



Submission to Productivity Commission  
Mental Health Public Inquiry

“The Social and Economic Benefits of Improving Mental Health”

April 2019

## About Eating Disorders Victoria (EDV)

For over 30 years, EDV has been listening to the stories of people affected by eating disorders. It provides us with a unique insight into their issues and what works for them. Guided by this lived experience and clinical expertise, we develop and provide a range of evidence-based peer support, education and clinical services, which respond across the spectrum of need.

Eating Disorders Victoria is a trusted and recognised organisation. We have an excellent track record of achieving outcomes, a “can do” attitude and positive relationships across the clinical, primary care and broader health and community sector.

In 2017/18, EDV connected with more than 460,000 people through our website, phone line and education programs. Specifically, we responded to ~2,000 direct requests for support, provided 528 psychology sessions and provided training to more than 900 people. For people whose lives were affected by eating disorders, we supported access to services and provided the hope they needed for recovery.

Our Victorian Government recurrent funding accounts for approximately 50% of our budget. This supports our core activities of helpline, support groups, stories of recovery speakers and education services. It also provides us with a strong foundation, which, along with our reputation, enables us to attract additional funding from a range of diverse sources, including philanthropic, fee for service and fundraising activities.

## The impact of eating disorders

Over 4% of the population lives with an eating disorder. This means there are about one million Australians with a diagnosable eating disorder and this number is increasing.<sup>1</sup>

Eating disorders are serious mental illnesses that are characterised by eating, exercise and body weight or shape becoming an unhealthy preoccupation of someone's life. They include binge eating disorder (47%), bulimia nervosa (12%), anorexia nervosa (4%) and others including atypical anorexia, avoidant/restrictive food intake disorder and other specified food or eating disorder (37%)<sup>2</sup>. They have the highest mortality of all mental illnesses, with 20% of deaths in those with anorexia nervosa caused by suicide. They also have a high disease burden, both acutely and chronically, compared to all other serious mental illnesses. They do not discriminate, affecting men and women of all backgrounds and age groups. They are the third most chronic illness for young women. Relapse rates are high at between 33–60%<sup>3 4</sup>. As a result, eating disorders cause our community significant distress and cost millions of dollars every year<sup>5</sup>.

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<sup>1</sup> Hay, P. J., Mond, J., Buttner, P., & Darby, A. (2008). Eating Disorder Behaviors Are Increasing: Findings from Two Sequential Community Surveys in South Australia. *PLoS ONE* 3(2), e1541.

<sup>2</sup> Eating Disorders Victoria website. Classifying eating disorders accessed on 5.4.2019

<https://www.eatingdisorders.org.au/eating-disorders/what-is-an-eating-disorder/classifying-eating-disorders/dsm-5>

<sup>3</sup> Couturier J, Lock J. What is recovery in adolescent anorexia nervosa? *Int J Eat Disord.* 2006;39:550–5.

<sup>4</sup> Steinhausen HC. The outcome of anorexia nervosa in the 20th century. *Am J Psychiatr.* 2002;159:1284–93.

<sup>5</sup> National Eating Disorders Collaboration (NEDC) (2012). Paying the Price: the economic and social impact of eating disorders in Australia. Available from: <https://thebutterflyfoundation.org.au/assets/Uploads/Butterfly-report-Paying-the-Price-Executive-Summary.pdf>

## **Addressing eating disorders in the Productivity Commission inquiry into Mental Health.**

EDV makes this submission to raise awareness of the impact of eating disorders on our Australian community, and highlight the continued need for investment of policy and funding frameworks to address these devastating illnesses. There have been many calls for increased investment over past decades from eating disorder organisations, professionals, and those who are most affected – people with eating disorders and their families and friends. Thankfully, there has been recent investment into the Medicare system (with new items specifically for eating disorders from November 2019) and just this week a commitment by the Australian government to provide residential services in every state and territory except NT.

However, more is needed to integrate policy and service systems across the country, across professional groups, and between clinical and nonclinical services. There is so much wastage currently with a messy and disjointed system. An integrated approach would support people to recover from their illness more fully and sooner, and the economic and social impacts would be significant for all Australians.

