



Submission to the Select Committee Inquiry into Mental Health and Suicide Prevention

House of Representatives

Eating Disorder Alliance of Australia

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About us

The Eating Disorder Alliance of Australia (EDAA) is a group of organisations representing people with lived experience of eating disorders, family members and other carers, and health care professionals. We formed under a Memorandum of Understanding in early 2020 to work cooperatively to support information provision, joint advocacy, and to support health care professionals in the eating disorders sector.

Membership

Butterfly Foundation: Butterfly Foundation is the national charity for all Australians impacted by eating disorders and body image issues, and for the families, friends and communities who support them. Butterfly operates a National Helpline that that supports close to 30,000 people each year.

Eating Disorders Queensland: Eating Disorders Queensland is a statewide, community-based not-for-profit organisation that promotes positive body image and prevention of eating issues. Supportive therapeutic options for individuals living with eating issues and their families and friends are also offered.

Eating Disorders Victoria (EDV): EDV is the leading community organisation helping Victorians understand and recover from eating disorders. A trusted source of support since 1983, EDV delivers a broad range of free and low-cost community services that respond across the breadth of the eating disorder experience – from discovery to recovery.

Eating Disorders Families Australia (EDFA): EDFA is a national, lived-experience, carer-led support organisation for parents, partners, siblings and carers of people with eating disorders. EDFA provides connection, support, knowledge via monthly online statewide support groups, bi-monthly education sessions and monthly sibling support, as well as specialty support groups and daily support via private online forums. Clinician training in emerging therapy is also provided.

Australia and New Zealand Academy for Eating Disorders (ANZAED): ANZAED is the peak body for eating disorder professionals involved in research, prevention, treatment and advocacy in Australia and New Zealand. ANZAED fosters networking and professional development in the eating disorder field and aims to provide leadership and advocacy to improve the understanding, prevention and treatment of eating disorders.

Acknowledgements

As organisations which work with people affected by eating disorders, including families and carers, we recognise the value of lived experience as a form of knowledge and as a force for positive change. We acknowledge the insights shared with us by lived experience advocates which are reflected throughout this submission.

Executive summary

The EDAA welcomes the Select Committee Inquiry into Mental Health and Suicide Prevention (the Inquiry) and values the opportunity to contribute to the implementation of mental health reforms in light of the findings of recent inquiries such as the Productivity Commission Inquiry into Mental Health and the Royal Commission into Victoria's Mental Health System.

Several EDAA members have provided submissions to previous inquiries, however this joint submission will only cover areas relevant to eating disorders and body image issues in relation to the following Terms of Reference:

Term of Reference 1: Recent report findings and changes in the social and economic environment – in this submission we refer particularly to the strengths and limitations of the Productivity Commission Inquiry Report into Mental Health, the Victorian Royal Commission, and the impact of Covid-19 on people with body image concerns and people recovering from eating disorders (throughout submission and p 4 and p 7 in relation to Covid-19).

Term of Reference 2: Emerging evidence-based approaches to effective early detection, diagnosis, treatment and recovery, including drawing on international experience and directions – in this submission we provide evidence and commentary in relation to eating disorders and body image, with particular reference to prevention and early intervention (pp 12-13).

Term of Reference 3: Effective system-wide strategies for encouraging emotional resilience building, improving mental health literacy and capacity across the community, reducing stigma, increasing consumer understanding of mental health services, and improving community engagement with mental health services – in this submission we make particular reference to the need for improvements in eating disorder literacy, drawing on new research on community perceptions (pp 12); stigma (pp 11-12); and lived experience engagement (pp 6-7).

Term of Reference 4: Building on the work of the Mental Health Workforce Taskforce and forthcoming National Medical Workforce Strategy, the roles, training and standards for all health and allied health professionals who contribute to mental health care, including peer workers, that are required to deliver quality care at different levels of severity and complexity, and across the spectrum of prevention, early intervention, treatment and recovery support – in this submission we focus on the development of an eating disorder peer workforce and the need for ongoing training for GPs and allied health professionals in order to improve care and recovery support for people with eating disorders (pp 9-11).

Term of Reference 7 (any related matters): We provide information on gaps in the evidence base and the need for greater investment in eating disorder and body image research (pp 7-8) and equity of access to treatment and support (pp 13-14).

We would welcome the opportunity to provide oral evidence in relation to any of the matters raised in this submission.

