Eating Disorders Victoria Submission to Productivity Commission Response to Draft Report Mental Health Public Inquiry January 2020

Following the release of the draft report for the Mental Health Public Inquiry on 31 October 2019, Eating Disorders Victoria (EDV) would like to highlight the importance of an increased awareness of the impact eating disorders has on the Australian community, and the need for continued dedication to fund services and frameworks for people experiencing eating disorders. We would like to thank the Productivity Commission for acknowledging the need for a significant increase in funding to Australia's mental health care system and the importance of employing people with lived experience of mental illness to assist others with their recovery.

About Eating Disorders Victoria (EDV)

Not for profit organisations provide a significant portion of education, prevention campaigns and treatment services in the mental healthcare sector. 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.¹

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,

¹ 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.

avoidant/restrictive food intake disorder and other specified food or eating disorder (37%)². 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%³⁴. As a result, eating disorders cause our community significant distress and cost millions of dollars every year⁵.

Addressing eating disorders in the Productivity Commission inquiry into Mental Health

Draft Recommendation 6.1 – Supported online treatment options should be integrated and expanded

EDV recognises the strong merit of online programs in the treatment of some eating disorders and other mental health conditions. Online programs have been shown to be effective in treating binge eating disorder (BED) and bulimia nervosa (BN)⁶⁷⁸. Studies examining internet-based cognitive behavioural therapy (CBT) for BED and BN with email guidance from a psychologist have showed that these interventions have long-term positive effects on eating disorder symptoms[^]. While online treatment options are not as effective as in-person therapies, the use of online treatment programs could be expanded to reach more people who may have more limited access to in person services, or as an additional part of a person's overall treatment plan.

There is significant time and resources needed to deliver online programs and monitor clients' progression, however these programs can be more easily accessed by people who are not in close proximity to a psychologist in their area. The Productivity Commission has identified that people in regional communities have less access to face-to-face psychological therapy and should be able to access MBS rebates for video-psychological therapy. Funding online programs, particularly for

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

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

⁶ Carrard, I., Crépin, C., Rouget, P., Lam, T., Golay, A. and Van der Linden, M. (2011). Randomised controlled trial of a guided self-help treatment on the Internet for binge eating disorder. *Behaviour Research and Therapy*, 49(8), pp.482-491.

⁷ Carrard, I., Rouget, P., Fernández-Aranda, F., Volkart, A., Damoiseau, M. and Lam, T. (2006). Evaluation and deployment of evidence based patient self-management support program for bulimia nervosa. *International Journal of Medical Informatics*, 75(1), pp.101-109.

² Eating Disorders Victoria website. Classifying eating disorders accessed on 22.1.2020 <u>https://www.eatingdisorders.org.au/eating-disorders/what-is-an-eating-disorder/classifying-eating-disorders/dsm-5</u>

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

⁸ Sánchez-Ortiz, V., Munro, C., Stahl, D., House, J., Startup, H., Treasure, J., Williams, C. and Schmidt, U. (2010). A randomized controlled trial of internet-based cognitive-behavioural therapy for bulimia nervosa or related disorders in a student population. *Psychological Medicine*, 41(2), pp.407-417.

illnesses such as BED and BN which have been shown to improve using online CBT, should be investigated to improve access to psychological therapy.

Draft Recommendation 10.2 – Online navigation platforms to support referral pathways

EDV endorses the use of HealthPathways as an effective referral tool, however it should be noted that carers and consumers do not currently have access to this platform. Consumers or carers would require access to HealthPathways or a similar online navigation platform if the Productivity Commission supports consumers or carers finding and booking into services directly, or accessing more general information about referral options.

Draft Recommendation 10.3 – Single care plans for some consumers

EDV strongly supports the implementation of the single care plan, and believe it should be prioritised to help coordinate treatment for individuals requiring complex care. People with complex mental illnesses often require the care of multiple health professionals to treat the mental and medical symptoms they experience as a result of their illness. In its current state, coordination between these professionals is ineffective as a single care plan is not in place.

This single care plan could be implemented more urgently than the current 2-5 year recommendation as an immediate improvement to the care of people receiving services under multiple providers. We are confident the implementation of this plan will see an immediate benefit to those experiencing complex mental illness.

Draft Recommendation 11.4 – Strengthen the peer workforce

We have discussed the importance of using lived experience and peer mentoring in the process of recovery in our previous submissions⁹ and at the public hearing in November 2019 in Melbourne. At the public hearing the panel expressed interest in hearing more about how EDV's Peer Mentoring Program (PMP) operates.

In 2016, EDV first received funding from three philanthropic foundations to pilot a PMP for people leaving hospital. The program uses a peer support model and harnesses the experience of those who have recovered as mentors with regular debriefing and supervision. This program is unique in that it addresses a gap in developing essential skills needed to recover from an eating disorder, and is based off peer mentoring principles that allow for the safe sharing of lived experience, so that participants are given hope by sharing their lived experience with someone who has recovered from the same eating disorder.

