develop a single integrated end-to-end school-based mental health programme building on the current platforms of MindMatters and KidsMatter. This presents an opportunity to consider how eating disorder prevention programs and positive body image programs could be incorporated into this.

## Policy responses

### Australian Government

The Australian Government does not have a policy framework or response to eating disorders or disordered eating. Eating disorders are acknowledged in the 4<sup>th</sup> Mental Health Action Plan in the context of life stages and opportunities for early intervention within a school and education context.

The Australian Government has provided funding to the Butterfly Foundation to provide support for the NEDC, which brings together eating disorder stakeholders and experts in mental health, public health, health promotion, education, and research, as well as the media, to help develop a nationally consistent approach to the prevention and management of eating disorders. Their work includes:

- Delivering a national approach and strategy to eating disorders;
- Identification of gaps in service provision;
- Building the evidence base of effective interventions; and
- Facilitating access to helpful information for young people and their families.

### State/Territories

There are three States in Australia that currently have an eating disorders policy. These are:

**Victoria:** The *Victorian Government Eating Disorder Strategy 2014* provides 'a joint agenda for working across the connected areas of prevention, early identification, treatment and support for people with eating disorders of all ages, stages and genders, and their families and carers.' The strategy is embedded within the government's broader commitment to recovery-oriented mental health care. Investment underpinning the strategy includes \$4.9 million over four years, enabling the ongoing operation and development of the BETRS program provided by Austin Health in partnership with St Vincent's, and the Wellness and Recovery Centre delivered through Monash Health and \$3 million to establish an intensive EDP at The Royal Children's Hospital (RCH), which has expanded the RCH family-based treatment program.

In 2015 the Victorian Government also announced funding for the Centre for Excellence in Eating Disorders (1.3 million) for early intervention in primary care settings and to strengthen the way services respond. Eating Disorders Victoria has received \$350,726 to enhance the skills of GPs and primary health care responders and develop a mobile phone application, while headspace will receive \$400,000 to develop an early intervention model for secondary school students.

**New South Wales:** The *NSW Service Plan, People with Eating Disorders 2013–2018* outlines the need for an increased focus on eating disorders in the State due to demand and the emerging evidence for evidence-based treatment responses that show promise for recovery. The plan presents a service delivery framework across the State for standards of care, data collection and service access, monitoring, service models across settings and the strategic priorities moving forward. For adolescents, the plan includes a community-based pilot child and adolescent day program with Sydney Children's Hospital Network and the Butterfly Foundation.

**South Australia:** Released in 2013, the *State-wide Eating Disorders Framework* describes the *South Australian Eating Disorders Service (SEDS)* and its integration with the eating disorder service system across the State. In 2014, the South Australian Government announced \$1.2 million for SEDS, a step up, step down model of integrated care and community-based treatment.

  
IMPLICATIONS

Neither the Better Access program nor ATAPS provides the level of funding required to deliver the evidence-based treatment course for eating disorder interventions. The number of sessions to be accessed in one year should be increased to a minimum of 20 for any eating disorder diagnosis, with a further ten sessions provided for a diagnosis of anorexia nervosa, comorbid presentations and complex persistent symptoms.

Eating disorders could be considered as conditions that are eligible for coordination of care through Chronic Disease Management Plans.

There is a need for a young person (12–25 years) focused specialist service response to eating disorders (providing a best practice continuum of care) within youth and community-based mental health settings.

There is a need to embed an eating disorder response across all government funded youth mental health services (including State and Territory-based child and youth mental health services and headspace centres, as identified by the National Mental Health Commission Review, 2014).

There is a lack of clinical professionals with the skills required for providing treatment responses for eating disorders in communities. Barriers to clinical services need to be addressed, including the limit to publicly funded mental health care access.

There is a continued need for national leadership to respond to eating disorders in Australia in lieu of a national policy framework and where only three out of eight jurisdictions have an eating disorders service framework. National leadership is required to respond to the current paucity of national data, research and evidence gaps, workforce development, as well as resource service system gaps.

## Section 7

# Future directions

There is strong evidence across the spectrum of interventions, including prevention, early intervention and treatment, for effectively responding to eating disorders and disordered eating in Australia. There is further evidence that in applying an evidence-based suite of interventions the benefits will outweigh the costs by more than 5.38 to 1 (Deloitte, 2015).

When responding to eating disorders in young people aged 12-25 years particular opportunities exist to increase access to services, evidence-based programs and treatments; to increase the capacity of the workforce; to build greater awareness in the community and reduce stigma; and to address gaps in research and data.

### Increase access to evidence-based early interventions for eating disorders

Currently young people and their families find it difficult to access help for eating disorders and experience confusing, unhelpful and potentially harmful service referrals and ad hoc pathways into treatment. The resulting delay in diagnosis and treatment, as well as the stress and frustration experienced, has a detrimental impact on all involved.