Introduction

There is limited attention in the Productivity Commission report on complex mental health conditions such as eating disorders and the more widespread experience of body image issues. While the Victorian Royal Commission provides a more comprehensive investigation and roadmap for change which acknowledges the work of EDAA member organisation Eating Disorders Victoria, several findings and recommendations may not be relevant at the national level. Given this, the Select Committee Inquiry is an opportunity to consider issues in the eating disorder system of care that were not given adequate consideration, and to share insights from new research and emerging findings from current projects, programs and activities being undertaken by EDAA members.

For the benefit of the Committee Members who are unfamiliar with eating disorders we provide the following brief introduction to eating disorders in Australia, and include more details information about body dissatisfaction and other body image concerns on p 13.

Overview of eating disorders in Australia

Eating disorders are serious psychiatric disorders with significantly distorted eating behaviours and high risk of physical as well as psychological harm. Left unaddressed, the medical, psychological and social consequences can be serious and long term. Once entrenched, eating disorders can impact on every aspect of an individual's life and for many, can be life-threatening.

Types of eating disorders include: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Other Specified Feeding and Eating Disorders (OSFED), Avoidant/Restrictive Food Intake Disorder (ARFID), Unspecified Feeding or Eating Disorder (UFED), Rumination Disorder, and Pica.

Prevalence

At any one time, approximately 4 per cent of the Australian population – or more than one million people – is experiencing an eating disorder, while lifetime prevalence is 9 per cent (Deloitte, 2015). Of those with eating disorders: 47 per cent have Binge Eating Disorder, 12 per cent have Bulimia Nervosa, 3 per cent have Anorexia Nervosa and 38 per cent have other eating disorders – such as Other Specified Feeding and Eating Disorders (OSFED) (Paxton et al, 2012). When 'disordered eating' behaviours are included (that is, sub-clinical behaviours), using a 3-month prevalence point, a large-scale community survey found that 16.3 per cent of people in Australia have experienced an eating disorder (Hay, Girosi & Mond, 2015).

The actual prevalence of eating disorders and disordered eating behaviour in the community may be much higher. Research recently conducted for Butterfly (unpublished – available to the Committee on request) shows that from a representative national sample of 3,030 people, 17 per cent of the population – almost one in five – either have an eating disorder or have greater than three symptoms of disordered eating.

While eating disorders can affect anyone at any age, they remain more prevalent among adolescents and young people, with the average onset for eating disorders occurring during adolescence and young adulthood (Volpe et al, 2016; Hart et al, 2011). While comprehensive data on prevalence at a state and territory level is not available it is estimated that prevalence is similar across different regions of Australia (Deloitte, 2019).

Comorbidities

Eating disorders are frequently associated with other psychological and physical disorders such as depression, anxiety disorders, substance abuse and personality disorders (Hudson et al, 2007).

Mortality rate and suicidality

Eating disorders carry an increased risk of premature death due to long term medical complications and increased rate of suicide. With the exception of some substance abuse disorders, eating disorders have the highest mortality rate of any mental illness (Chesney, Goodwin & Fazel, 2014). The mortality rate for eating disorders is between one and half times to twelve times higher than the general population (Arcelus et al, 2011).

Gender differences

Eating disorders can affect both women and men, however the highest prevalence rates in Australia occur in women and girls aged 15 to 29 years, with a prevalence rate of 13.6 per cent in the 20-24 age group (Deloitte, 2019: 3). In any given year, the majority of contacts to Butterfly Foundation's National Helpline are from girls and women under 25, with numbers of contacts particularly elevated during the height of the Covid-19 pandemic – overall contacts to Butterfly's Helpline in 2019-20 increased by 47 per cent from the previous year (Butterfly Foundation, 2021). According to a large UK study, by mid-life 15 per cent of women have experienced an eating disorder, including through new onset and chronic disorders (Micali et al, 2017). According to a nationally representative study of 100,000 people in the USA, 1 in 5 women (19.7 per cent) will have had an eating disorder by the age of 40 (compared with 1 in 7, or 14.3 per cent of men) (Ward et al, 2019).