This program is coordinated by a dedicated Peer Mentoring Program Coordinator who matches participants with mentors based on their preference for someone with a similar age, gender, eating disorder diagnosis and area of residence. Participants are able to self-refer or are referred by a healthcare professional. To participate in the program, participants must have a General Practitioner (GP), mental health professional and other social support at all times to ensure that they are adequately supported in their recovery. EDV sends letters to the participants' GP 3 times during the course of the program and has the ability to contact the GP if they become aware of any risks to the participants' health.

⁹ Eating Disorders Victoria Submission to Productivity Commission 2019 – Peer mentoring program for people with eating disorders leaving hospital treatment. Eating Disorders Victoria.

Mentors are paid as employees of EDV, rather than volunteers. They are recruited based on their professional and lived experience and must have been in recovery for at least two years. Sessions between participants and mentors are structured dependent on what will be useful to the participants' recovery, particularly in regards to developing their practical skills. The program aims to address a gap in treatment where key impacts of an eating disorder are not addressed in psychological or medical services. People with eating disorders may experience significant difficulty in completing grocery shopping or preparing a meal, so this is challenged within the meetings between participants and mentors. Using mentors with lived experience allows participants to discuss their recovery with someone who understands their symptoms and experiences. Peer mentoring does not aim to counsel participants, instead showing them how recovery is possible and encouraging them to challenge eating disordered behaviours that have prevented them from fully participating in the community due to the isolation their symptoms have encouraged.

After each meeting the Coordinator debriefs with the mentor to discuss any challenges they may have experienced and ensure both the participant and mentor are receiving benefit from their meetings. The mentor completes an online survey regarding the meeting and discusses the experience over the phone with the Coordinator. The mental health of the mentors and participants is monitored through completion of a DASS and EDEQ at the beginning, 3 month and 6 month points of the program. These evaluations are assessed by a psychologist at EDV and any increase of symptoms are discussed with the mentor or participant, with the possibility of contact with their mental health professional or GP.

Participants meet with their mentors 13 times over a 6-month period, with meetings lasting up to 3 hours. At least 3 of these meetings are held at EDV offices to ensure participants become familiar with other supports and services. After the 13 sessions are complete, participants are welcome to attend monthly peer mentoring alumni group meetings which are structured around similar practical support.

EDV procured an independent economic evaluation of the PMP in September 2018 and found that the expected cost benefit ratio of the program is 2.5, meaning that for every \$1 spent on the program, the government is expected to save up to \$2.50 in future inpatient treatment costs due to the program's effectiveness in reducing hospital readmission rates¹⁰¹¹. The program has also demonstrated effectiveness in improving the quality of life for participants, and affirming the recovery of mentors.

The program is currently funding by the Victorian State Government until June 2020, with current funding allowing for a maximum of 20 participants to complete the program each year. EDV would welcome the opportunity to increase the program capacity, but are unable to with current funding arrangements and financial uncertainty about the future of the program.

EDV is available for future consultation regarding peer mentoring programs and is passionate about the increase of the use of a clear peer mentoring framework in recovery from mental illness.

¹⁰ Economic Evaluation of the Peer Mentoring Program – Eating Disorders Victoria, 2018. Prepared by The Incus Group

¹¹ Appendix 1 – Cost Benefit Analysis infographic.

Draft Recommendation 13.1 – Reduce barriers to accessing income support for mental health carers

We applaud the recommendation to make the Carer Payment and Carer Allowance more readily available and hope this support becomes more accessible to people caring for people with an eating disorder. However, it should be noted that the current payment rate does not meet the financial needs of many individuals, and innovative payments and payment mechanisms for carers and people with disabilities should be explored.

Draft Recommendation 22.3 – Structural reform is necessary

We do not agree that the Rebuild model is the best option for structural reform of Australia's mental health system. The Rebuild model pools mental health funding and delegates sole responsibility to the State and Territory Governments to administer a mental health system. While this model may simplify funding arrangements, it splits the operation of the mental and medical health care systems in Australia.

People with complex mental health conditions, such as eating disorders, experience a variety of physical and mental symptoms that require an integrated approach between the medical and mental health sectors. A person with an eating disorder may experience nutritional deficiencies, which in turn impacts their cognitive capacity and ability to engage in effective psychological treatment. They require simultaneous and coordinated treatment of their medical and mental symptoms in order to recover from their illness.

In the system's current state, people are already not receiving best practice treatment outside of a small number of specialist eating disorder wards, as they receive treatment for mental and physical symptoms separately. An integrated approach is necessary for the care of people with complex mental health conditions and should be considered when structuring services.

For this reason, EDV supports the Renovate model. The separation of mental and medical health services will hinder the treatment of people with eating disorders or other complex mental health conditions. Creating a distinction between medical and mental health systems will mean people with complex conditions will not experience best practice treatment.