We have approached this submission by responding to the questions outlined in section 3 of the Productivity Commission Issues Paper: Contributing components to improving mental health and wellbeing.

### **1. Healthcare**

#### **1.1 Regarding structural weaknesses in Healthcare**

- There is no current national agenda or policy for eating disorders in Australia. This has resulted in various care models and levels of investment in the different states and territories.
- There are currently no data collection requirements for eating disorders in Australia, including through hospitals and GPs/PHNs. This was identified in 2012 in the Paying the Price report<sup>6</sup> which recommended a pressing need for data relating to prevalence of all eating disorder diagnoses, mortality data, productivity and welfare expenditure data and health system data. In 2019 we are no closer to collecting even the most basic of prevalence data, neither through the Australian Bureau of Statistics national health survey nor the primary health care system. Yet a myriad of data is collected on weight and obesity.
- The current system focuses resources on crisis care. This means that people experiencing eating disorders must be acutely unwell to access services, often meaning they have been unwell for a prolonged duration (often many years) before receiving treatment for the first time.
- Recovery from an eating disorder requires clinical and non-clinical intervention. Current pathways for treatment do not include community support as a standard part of care.

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<sup>6</sup> National Eating Disorders Collaboration (NEDC) (2012). Paying the Price: the economic and social impact of eating disorders in Australia. Available from: <https://thebutterflyfoundation.org.au/assets/Uploads/Butterfly-report-Paying-the-Price-Executive-Summary.pdf>

- Eating disorder care requires an integrated approach<sup>7</sup> between the medical and mental health sectors<sup>8</sup>. Outside the limited number of specialist eating disorder wards, the lack of integrated care means that Australians are not receiving best practice treatment.

### 1.2 Regarding specific health concerns

- Strategies that promote help seeking and early intervention for eating disorders are essential. A lack of community understanding around eating disorders results in shame, stigma and delayed help seeking. Delays in help seeking contribute to the chronicity of eating disorders. Front line health workers, especially GPs, must be confident in their ability to recognise, treat and refer patients to allied health professionals for treatment.
- Suicide has been identified as a major cause of death for people with an eating disorder.<sup>9</sup> Specifically, Anorexia Nervosa has the highest mortality rate of any psychiatric illness.<sup>10 11</sup>
- Eating disorders have a high co-morbidity rate. Research demonstrates that 55 - 97% of individuals diagnosed with an eating disorder also receive a diagnosis for at least one more psychiatric diagnosis. The most common of these are depression and anxiety disorders, followed by substance abuse and personality disorders.<sup>12</sup>

### 1.3 Regarding the health workforce and informal carers

- The current range of professionals supporting people with eating disorders is generally limited to GPs, psychologists, psychiatrists, and dietitians. The scope of professionals working in eating disorder support should be expanded to account for the diverse skills of other allied health professionals, including mental health nurses, social workers, occupational therapists and peer workers.
- Often people experiencing eating disorders have never met anyone who has recovered from an eating disorder. This diminishes hope for recovery and places eating disorders as a perceived 'life sentence'. Peer support workers who themselves have recovered from an eating disorder and work with people with eating disorders are essential in helping counteract the perceived futility of recovery<sup>13 14</sup>.

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<sup>7</sup> National Eating Disorders Collaboration (NEDC) (2018). National Practice Standards for eating disorders. Workforce Development Blueprint to the Australian Government Department of Health, May 2015. Available from: <https://www.nedc.com.au/assets/NEDC-PRACTICE-STANDARDS-final.pdf>

<sup>8</sup> Hay, P., Chinn, D., Forbes, D., Madden, S., Newton, R., Sugenor, L., Touyz, S. & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. *Australian & New Zealand Journal of Psychiatry*, 48(11): 1–62. Available from: <https://www.ranzcp.org/Files/Resources/Publications/CPG/Clinician/Eating-Disorders-CPG.aspx>

<sup>9</sup> Pompili M1, Girardi P, Tatarelli G, Ruberto A, Tatarelli R. (2006). Suicide and attempted suicide in eating disorders, obesity and weight-image concern. *Eating behaviors* 7(4):384-94.

<sup>10</sup> The National Eating Disorders Collaboration. (2012). *Eating disorders in Australia*. Sydney: NEDC.