While approximately 90 per cent of people diagnosed with Anorexia Nervosa and Bulimia Nervosa in Australia are women or girls, there are significant numbers of men and boys affected by eating disorders and body dissatisfaction. National estimates produced in 2012 for Butterfly Foundation found that 36 per cent of those experiencing eating disorders are male. Instances of binge eating disorder are evenly represented across both women and men in Australia (Paxton et al, 2012), while body dissatisfaction (a risk factor for the onset of eating disorders) is a significant issue for younger men and boys. A 2017 Butterfly Foundation survey found that 40 per cent of respondents identifying as male were dissatisfied or very dissatisfied with their appearance (compared with 46 per cent of respondents identifying as female). Men and boys are subjected to specific cultural messages about appearance that can increase their vulnerability to eating disorders. These include an idealised physical body shape that is lean and muscular, and social norms that frame masculinity as about control and 'taking charge' (Griffiths, Murray, & Touyz, 2015). Eating disorders among boys and men may present differently than in girls and women, particularly with muscularity-oriented disordered eating (Nagata, Ganson & Murray, 2020). These features can mean that eating disorders among men and boys are overlooked or misdiagnosed by health care professionals.

Other demographic characteristics

Contrary to common stereotypes, large scale surveys show that eating disorders do not discriminate by income or education (Hay, Girosi, & Mond, 2015), while emerging research suggests Aboriginal and Torres Strait Islander people experience eating disorders and body image issues at a similar or higher rate than non-Indigenous people (Burt et al, 2020).

People who are LGBTIQ+ are at greater risk for disordered eating behaviours (Calzo et al, 2017). An Australian study found that two out of three young trans people have limited their eating in relation to gender dysphoria during puberty, while 23 per cent have a current or previous diagnosis of an eating disorder (Strauss et al, 2017).

Economic costs

The total social and economic cost of eating disorders in Australia in 2012 was estimated at \$69.7 billion. This includes health system costs, productivity cost and carer costs. Direct financial costs total \$17.1 million and the burden of disease costs are \$52.6 million (Paxton et al, 2012).

The estimated cost of eating disorders (in terms of disability-adjusted life years) is higher than that of depression and anxiety combined (Ibid).

Key challenges in addressing eating disorders

As set out in the National Agenda for Eating Disorders 2017-2022 (Butterfly Foundation, 2017) – which was endorsed by the Commonwealth Government – key challenges in addressing eating disorders include: the availability of a skilled workforce; access to affordable, integrated physical and mental health care; the need for early identification; gaps in the continuum of care; and enabling sustainable recovery.

In addition, and with consideration of the proposed mental health system reforms, we would add the following challenges and opportunities to this list:

- The importance of lived experience
- Limited data on prevalence, including national and state/territory breakdowns
- Limited funding for research relative to other mental health conditions
- Workforce challenges, including an under-developed peer workforce
- Lack of knowledge and high levels of stigma in the community and among health care professionals, which contributes to delayed help-seeking and poor treatment outcomes
- Low investment in prevention and early intervention programs, including limited coverage of eating disorders and body image issues within generic mental health programs in schools and community settings
- The need for equity of access to treatment and recovery support.

The following sections cover these topics in more detail as they relate to aspects of the Inquiry's Terms of Reference.

Listening to and amplifying lived experience

Under the Productivity Commission report's governance recommendation (Recommendation 22), a priority action is for 'The Australian, State and Territory Governments should establish a clear, ongoing role for consumers and carers in all aspects of mental health system planning, design, monitoring and evaluation' (Action 22.4). We note that the report recommends 'consumer and carer participation and advocacy in all aspects of the mental health system', with several recommendations including expanded consumer involvement in strategy development, design of new initiatives, greater choice of service providers and treatment options, advocacy through an expanded National Mental Health Commission, and accountability in relation to service and program outcomes.

We welcome the strong focus on lived experience throughout the Victorian Royal Commission report, which recognises lived experience as an important form of knowledge and embeds it in governance structures. This approach of centering lived experience is one that EDAA member organisations have followed. EDAA member organisations have people with lived experience of eating disorders – including as carers and family members of people with eating disorders – on their boards, various advisory groups, and across all levels of employment including roles as peer mentors, peer support group leaders, counsellors, managers, researchers, communications coordinators, and community engagement positions.

The benefits of genuine and meaningful engagement with lived experience are multiple, and include:

- development of new knowledge;
- policy design and service system improvements, including understanding how the different components of the system are functioning;
- continuous quality improvement through a person-centred approach;

- breaking down stigma through direct or indirect contact with people affected by eating disorders;
- laying the groundwork for the further development of innovative approaches to care such as peer support workers and recovery coaches; and
- effective promotion of help-seeking and help-accepting.

For people with lived experience of eating disorders, engagement can instil a sense of choice, control, confidence and wellbeing, which may form part of long-term recovery. When payment and upskilling is involved there are financial benefits and potential future employment opportunities for individuals within the mental health sector.