There is an urgent need to invest in enhancing and extending a system of primary and specialist care for young people with disordered eating/ eating disorders that is accessible, affordable and effective in both metropolitan and regional settings. This system requires funding, commitment and coordination across both mental health and medical care. There are a number of opportunities to enable this to happen, including:

- Increasing the number of Better Access sessions for a young person deemed to be experiencing the onset of an eating disorder to match the evidence base for the number of sessions required;
- Supporting early intervention services, such as headspace and other youth mental health services, to provide effective responses to eating disorders (such as CBT-E for binge eating disorder and bulimia nervosa) and referral points when higher/more urgent responses are required (anorexia nervosa and other severe presentations);
- Increasing the number of specialist services (including the capacity of child and youth mental health services, such as CAMHS/ CYMHS) with the capacity to deliver evidence-based treatment along a continuum of care; and
- Developing, and providing access to, innovative online services and supports (including CBT-E and guided self-help), which can address service access issues for those living outside metropolitan areas, and increasing opportunities for existing resources to include information on eating disorders for young people and their families.

### Increase provision of publicly funded health care for eating disorders

Current public health care funding arrangements are unable to respond adequately to eating disorders. There is a need to increase the number of Better Access MBS sessions over a 12 month period for a person with a diagnosed eating disorder so as to provide for the evidence-based treatment dosage and duration. This includes:

- 20 sessions of CBT-E for bulimia nervosa and binge eating disorder plus ten more sessions for those with comorbid conditions (e.g. drug and alcohol disorders, anxiety, depression) or delays in diagnosis (subject to review points at ten sessions and again at 20 sessions); and
- 30 sessions of FBT for anorexia nervosa.

### Improve access to coordinated care

There is a need to improve access to funding for coordinated care for a person with a diagnosed eating disorder. This includes coordination of a range of allied health services including, but not limited to, dietitians, social workers, family therapists and occupational therapists.

Clarification is required among GPs and other primary health care professionals that eating disorders (and other serious mental health illnesses) are eligible for coordination of medical care through the Chronic Disease Management Plan.

### Trial early intervention responses in headspace

Investment in an innovative early treatment response to increase access to treatment for young people with binge eating disorders and bulimia nervosa is required. Trial across four headspace centres in regional areas and cities where there is currently limited access to eating disorder services should be undertaken. The trial will build the capacity of these services to:

- Deliver evidence-based treatment of 20 sessions of CBT-E.
- Deliver family education and support for eating disorders.
- Develop and trial new treatment programs from 2017-18 that respond to eating disorders, disordered eating and other comorbid dependencies, such as obesity, anxiety, depression and drug and alcohol disorders.

This is currently outside the funding scope of current headspace centres and therefore

additional investment would be required to employ in each centre:

- A clinician trained to deliver CBT-E
- A dietician
- A family therapist
- A qualified professional to support the development of life-skills (e.g. an occupational therapist/ social worker)

The response should be embedded within the existing headspace governance, including the primary health care clinic, training and education programs, e-headspace and headspace school support.

The trial sites should be rigorously evaluated and, if effective, will provide a model to be rolled out nationally across other headspace centres and youth mental health services. Further, once capacity has been developed, an appropriate early treatment response should also be developed and implemented for more complex eating disorders, including anorexia nervosa, in headspace centres.

### Local service mapping and responses

Through a national commitment to respond to eating disorders, and the role allocated to the PHNs by the Australian Government in the response to the National Mental Health Commission review, service mapping should be tasked to each Primary Health Network to:

- Develop an eating disorders service map and gap analysis in catchment areas (where they do not already exist);
- Work with eating disorder professional associations and local service providers to develop locally relevant information and referral options (including online) for young people, their families and primary care professionals; and
- Work with existing stakeholders and eating disorder service providers to identify opportunities to respond to gaps in local treatment pathways.

This should be prioritised by those PHNs tasked with developing regional service pathways for young people with persistent mental ill- health, comorbid substance misuse and increased risk of physical ill health.

### Provide the continuum of care for anorexia nervosa and other severe presentations of eating disorders

As a priority, COAG should consider how investment could be targeted to address identified gaps in the best practice continuum of care for 12–25 year olds with anorexia nervosa and severe presentations of other eating disorders (which require a rapid referral and an intensive treatment response). This includes ensuring access for young people with a diagnosis of anorexia nervosa to:

- A multidisciplinary team providing evidence-based psychosocial treatment, medical treatment, nutritional support, family support, home and/or community-based treatment and crisis intervention services;
- Support at points of transition into adult mental health care and other points of step-up, step-down care; and
- A treatment period of up to 3 years including recovery-focused interventions and ongoing care (e.g. through the Butterfly Foundation ED Hope online programs).
- This response should be developed in partnership with the expertise of existing specialist eating disorder services.