<sup>11</sup> Harris EC, Barraclough B. Excess mortality of mental disorder. *Br J Psychiatry*. (1998);173:11–53.

<sup>12</sup> The National Eating Disorders Collaboration (2010). *Eating disorders: The way forward: An Australian national framework*. Sydney: NEDC.

<sup>13</sup> Davidson L, Chinman M, Sells D, Rowe M. (2006) Peer support among adults with serious mental illness: a report from the field. *Schizophr Bull.*;32:443–50.

<sup>14</sup> Davidson L, Chinman M, Kloos B, Weingarten R, Stayner D, Tebes JK. (1999) Peer support among individuals with severe mental illness: a review of the evidence. *Clin Psychol Sci Pract*.6:165–87.

- Peer support workers in the eating disorders sector must have thorough support systems in place through their employer. EDV have established a system for supporting peer support workers in the eating disorders space that has proven effectiveness.<sup>15</sup> This includes the use of a Wellness Plan to help manage any psychological risks as well as regular supervision.
- Informal carers play a major role in the eating disorder sector. Carer burnout is not uncommon. Informal carers need access to psycho-education programs, peer support, and psychological supports for their own mental health.

## 2. Housing, income support and social services

### 2.1 Regarding social services

- There are currently significant gaps for people with eating disorders who are not eligible for NDIS services. The system needs to address how to support people who fall into the gaps, as programs such as Partners in Recovery and PHAMS are replaced by the NDIS.
- Eating disorders are episodic illnesses. Periods of recovery and relapse are common. This impacts the tenure of employment and the ability to remain financially self-supporting. However, there is no income support for people when they are ill, especially when the illness requires long periods of hospitalisation.

### 2.1. Regarding social participation and inclusion

- Eating disorders by nature are self-isolating and exclusionary illnesses. Many people experiencing eating disorders engage in a level of secretive behaviour that disconnects them from family and social supports.
- Improving the paradigm around social supports, including home, work, family and community engagement, is needed.
- Social media can play a significant role in the development of eating disorders. Negative effects include developing low self-esteem and body image concerns. The use of social media to replicate social connectedness is a false paradigm that risks the establishment of real life relationships.

## 3. Skills acquisition, employment and healthy workplaces

### 3.1 Regarding education and training

- School staff have a role to play in the early identification of eating disorders.
  - Teachers and staff need to be aware of their own personal attitudes towards food, eating and body image and the impact this may have on students.
  - Teachers and staff require knowledge of health referrals and best practice health pathways for students who need support.
  - An example of a program that has been developed for schools is Headspace's Food for Thought.<sup>16</sup>

<sup>15</sup> Beveridge et al. Pilot and Feasibility Studies (2018) Peer mentoring for eating disorders: evaluation of a pilot program

<sup>16</sup> Headspace in schools. Food for Thought developed in 2016. Available from: <https://headspace.org.au/schools/headspace-in-schools/>

#### 4. Funding arrangements

##### 4.1 Regarding funding arrangements

- There is no national policy framework to guide funding for eating disorders. Each state has different investment and high variation, both for clinical and non-clinical services. It really is a postcode lottery for treatment, which results in sub-optimal care for many people.
- The PHNs have a role to play in the provision of eating disorder services. Eating disorders tend to miss out on funding because PHNs are not collecting data regarding eating disorder prevalence or treatment in the community.

#### 5. Measurement and the reporting of outcomes

##### 5.1 Regarding monitoring and reporting outcomes

- Without data it is near impossible to measure and report on meaningful outcomes. How can we measure what is not collected, and so Australia need a strategy to ensure consistent data collection, to then determine measurement and reporting outcomes.
- We need to collect data to measure:
  - Prevalence and type of eating disorders in Australia
  - Prevalence by geography, demographics, cultural background
  - Use of clinical and nonclinical treatment types
  - Readmission rates to acute care
  - Time from first symptoms to diagnosis, duration of illness
- In 2017 the *Delaying for years, denied for months*<sup>17</sup> report was compiled by Beat (the UK eating disorder charity). This type of insight into the Australian context is not possible because the data is not available.

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<sup>17</sup>Accessed 5 April 2019 <https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-months.pdf>