Principles set out in several existing guides and reports developed by federal and state mental health commissions provide a good foundation for this engagement, and should be considered as part of national mental health reforms. Resources we recommend include: the National Mental Health Commission's Consumer and carer engagement: a practical guide, *Engage and Participate in Mental Health project* (2018) and *Policy on payments for people with lived experience* (2019); the NSW Mental Health Commission's *Lived Experience Framework* (2018); and – developed by Butterfly – the *Insights into Recovery from Eating Disorders: A consumer-informed guide for health practitioners working with people with eating disorders* (2016).

Governments should seek to realise the benefits of lived experience engagement just as EDAA member organisations have sought to do through the integration of lived experience throughout the work of our organisations.

Elements of the Victorian mental health reforms that the EDAA would like to see replicated nationally are:

- More leadership roles for people with lived experience, including recognition of their contributions as thinkers and innovators. These roles are set out in the Royal Commission's recommendation for the development of a collaborative research centre for mental health and wellbeing, which will lead exemplary practice for the full and effective participation and inclusion of people with lived experience across the mental health system. Dedicated roles for people with the unique lived experience of eating disorders must be provided for in such a context.
- A focus on communities to promote good mental health and wellbeing. As has been illustrated during the Covid-19 pandemic, social connectedness, community interactions and a shared sense of belonging are critical to positive mental health outcomes. The Victorian Royal Commission recommends that 'community collectives' be resourced to drive social connection and inclusion at the local government level, as well as 'consumer-led' approaches to the design, commissioning and delivery of services.
- The integration of carers, family members and supporters in workforce capability frameworks including in dedicated support services, and a dedicated carer or family member lived experience Mental Health Commissioner role. This requires attention to family and carer inclusive values and approaches.

It is our strong view that meaningful engagement with lived experience can drive greater responsiveness to eating disorders and body image concerns across the mental health system. The EDAA would welcome

the opportunity to assist with the implementation of accepted Productivity Commission and Royal Commission recommendations by engaging with people with eating disorders and their carers and family members.

Limited data on prevalence

In relation to Term of Reference 7 ('any related matters') we note the high level of comorbidities among people with eating disorders. Eating disorders are often missed when people seek help for co-existing mental health conditions which mean eating disorders can remain undetected and untreated for many years. In this context the EDAA welcomes work underway by the Australian Bureau of Statistics on a new National Survey of Mental Health and Wellbeing, which for the first time will include two questions relating to eating disorders and body image. While we recognise the constraints on the length of the survey, we note that these two questions will not provide adequate data on eating disorder prevalence within Australia, including data on service utilisation.

Lack of nationally representative data on eating disorders is problematic given its foundational role in the development of policy and service responses. There are several impacts which follow from a lack of data of eating disorders, such as poor service planning and service provision, and limitations on service development that could support better treatment outcomes across the health system outside of specialist eating disorder services.

We recommend that future iterations of the Australian Bureau of Statistics National Survey of Mental Health and Wellbeing (or an alternative nationally representative survey) include questions which will provide a full picture of eating disorder prevalence in Australia. Given the high prevalence of eating disorders among adolescents and an apparent increasing prevalence among children, we also recommend that any future iteration of the national Child and Adolescent Survey of Mental Health and Wellbeing also include questions on eating disorders.

Limited funding for research relative to other mental disorders

In relation to Term of Reference 7 ('any related matters'), we note the small share of research funding provided to eating disorder research relative to other mental health conditions. Analysis of National Health and Medical Research Council (MH&MRC) mental health funding shows that year on year eating disorder research attracts the lowest share of the total funding pool. In 2019, just 1.6 per cent of MH&MRC mental health research funding was provided for eating disorder research. In contrast, 3.7 per cent was provided for autism research, 11.9 per cent was provided for schizophrenia research, 14.8 per cent was provided for depression research and 18.3 per cent was provided for anxiety research. This disjuncture is notable given research commissioned by Butterfly in 2012 found that the burden of disease from eating disorders (including health system costs and productivity impacts) is higher than the burden of disease from anxiety and depression combined (Paxton et al, 2012).

There is a need for appropriate funding for evaluation for existing and new services. We recommend that funding for evaluation be included part of any new funding agreements relating to eating disorder services and programs.

