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Inquiry into the opportunities to improve mental health outcomes for Queenslanders

Submission

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Who is Eating Disorders Queensland (EDQ)?

EDQ is a state-wide, community-based not-for-profit organisation, funded by Queensland Health. We provide the largest community support and treatment services in QLD for individuals and families living with and recovering from eating disorders, their carers and loved ones. Through the sharing of recovery wisdom, we aim to involve people with a lived experience, carers and family members and loved ones.

Support options include therapeutic and psychosocial support for individuals and coaching and community connection for carers. EDQ also provides early intervention opportunities with community education events focussed on creating healthy relationships with food and our bodies. **We are passionate about eradicating weight stigma and diet culture**.

EDQ welcomes the Select Committee Inquiry into Opportunities to Improve Mental Health Outcomes for Queenslanders and values the opportunity to contribute to the implementation of mental health reforms considering the findings of recent inquiries such as the Productivity Commission Inquiry into Mental Health.

There was 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[1] did provide a more comprehensive investigation and roadmap for change which acknowledges the work their state funded NGO, Eating Disorders Victoria (EDV) achieved. EDQ sits in the same space as EDV and hope to have a similar impact as our Eating Disorder Alliance of Australia (EDAA) partner, during this enquiry.
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

[1] Royal Commission into the Victorian Mental Health System. (2019). Interim Report. Melbourne, Victoria: State of Victoria

new research and emerging findings from current projects, programs and activities being undertaken by EDQ and their EDAA partners.

Our Response:

(a) The economic and societal impact of mental illness in Queensland:

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.[2]
The estimated cost of eating disorders (in terms of disability-adjusted life years) is higher than that of depression and anxiety combined.[3]

Societal impacts – Stigma

There is a strong link between the low level of help-seeking among people with eating disorders and link to stigma. Less than one in four people (23.2 per cent) with eating disorders seek professional help.[4] 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.[5]

Stigmatising views about eating disorders are common within the community. New (unpublished – available to the Committee on request) research conducted by Butterfly with a large community sample (n = 3,030 people) show 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'.

[2] Deloitte Access Economics. (2012). *Paying the price. The economic and social impact of eating disorders in Australia*. Report for the Butterfly Foundation. Canberra.
[3] Submission to the Select Committee Inquiry into Mental Health and Suicide Prevention-Eating Disorders Alliance of Australia 2021
[4] Hart, Granillo, Form, & Paxton. (2011). Unmet need for treatment in the eating disorders: a systematic review of eating disorder specific treatment seeking among community cases. *Clinical psychology review*, 31(5), 727–735. https://doi.org/10.1016/j.cpr.2011.03.004
[5] Ali et al. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *The International journal of eating disorders*, 50(1), 9–21. https://doi.org/10.1002/eat.22598

These responses demonstrate the need for a well-funded and resourced Community based sector, who is best placed 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.[6] Another study found that attitudes toward people with eating disorders are significantly more stigmatising than attitudes toward people with depression.[7]
EDQ 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. Similarly, many Butterfly survey respondents have felt that healthcare 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.'*
>
> *'Professionals treated me reaching out for help as an excuse for my obesity, rather than helping me get the right support I needed.'*[8]

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'.

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[6] Stewart, Keel, & Schiavo. (2006). Stigmatization of anorexia nervosa. *The International journal of eating disorders*, 39(4), 320–325. https://doi.org/10.1002/eat.20262
[7] Roehrig, & McLean. (2010). A comparison of stigma toward eating disorders versus depression. *The International journal of eating disorders*, 43(7), 671–674. https://doi.org/10.1002/eat.20760
[8] Butterfly Foundation. *Maydays 2020 Service Report: Barriers to accessing eating disorder healthcare and support.*

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'.[9]

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). EDQ 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 QLD and EDQ would welcome the opportunity to either lead or partner in this work and research.

We recommend that resourcing be dedicated for investigation and implementing community-based programs for 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.

(b) The current needs of and impacts on the mental health service system in Queensland :

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 **(AN),** Bulimia Nervosa **(BN),** Binge Eating

[9] Butterfly Foundation. *Maydays 2020 Service Report: Barriers to accessing eating disorder healthcare and support.*

Disorder **(BED),** Other Specified Feeding and Eating Disorders **(OSFED),** Avoidant/Restrictive Food Intake Disorder **(ARFID),** Unspecified Feeding or Eating Disorder **(UFED),** Rumination Disorder, and Pica.[10]

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.[11]

The actual prevalence of eating disorders and disordered eating behaviour in the community may be much higher. Research recently conducted for Butterfly (unpublished) 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. [12,13]
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.[14]

QLD Presentations

"The methods used in this report apply national prevalence rates to local population cohorts, since there are no region-specific data available. Using this method, ***approximately 4%*** *of the population in each PHN will be directly affected by EDs, and each person would be best served through a multidisciplinary treatment approach for the highest chance of recovery. The estimates in this report could be compared with the number of people covered under existing treatment regimens to assess unmet care needs.*[15]

[10] *Understanding Eating Disorders'* is available - https://eatingdisordersqueensland.org.au/help-with-eating-disorders/
[11] Deloitte Access Economics. (2015). *Investing in need: cost-effective interventions for eatying disorders.* Butterfly Foundation.
[12] Volpe, Tortorella, Manchia, Monteleone, Albert, & Monteleone. (2016). Eating disorders: What age at onset?. *Psychiatry research*, 238, 225–227. https://doi.org/10.1016/j.psychres.2016.02.048
[13] Hart et all. (2011)
[14] Deloitte Access Economics. (2019) *Prevalence of eating disorders by primary health network.* National Eating Disorders Collaboration.
[15] Deloitte Access Economics. (2012).