### Increase the capacity of the workforce to deliver evidence-based early interventions

There is a need to support all relevant professions involved in the early intervention and treatment of eating disorders (including psychologist, psychiatrists, dieticians, GPs, youth mental health workers and social workers) to deliver effective interventions for eating disorders to a level of competency and facilitate local pathways through care. Ways this may be achieved include:

- Acknowledging that there are gaps in service provision and that efforts to increase identification and referral need to be mirrored by investment in national workforce development and alignment;
- Improving access to workforce development activities (for example through online training) and appropriate ongoing professional supervision to ensure fidelity in treatment provision across eating disorder interventions, including those in rural and regional locations;

- Promoting the establishment of training and sector development organisations in jurisdictions where they currently don't exist; and
- Involving young people, particularly those who have recovered from an eating disorder, in the development and delivery of services and peer-based interventions and support. As first-line evidence-based treatment for young people under 18 with an eating disorder involves families it is also important that families are also involved in this process.

### Better screening and delivery of eating disorder treatments

Youth mental health and youth health services should identify an early intervention response to eating disorders and disordered eating as part of their core business, there is a need for:

- All staff in youth mental health and youth health organisations to be trained in basic screening, supporting help-seeking and identifying referral pathways for all eating disorders; and
- A subset of staff in these organisations to be trained in advanced practice to deliver treatments and interventions at a nationally agreed level of competency.

To achieve this, national coordination (involving collaboration and partnership development) between existing training and sector development organisations) is needed to align and increase access to existing national and jurisdictional workforce development activities and resources including:

- An online platform to deliver and access training modules, information, tools and resources;
- 'Train-the-trainer' workforce development strategies;
- Direct training for organisational managers and supervisors to ensure staff are supported appropriately and that there are regular review points in organisational staff development policy; and
- Establishment and support of Communities of Practice.

### Involve young people in the response

The Australian Government should fund a national project to investigate the evidence for safely involving young people with a lived experience of an eating disorder in the development and delivery of effective interventions, including prevention programs, online and offline treatment responses.

This project should then produce a range of resources and tools to support:

- Youth engagement in eating disorder prevention and early intervention initiatives;
- Peer support models for treatment and recovery; and
- Safe and ethical use of online and social media supports.

### Increase access to evidence-based prevention programs for young people at risk

There are a number of prevention activities for body image and disordered eating that have been shown to be effective at reducing risk and eating disorder symptoms. However, these are implemented in an ad hoc fashion across schools, States and Territories, depending on funding and priorities.

Prevention and early intervention activities for disordered eating and body dissatisfaction should be delivered across schools through student health and wellbeing funded programs, as well as in community and family environments, and focus on evidence-based responses to disordered eating, such as media literacy programs and risk factor based interventions (Years 7–9), dissonance-based approaches (older age groups), mental health literacy, positive self-image and development of healthy and constructive coping strategies for with the management of psychological or emotional stress.

### Increase the capacity for schools to deliver prevention activities

Commonwealth and jurisdictional funding for health and wellbeing programs in schools and tertiary institutions should require that programs deliver and evaluate evidence-based prevention activities which specifically address eating disorders and disordered eating behaviours appropriate for the age group.

The NEDC website provides a portal to access a comprehensive list of evidence-based prevention programs and resources. This should be promoted to education based health and wellbeing program funders and providers.

### Respond to comorbid conditions

Although there are a range of evidence-based prevention activities for eating disorders and disordered eating, currently there are no programs which simultaneously address comorbid conditions and shared risks such as obesity, depression, drug and alcohol use and anxiety.

It is recommended that the NEDC and the National Centre of Excellence in Youth Mental Health are supported to take a lead role in building sector partnerships to develop and trial prevention and early intervention programs that also address eating disorders and comorbid conditions.

### National coordination and leadership

There is an opportunity to develop a national agenda that responds to eating disorders and their impact on young people, their families and the community. This agenda should be developed by the Australian Government in partnership with all State and Territory governments (and their relevant departments) and the Butterfly Foundation, on the knowledge base developed by the NEDC, the National Centre of Excellence in Youth Mental Health and involve representation from all systems and sectors necessary to deliver the best practice multidisciplinary model of intervention.

### National leadership and direction

A national commitment to respond to gaps in eating disorder service provision should be prioritised through the COAG mental health reform process and the development of the Fifth National Mental Health Plan. Prevention and early intervention responses to eating disorders should be clearly identified within all Commonwealth, State and Territory mental health frameworks; mental health policy, service and program responses; and youth policy and program responses.

This should include that all federal and state/territory funded youth mental health (including child and adolescent mental health services and headspace) and youth health services identify an early intervention response to eating disorders and disordered eating as part of their core business.