There is also a need for investment in translational research, and in this regard we welcome the Commonwealth Government-funded project currently being led by the InsideOut Institute to develop a National Eating Disorders Research and Translation Strategy. Several EDAA member organisations are on

the advisory committee guiding this project, which aims to establish agreed research priorities, drive excellence within the eating disorder sector, and support the transformation of service delivery in pursuit of better outcomes in prevention, early intervention, treatment and recovery. We recommend that the Commonwealth Government commit to implementing the priority actions set out in the strategy once it has been delivered in 2021, and that findings be considered as part of the broader mental health reform agenda.

Workforce challenges

Peer workforce

In relation to Term of Reference 4 (mental health workforce), we were disappointed by the relative lack of attention to peer work in the Productivity Commission report. The development of the peer workforce is of particular interest within the eating disorder sector; for example, Eating Disorders Victoria, Eating Disorders Queensland, and Eating Disorders Families Australia all deliver peer support programs as core service offerings.

The role of peer workers in supporting recovery from mental disorders is increasingly recognised as an important adjunct to clinical treatment. Peer work involves connecting with others who have similar life experiences with the aim of improving understanding, increasing hope, increasing engagement in treatment and reducing the risk of relapse (Basset, Faulkner, Repper, & Stamou, 2010; Lawn, Smith & Hunter, 2008).

The National Eating Disorders Collaboration (NEDC) recently commissioned the development of a Peer Work Guide (2019, see <https://nedc.com.au/professional-development/peer-work/>), to promote and facilitate the implementation of evidence-based peer work in treatment and support services for people with eating disorders. The Peer Work Guide included an evidence review which concluded that there is a limited evidence base on peer work for eating disorders, however this research shows that the experience and outcomes of peer work are similar to those found in other mental health settings (Part A, 2019). For people recovering from eating disorders benefits include increased hope, improved engagement with treatment, and sustained remission of symptoms during the long process of recovery post treatment. For carers and family members, benefits include a reduction in stress, overcoming isolation, and increased sense of agency and efficacy as partners in the treatment process.

Developing the evidence base for the efficacy of peer support and/or peer recovery coaches in the care of people with eating disorders is a priority for EDAA member organisations. As with the broader mental health peer workforce, eating disorder peer programs have shown some promising initial results, for example, the peer mentoring program pilot run by Eating Disorders Victoria. Mentees in this program demonstrated improvements in body mass index, quality of life, eating disorder symptomatology, mood (depression, anxiety and tension/stress) and perceived disability from pre- to post-program. Qualitative findings from both mentees and mentors were positive: themes included hope for recovery, a sense of agency, and inspiration gained from interaction with someone with lived experience of an eating disorder (Beveridge et al, 2019).

While there was discussion of the role of peer work in the mental health system in the Productivity Commission report (Chapter 16) and a recognition of some of the challenges in terms of standards and training, the accompanying recommendation was not listed as a priority reform, and was limited to the following:

The Australian Government should strengthen the peer workforce by providing once-off, seed funding to create a professional association for peer workers, and in collaboration with State and Territory Governments, develop a program to educate health professionals about the role and value of peer workers in improving outcomes. (Action 16.5)

By contrast, the Victorian Royal Commission report found that: 'The experiences, points of view and expertise of people with lived experience of mental illness or psychological distress are not valued, understood or recognised' (Final Report – Summary, 2021, p 12). As part of their response to this finding, the Interim report of the Royal Commission made recommendations for the development of the lived experience workforce, including peer worker pathways and training – such as free TAFE courses in Certificate IV in Mental Health Peer Work (Interim Recommendation 6, 2019). The free TAFE courses have already been implemented by the Victorian Government.

We recommend that supporting the development of the peer workforce, including defining roles, pathways, and training be a key feature of mental health workforce strategy to underpin the mental health system reforms. The EDAA would welcome the opportunity to be involved in this process as it relates to the communities we serve, noting the complexity and differing levels of severity across the spectrum of eating disorders.

Training for health professionals

Another area that requires ongoing investment in relation to eating disorders is improving the knowledge and skills of health professionals (Heruc et al, 2020; Hurst et al, 2020; Heruc et al, 2020). EDAA member organisations have heard many stories of inadequate responses within the health system, both through direct engagement with the community and through research reports. For example, people seeking treatment for eating disorders surveyed by Butterfly in 2020 found that 57 per cent of the sample said that their experience of care would have been improved if the health professional had a greater knowledge of eating disorders. Comments shared by survey participants included the following:

GPs need to be provided with more training and information about eating disorders so that they can spot the symptoms, monitor patient's condition more closely and refer patients to appropriate services within a reasonable timeframe

I believe GPs need greater knowledge about eating disorders as I was initially referred to inappropriate psychology services which could not cater to the treatment of anorexia. I also believe that GPs need improved and clear guidelines on how to look after someone with an eating disorder.