Estimated Qld Prevalence by type of ED on 30 June 2019, by PHN (thousands of people)[16]

PHN	# Affected (000s)	AN	BN	BED	EDNOS (OSFED)	Prevalence %	General Population
BNE North		1.3 (0.12%)	*5.3 (0.51%) (0.47% National)	***19.8 (1.91%)**	16.5 (1.59%)		
Male	15.2						510.6
Female	27.7						525.6
Persons Total	42.9					***4.14%**	1,036.2
BNE South		1.4 (0.12%)	5.9 (0.50%)	***22.5 (1.91%)**	18.6 (1.58%)		
Male	17.3						582.8
Female	31.1						595.2
Persons Total	48.4					***4.11%**	1,178.0
Gold Coast		0.7 (0.11%)	2.9 (0.46%)	***11.7 (1.87%)**	9.6 (1.53%)		
Male	8.8						305.1
Female	16.1						321.1

[16] Deloitte Access Economics. (2019) *Prevalence of eating disorders by primary health network*. National Eating Disorders Collaboration.

Persons Total	24.9					3.98%	626.2
Darling Downs & West Moreton		0.6 (0.11%)	2.7 (0.45%)	***10.5 (1.80%)**	8.6 (1.47%)		
Male	8.0						289.8
Female	14.4						294.8
Persons Total	22.4					3.83%	584.6
Western QLD		0.1 (0.11%)	0.3 (0.45%)	***1.2 (1.84%)**	1.0 (1.50%)		
Male	0.9						33.0
Female	1.6						31.1
Persons Total	2.5					3.89%	64.1
Central QLD, Wide Bay, Sunshine Coast		0.8 (0.09%)	3.4 (0.39%)	***15.5 (1.76%)**	12.4 (1.40%)		
Male	11.7						435.0
Female	20.4						446.7
Persons Total	32.1					3.65%	881.6

Northern QLD		0.8 (0.11%)	3.3 (0.46%)	***13.3 (1.86%)**	10.9 (1.52%)		
Male	10.3						361.3
Female	17.9						355.8
Persons Total	28.3					3.94%	717.2

The prevalence of Bulimia Nervosa (BN) - adjusting for population size, the 3 PHNs with the highest rates of BN are North-western Melbourne, Central and Eastern Sydney and **Brisbane North.**

***Indicate higher estimated prevalence by diagnosis**

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.[17] The mortality rate for eating disorders is between one and half times to twelve times higher than the general population.[18]

Other demographic characteristics

Contrary to common stereotypes, large scale surveys show that eating disorders do not discriminate by income or education[19], while emerging research suggests Aboriginal and

[17] Chesney, Goodwin, & Fazel. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World psychiatry : official journal of the World Psychiatric Association* (WPA), 13(2), 153–160. https://doi.org/10.1002/wps.20128

[18] Arcelus, Mitchell, Wales, & Nielsen. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. *Archives of general psychiatry*, 68(7), 724–731. https://doi.org/10.1001/archgenpsychiatry.2011.74

[19] Hay, Girosi, & Mond. (2015). Prevalence and sociodemographic correlates of DSM-5 eating disorders in the Australian population. *Journal of eating disorders*, 3, 19. https://doi.org/10.1186/s40337-015-0056-0

Torres Strait Islander people experience eating disorders and body image issues at a similar or higher rate than non-Indigenous people.[20]

People who are LGBTIQA+ are at greater risk for disordered eating behaviours.[21] 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.[22]

Equity of access to treatment and recovery support

Eating disorders can affect everyone, including cohorts which are traditionally under-served by the mental health system. These include people with low socioeconomic status, LGBTIQA+ 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-centred' reform areas), which the EDQ will 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 any 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.[23] 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.