This should include at a minimum:

- Screening for eating disorders and facilitation of appropriate referral pathways;
- Guided self-help.
- The above early detection response should be identified in federal and state/territory service work plans and key performance indicators.
- This response should include a commitment that the Australian Government continue to resource the NEDC at sufficient levels to provide ongoing national collaboration and coordination.

## Build awareness of all eating disorders and reduce stigma in the community

There are still significant misconceptions and stigma around eating disorders and disordered eating in the community, and young people report accessing information from potentially damaging sources. There is a need to address these misconceptions with particular attention to:

- Obesity prevention and public health messages on healthy weight/ lifestyles;
- The relationship between eating disorders and other experiences of mental ill-health for a young person;
- The link between emotional distress and stress on the development of disordered eating behaviours and the need to direct awareness and strategies to better cope;
- Role modelling of eating behaviours and relationships with food from significant adults; and
- Incorporating elements of social media (taking into account both the opportunities and risks).

## Youth led and designed tools and resources for young people and their families

A national project should be funded to further develop both online and offline awareness-raising and information tools for young people (such as the young person resource released by the NEDC), using the evidence base from the NEDC. The project should also design effective dissemination and promotional strategies to reach young people and their parents and improve understanding of the dangers of dieting, disordered eating, all eating disorders and over-exercise for some young people.

The project should be developed in partnership with young people (including those with a lived experience of an eating disorder and those who have not experienced, or do not identify as having experienced an eating disorder).

## Address gaps in research and data

There is a need to increase data collection about all eating disorders in national and state-based population health surveys and adolescent health and wellbeing surveys. Without adequate data collection it is not possible to:

- Understand the true prevalence and nature of all types of eating disorders and disordered eating in young people;
- Understand the impact of eating disorder prevention and early intervention strategies; or
- Ensure eating disorders are part of the broader statistical picture that informs mental health funding and service design.

There are also opportunities to address research gaps and build an understanding of the prevalence and impact of eating disorders and effectiveness of interventions in a number of areas, including among young men and Aboriginal and Torres Strait Islander young people; the treatment of eating disorders alongside comorbid conditions; peer support in early intervention, treatment and recovery; prevention and effective online interventions across all stages of illness.

### Research focused on Aboriginal and Torres Strait Islanders and young men

Appropriate responses for eating disorder and disordered eating in Aboriginal and Torres Strait Islander young people and young men need to be developed.

Further research should be funded (through consideration and prioritisation by the National Health and Medical Research Council or through other targeted research funding) to better understand the nature and prevalence of eating disorders and disordered eating in these groups, determine the particular barriers to help-seeking and build an evidence base for effective and culturally appropriate prevention and early interventions.

### National data collection and harmonisation

Data collection on community prevalence should also be prioritised through the inclusion of questions relating to eating disorders in relevant ABS and upcoming AIHW population surveys on health, wellbeing and mental health. Consideration should also be given to the harmonisation of current diagnostic data collection across all jurisdictions.

The additional sessions provided through the Better Access MBS program will also provide accessible national data on the prevalence of diagnosed eating disorders in Australia.

# Conclusion

Eating disorders are a significant and urgent health issue for Australian young people, and the personal, social and economic costs of the illnesses far outweigh the investment required to provide a system that can respond early and effectively.

While many people will associate eating disorders with anorexia nervosa, for the majority of young people who are experiencing, or will experience an eating disorder, it will be binge eating disorder, bulimia nervosa or other diagnosis of the illness which they will find themselves battling.

All eating disorders are subject to significant community stigma, low recognition and understanding, poor identification, ad hoc referrals and a treatment system without resources and adequate trained personnel. What there is, however, is a strong body of evidence for an effective early treatment model across all diagnoses. This model, consisting of evidence-based treatment from a skilled workforce across many disciplines (including medical, psychological and nutritional), and across a continuum of care, provides for an excellent likelihood of recovery. Compared to the cost of lost lives, lost productivity, family breakdown, interrupted career pathways and intensive lifelong treatment once the eating disorder has become entrenched, the model may also be cost-effective.

Further, there is evidence for a number of preventative approaches, often delivered in schools and universities, that can build a healthier body image and healthy eating behaviours in all young people, and 'nip in the bud' potential pathways into an eating disorder for particularly vulnerable young people. That these programs are implemented in a piecemeal, inconsistent manner, dependent on stretched budgets and competing priorities, means that opportunities for prevention and early intervention are missed.

Much of the evidence for what works in responding to eating disorders exists. Through building this body of evidence, researchers, clinicians, service providers and experts in the field have already made significant progress in responding to these illnesses. What is needed now is a commitment and investment from governments to deliver the best practice model of care to young people in Australia, ranging from prevention and early identification, to early intervention and treatment. It is a commitment that needs to be led nationally, with all funders and providers of youth mental health services and supports in Australia viewing eating disorders as something they should have the capacity and responsibility to respond to.

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