GPs need further education on how to identify and treat eating disorders. Many of them are old school and just have no clue. (Butterfly Foundation, 2000a)

These findings, and research in the Australian context (Cain et al., 2017) demonstrate the need for ongoing education and training for GPs and allied health professionals in order to improve care and recovery support for people with eating disorders. ANZAED's recently developed practice and training standards for mental health professionals and for dietitians, along with the NEDC's core competencies for eating disorder treatment, provide a solid foundation from which training content and workforce capability targets can be evaluated (Hurst et al, 2020; Heruc et al, 2020).

EDAA member organisations have been contributing to the education of health professionals, including most recently through supporting and monitoring the roll out of Medicare-subsidised Eating Disorder Management Plans (EDMPs). Since November 2019 new MBS item numbers for eating disorders have been supporting greater access to care of appropriate intensity and duration, with positive feedback received through Butterfly (2020b) and ANZAED (2020) surveys.

Notwithstanding this very welcome policy change, significant issues and gaps in the continuum of care for people with eating disorders remain, and there is variability in the quality and accessibility of services for people living in different areas of Australia. Even with the MBS rebates, out of pocket costs are still in the order of \$4,000 per annum, which is prohibitive for people living on low incomes. For people in regional, remote and very remote areas in particular, factors such as geographical distance, lack of awareness and training among primary health practitioners, and service fragmentation have a disproportionate negative impact on those living outside of metropolitan areas (Butterfly Foundation, 2020a).

ANZAED's recent survey of health professionals found there were mixed views on whether MBS Items ensured access to competent care. In both the ANZAED and Butterfly surveys concerns were raised regarding GPs having a lack of knowledge about eating disorders and in initiating the Eating Disorder Plan. Another issue that has been identified is access to psychiatrists and paediatricians with appropriate expertise. Several recommendations for improvements have been made to the Department of Health.

With regard to access to psychiatrists and paediatricians, we note the Productivity Commission report's Recommendation 10, Action 3 ('The Australian Government should introduce a Medicare item for GPs and paediatricians to get advice from a psychiatrist about a patient under their care') regarding GPs having timely access to psychiatrists. If accepted by the Commonwealth Government this recommendation could be used to address a barrier that has been identified in the roll out of EDMPs, namely, the requirement for psychiatric review mid-plan. This recommendation could be considered as part of a review of the implementation of MBS-subsidised EDMPs.

Community attitudes, stigma and help-seeking

In relation to Term of Reference 3 ('improving mental health literacy and capacity across the community, reducing stigma, increasing consumer understanding of mental health services, and improving community engagement with mental health services') we note the Productivity Commission report recommendation for a national anti-stigma strategy (Recommendation 8), and welcome the government's agreement to fund the National Mental Health Commission to undertake this work as a priority action.

There is a strong link between the low level of help-seeking among people with eating disorders and stigma. Less than one in four people (23.2 per cent) with eating disorders seek professional help (Hart et al, 2011). Stigma and shame are the most frequently identified barriers for accessing treatment. Other factors include denial of and failure to perceive the severity of the illness, practical barriers such as cost of treatment, low motivation to change, negative attitudes towards seeking help, lack of encouragement from others to seek help, and lack of knowledge about help resources (Ali et al, 2017).

Stigmatising views about eating disorders are common within the community. New (unpublished) research conducted by Butterfly with a large community sample (n = 3,030 people) shows that one in four people in Australia believe that if people with eating disorders 'were stronger people, they wouldn't be doing this to themselves', while three in five people believe that 'most people think that bingeing/purging is disgusting'.

These responses demonstrate the need for a strong evidence base to guide effective anti-stigma interventions in relation to eating disorder. Existing research on eating disorder stigma in community samples – largely from the USA – shows that eating disorder stigma differs from other types of mental health stigma. For example, in one study people with anorexia nervosa were viewed as ‘most to blame for his/her condition’, were best able to ‘pull him/herself together if he/she wanted to’, and were most ‘acting this way for attention’ compared to people with other conditions (Stewart, Keel, & Schiavo, 2006). Another study found that attitudes toward people with eating disorders are significantly more stigmatising than attitudes toward people with depression (Roehrig & McLean, 2010).