[20] Burt, Mitchison, Doyle. et al. Eating disorders amongst Aboriginal and Torres Strait Islander Australians: a scoping review. *Journal of eating disorders*, 8, 73 (2020). https://doi.org/10.1186/s40337-020-00346-9
[21] Calzo, Blashill, Brown, & Argenal. (2017). Eating Disorders and Disordered Weight and Shape Control Behaviors in Sexual Minority Populations. *Current psychiatry reports*, 19(8), 49. https://doi.org/10.1007/s11920-017-0801-y
[22] Strauss et al. (2017). Trans Pathways: the mental health experiences and care pathways of trans young people. Summary of results.. 10.13140/RG.2.2.19410.25284.
[23] Hazzard, Loth, Hooper. et al. Food Insecurity and Eating Disorders: a Review of Emerging Evidence. *Current Psychiatry Reports* 22, 74 (2020). https://doi.org/10.1007/s11920-020-01200-0

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. According to The National Agenda for Eating Disorders "the separation of primary care and care originating from hospital leaves the intermediate levels of care to be delivered by private health providers. This is not an effective approach to meeting the needs of people with eating disorders who require longer term, multi-disciplinary and relatively intensive treatment and recovery support which cannot be readily provided in primary health. This gap in community-based care directly contributes to the escalation of both physical and psychological health problems and the risk of suicide. The solution to the significant gap in the mental health system lies between primary and secondary care, in **genuine community-based care of intermediate intensity**" page 5.[24]
Without affordable, accessible, and equitable community-based care, people with eating disorders will continue to present for the first time to Emergency Departments with all the attendant consequences for their own health and safety as well as **costs to the health system.**

These issues are of ongoing concern for the community that EDQ work with, even with the introduction of MBS subsidised items. Many clients are bouncing back to EDQ as the gap fees for 40 sessions with a health professional in private practice become unaffordable. The 20-session review by a psychiatrist is also an access and affordability barrier.

This situation points to the need for ongoing and increase funding for the community sector, especially for specialist service like EDQ.

EDQ is grateful that the Queensland government has acknowledge the need for more funding during the pandemic, as the peak NGO community service and a key component of the current QLD stepped care model in collaboration with Hospital and Health services.
We urge the committee to review the impact the on-going pandemic and the steady increase demand for our services in relation to our current state funding has. [25] EDQ has seen an increase in the number of clients engaging in therapeutic services, individual and

[24] *The National Agenda for Eating Disorders 2017 to 2022* – Butterfly Foundation for Eating Disorders
[25] *Clinical Guidelines – For Therapeutic Interventions in Eating Disorders* – Gilmore; EDQ (2021)

group-based peer work and individual carer coaching between 2019/20 and 2020/21. Notably, there was a 77% increase in the number of clients who engaged in individual counselling or therapeutic groups. There were substantial increases in the number of hours that clients were engaged in individual peer work (+ 94%), and therapeutic services (+ 48%).[26]

(c) Lived Experience

EDQ support a vibrant community of individuals recovering from an eating disorder, including people with lived experiences, carers and family members. Lived experience drives our service delivery. We promote the voices of lived experience through consultation, employment opportunities and Board representation of both Carer and Peer Lived Experience.'
EDQ has developed a robust Peer Mentor Program, with strong positive outcomes since 2013.

We have found our internal Peer Training, support, and ongoing workforce development far more useful than the current CERT IV- In Mental Health Peer Work. The feedback from our lived experience workers is that that the CERT IV is not up to standard and does not meet the needs of their roles. "The implementation of peer work strategies in eating disorders has been relatively slow by comparison with other areas of mental health and there is a very small body of evidence on peer work for eating disorders." [27]

Peer work initiatives for eating disorders also identify challenges and barriers to peer work that are very similar to those found in the general mental health literature. Key areas of concern are lack of understanding of the peer work role[28], unsupportive work environments and maintaining personal mental wellbeing.[29] Introducing peer work into existing service delivery approaches requires complex change at the organisational level as well as in individual beliefs and practices.[30] Achieving the benefits of peer work is dependent on organisational commitment to change and a skilled and supported peer workforce. [31]

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[26] *EDQ Annual Report 20/21* https://eatingdisordersqueensland.org.au/about/
[27] *Developing a Peer Workforce - Part A.* National Eating Disorder Collaboration. 2019
[28] Kemp, & Henderson. (2012). Challenges faced by mental health peer support workers: Peer support from the peer supporter's point of view. *Psychiatric Rehabilitation Journal*, 35(4), 337–340. https://doi.org/10.2975/35.4.2012.337.340
[29] Moran, Russinova, Gidugu, & Gagne. (2013). Challenges experienced by paid peer providers in mental health recovery: a qualitative study. *Community mental health journal*, 49(3), 281–291. https://doi.org/10.1007/s10597-012-9541-y
[30] Repper. *Peer Support Workers: Theory and Practice.* Implementing Recovery Through Organisational Change. 2013.
[31] *Developing a Peer Workforce – Part A.* 2019

EDQ would like to see support/funding for our well established, with evidence attached to it, Eating Disorder Peer Mentor/Speaker Training.[32]

Thank you for the opportunity to contribute to this important Inquiry. We look forward to reviewing the recommendations put forward by the Committee. We have a cohort of persons with lived experience as workers, carers, and people with/recovering from eating disorders who are available to discuss their feelings and experiences further if needed. Please do not hesitate to contact EDQ should you require any further information.

EDQ would like to thank The Butterfly Foundations' Dr Sarah Squire for some of the write up of this submission.

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[32] *EDQ Annual Report 20/21* https://eatingdisordersqueensland.org.au/about/