Stigma and low mental health literacy is not just limited to the general community but is evident within health care settings (Hay et al, 2005; Anderson et al, 2017; Currin, Waller & Schmidt, 2009). EDAA member organisations have multiple examples of stories from people with eating disorders and their family members and carers who have experienced unhelpful responses in accessing health care. For example, many Butterfly survey respondents have felt that health care workers minimised the seriousness of eating disorders. Some people said that health care workers did not believe that eating disorders were real illnesses, with a number of respondents told they were wasting hospital beds and that they should simply ‘eat more’ or ‘eat less’. Examples provided by survey respondents included the following:

A nurse once told me to go to McDonalds and get a burger, it couldn't be so hard.

I was told at a hospital that they would not treat her, as it is her choice to have an eating disorder.

I've had medical professionals not take me seriously because binge eating wasn't seen as a real disorder. Also, I felt like some of these professionals treated me reaching out for help as an excuse for my obesity, rather than helping me get the right support I needed.

Professionals treated me reaching out for help as an excuse for my obesity, rather than helping me get the right support I needed. (Butterfly Foundation, 2020a).

Stigma is also closely related to discrimination. In the survey mentioned above, Butterfly found that experiences of discrimination were common, with nearly a third of respondents saying they had experienced discrimination in accessing services. When elaborating, one respondent said: ‘I was told that my ethnic background doesn't get eating disorders and that I would grow out of it’. Another respondent referred to: ‘Being called the wrong name and pronouns consistently. Accessing some of the health care systems made me worse instead of better’ (Butterfly Foundation, 2020a).

Related to stigma, community knowledge about eating disorders is another area that requires attention. While community understanding of conditions such as depression and anxiety has improved markedly in recent decades thanks to the efforts of organisations such as Beyond Blue, knowledge of eating disorders remains very low. Only one in ten people in Australia can recognise the signs and symptoms of eating disorders (Butterfly Foundation, unpublished). EDAA member organisations will continue efforts to improve knowledge of eating disorders however without additional resources it will be difficult to shift this low benchmark among the general population.

The evidence outlined above points to the need for greater community awareness activity, targeted education about eating disorders for health professionals, and eating disorder-specific anti-stigma initiatives under the national anti-stigma strategy. It is critical that a robust evidence base be established to support anti-stigma eating disorder interventions in the Australian context, and the EDAA would welcome

the opportunity to either lead or partner in this research. We recommend that resourcing under the strategy be dedicated for investigation of eating disorder stigma, including research and consultation with sector and lived experience representatives. A 'one size fits all' approach to improving knowledge and reducing mental health stigma will not be sufficient to tackle eating disorder stigma and may even be harmful if not grounded in evidence.

Lack of investment in prevention and early intervention

In relation to Term of Reference 2 ('emerging evidence-based approaches to effective early detection') the EDAA welcomes the focus of Productivity Commission report on the social and emotional wellbeing of children – early childhood and schooling (Chapter 5) and the Victorian Royal Commission's recommendation in relation to two service streams: an infant, child and family mental health and wellbeing service stream for those aged 0–11 years old, and a youth mental health and wellbeing service stream for those aged 12–25 years old.

Body image and eating concerns can start early in life, and the more preventative measures that can be made during this time the greater the return in terms of positive health outcomes (and associated health system cost savings). We note that the Productivity Commission report cites Butterfly's evidence that 'eating disorders funding focuses on treatment while prevention remains ad hoc' (Volume 2, p246). However, there is little in the recommendations that supports a change to this situation.

Body dissatisfaction, dieting and stigmatising attitudes among children

To provide some context for the importance of prevention and early intervention in relation to body image and eating disorders, body dissatisfaction is now common among children under 12. Stigmatising weight attitudes form from very early in childhood, and are related to appearance-based teasing, which are linked to the development of body dissatisfaction and unhealthy behaviours. Body dissatisfaction is an important risk factor for negative physical, mental and social outcomes including unhealthy dieting and muscle building behaviours, depression, anxiety, higher weight and eating disorders (Paxton & Damiano, 2017). In one study, nearly 50 per cent of girls aged 9 to 12 years old reported feeling dissatisfied with their body (Clark & Tiggemann, 2008). Another study found that found that 54.8 per cent of boys ages 12 to 18 expressed a desire to alter their body in some way (Lawler and Nixon, 2011).

Importantly, greater body concerns from ages 5 and 7 have been shown to predict dieting by age 9 (Evans et al., 2013; Dohnt & Tiggemann, 2006). By the time they reach adolescence, 1 in 6 girls have already employed at least one potentially dangerous method of weight reduction.

This research underscores the importance of working to address the social determinants of negative body image and disordered eating with children and adolescents before thoughts and behaviours become entrenched. Without preventative strategies and early intervention, interrupted physical, educational and social development can pose risk of significant medical complications in the long-term, along with other mental health issues.

Relatedly, it is important to acknowledge that general mental health and wellbeing programs for children and young people (as discussed in Chapter 5 of the Productivity Commission report) will not necessarily address body image issues and the thoughts and behaviours which are precursors for the development of eating disorders.

The EDAA would welcome the opportunity to be involved in the development or redevelopment of any programs which will support knowledge and skill development in the prevention and early intervention domains. It is also critical that the role of diet culture, weight stigma, and associated discrimination (including weight stigma in many well-intentioned physical health campaigns) be addressed, along with the dominance of social media 'wellbeing influencers' in the lives of children and young people.

The EDAA would welcome Commonwealth Government funding to further develop prevention initiatives in home and community settings (such as education and recreational sport settings) so that current efforts such as those delivered by Butterfly's Prevention Services (which are funded largely by corporate partnerships and modest fees for service) can have greater reach and impact in the Australian community.

Equity of access to treatment and recovery support

As noted in the Introduction, and with reference to Term of Reference 7 ('any related matters'), eating disorders can affect everyone, including cohorts which are traditionally under-served by the mental health system. These include people with low socioeconomic status (deciles 1-3), LGBTIQ+ communities, and Aboriginal and Torres Strait Islander people. The Productivity Commission report provides several recommendations in relation to these groups (Recommendations 9, 22 and 24, plus across all 'person-centered' reform areas), which the EDAA would support as critical priority areas for action.

Also critical are cohorts who experience complex mental health conditions and for whom universal public health initiatives and low intensity approaches are often either unsuitable or ineffective. As canvassed throughout this submission, this group includes people with eating disorders, who may present with a range of comorbidities and physical health complications.

As with other mental health conditions, social and economic determinants of eating disorders and body image issues must be central in the reform agenda. Multiple factors outside of the health care service system can precipitate the development of eating disorders. For example, food insecurity is correlated with eating disorder symptomatology along with anxiety and depression (Becker et al, 2019). These factors call for a mental health lens to be cast over economic and social policies which may on the surface bear little relationship to the outcomes sought by the Productivity Commission report recommendations.

In relation to eating disorders, feedback from practitioners and people with lived experience is that the current system is often difficult or even impossible to access (due to cost, geographic distance, availability of specialist care, or/and hospital beds). The system of eating disorder care is difficult to navigate for many, while as noted above, knowledge and skill in the identification and treatment of eating disorders is lacking among many GPs and allied health professionals. These issues are of ongoing concern for the community that EDAA member organisations work with, even with the introduction of MBS subsidised items. This situation points to the need for ongoing universal and targeted awareness-raising and health professional training to be built into the implementation of the suite of mental health reforms.

Of relevance here are the emerging findings from the Sunshine Coast Eating Disorders Access Trial (SCEDAT), which is currently in its final phase. A research trial partnership with Butterfly, Flinders University, the Thompson Institute and the Sunshine Coast Primary Health Network, this wrap-around service features a care navigator that links participants with the right care team at the right time and via the right method and treatment pathway. Under SCEDAT, no psychiatric review is required; this is a current

barrier in the implementation of EDMPs as noted above. Observations to date show that the trial is supporting coordinated, person-centered care. Of particular relevance in the mental health reform context is the trial's approach which uses a new tool designed to detect disordered eating before it develops into a full-threshold disorder, thereby avoiding the costs of treatment for more severe conditions. While a confidentiality agreement is in place which limits the public sharing of further information on SCEDAT, with the permission of the Department of Health we would be happy to provide more information to Committee Members should this model be of interest.

Conclusion

There is limited attention in the Productivity Commission report on complex mental health conditions such as eating disorders and the more widespread experience of body image issues. Without genuine engagement with lived experience, greater investment in research and the mental health workforce, targeted anti-stigma initiatives, improvements in community attitudes and a greater weighting of the mental health dollar towards prevention, there will be little change in the eating disorder system of care and the people whose lives depend on it.

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