

The Social and Economic Benefits of Improving Mental Health: Eating Disorders and Negative Body Image

- Economic Impacts and Funding

A submission by the Butterfly Foundation to Productivity Commission 2019

Funding Related Issues

The Butterfly Foundation represents all people affected by eating disorders and negative body image, individuals with the illness, their family and their friends. As a leading national voice in supporting their needs, Butterfly highlights the realities of seeking treatment for recovery, and advocates for improved services from both government and independent sources. Throughout its work Butterfly also emphasises the critical importance of prevention and early intervention strategies in limiting the development of, and suffering from, negative body image and eating disorders.

Butterfly collaborates with many organisations who are engaged in prevention or assistance to those working to improve the lives of those affected by eating disorders with contributions to this report acknowledged within the narrative. Butterfly has been appointed to co-ordinate the National Eating Disorder Collaboration 'NEDC' for the Australian Department of Health and Ageing and recognises the members of the NEDC for ongoing contributions to establishing evidence based best practice guidelines for delivery of optimal care.

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.

Currently around 4% of the Australian population, approximately one million people, is experiencing an eating disorder.

Eating disorders do not discriminate by age, gender, ethnicity or socio-economic status. Eating disorders not only impact on the person experiencing the disorder, but also on their family, friends and community. Many eating disorders peak in the teenage years resulting in a prolonged waste of personal and economic potential. Inability to prevent the development of eating disorders followed by delays in early diagnosis and access to integrated care, exacerbate and prolong the illnesses, at significant expense in both

suffering and dollars for both those directly affected plus their carers and also for the community.

In 2012 Deloitte Access Economics, in its *Paying the Price* Report (1), estimated there were more than 913,000 people in Australia with eating disorders with total socio economic cost including burden of disease of \$69.7 billion. The productivity impacts of eating disorders were estimated to be similar to those of anxiety and depression with costs born largely by individuals but also by government and employers. The 2015 Deloitte Access Economics report *Investing In Need* (2) further illustrated the clear business case for optimal treatment interventions for eating disorders, delivering a five to one benefit cost ratio for government investment on behalf of the community.

Why have past reform efforts by governments over many years had limited effectiveness in removing the structural weaknesses in healthcare for people with an eating disorder mental illness? How would you overcome the barriers which government have faced in implementing effective reform?

An historic problem as illustrated in the *National Agenda for Eating Disorders 2017-2022* (3) is the 'cycle of neglect' whereby the absence of eating disorders from many health policies plans and protocols reflects a history of failure to treat eating disorders as serious and complex illnesses. A cycle has developed in which the needs of people with eating disorders are not prioritised and therefore people continue to experience avoidable harm.



National Agenda for Eating Disorder 2017-2022

Governments have begun to recognise eating disorders as a significant issue including with recognition as an issue in the Fifth National Mental Health Plan. Federal government funding has been announced expanding the National Helpline coverage, support of research, increased Medicare coverage available from November 2019, and with ongoing

support for the NEDC with the mandate to provide best practice evidenced based guidelines. State government funding and services, plus not for profit entities, are also active stakeholders though with variation in service provision between geographies.

A fundamental issue and barrier to success in treatment is lack of general societal understanding of the nature of eating disorders as a serious issue and one which is beyond the control of the affected individuals or their carers. Stigma remains significant with a lack of open discussion around experience and impact of eating disorders and hence need for services. Early intervention is paramount however with a lack of focus on prevention, diagnosis and treatment in community care.

Availability of data is limited with need to understand barriers and focus on physical recording and information analysis plus qualitative issues driving willingness for data to be recorded (by health care provider or sufferer).

A further structural weakness relates to the need in working with eating disorders to engage a multidisciplinary team e.g. GP, psychology, dietician, psychiatrist, social worker. Arrangements to provide such a structure including effective communication and data sharing are sub optimal.

Workforce availability and training

What, if any, structural weaknesses in healthcare are not being targeted by the most recent and foreshadowed reforms by governments? How should they be addressed and what would be the improvements in population mental health, participation and productivity?

To support service planning there is need for improved understanding and hence evidence of the need with data collection and analysis a necessary area of focus.

Need for focus on data recording, reporting measures and accountability to ensure that service planning and development at all levels continues to prioritise the development of a variety of evidence based responses to eating disorders.

How could training and continuing professional development be improved for health professionals and peer workers caring for people with a mental illness?

For people with eating disorders, safe treatment requires access to skilled professional treatment for psychological, physical and nutritional aspects of their illness. Best practice management of eating disorders requires an integrated, multidisciplinary network of primary and specialist care. Depending on the age of the patient and the severity of the illness, it may also require close liaison with the education, social work and voluntary sectors. The evidence based component of treatment is located in the skill of the staff

working with the patient. Therefore all patients with eating disorders need to be treated by someone who is trained to deliver this treatment (4).

Scope of practice as relates to eating disorders is under developed. Investment is required to ensure adequate provision of quality training for health service professionals and, as relevant, initiation of credentialing for the various professions.

An appropriate balance is required between ensuring an adequate workforce and delivery of quality, safe and effective, services.

Need for investment to put in place systems of accredited training (and materials) and scope of practice/credentialing

NEDC information (5) indicates that implementation of **peer work strategies** in eating disorders has relatively low take up by comparison with other areas of mental health and there is also a relatively small body of evidence. The evidence that does exist however, indicates that the experience and outcomes of peer work are comparable to those found in general mental health settings. Identified benefits include increased hope, improved engagement with treatment and sustained remission of symptoms during the long process of recovery post treatment. For families, benefits include a reduction in stress, overcoming isolation, and increased sense of value as partners in the treatment process.

The future NEDC publication Guide to Peer Workforce will indicate the health outcomes benefits to be achieved from utilising a peer workforce whilst also emphasising that commitment to organisational change and investment is required to establish a skilled and supported peer workforce.

More broadly Butterfly encourages the participation of local consumers and carers in all service decision making, working collaborating with local community or state based agencies. As noted stigma remains significant with lack of open discussion around the nature of lived experience and hence service needs. Discussion and story-telling is significant to the reduction of stigma.

Butterfly recommends further research and consideration of investment to support enhanced communication around the nature of lived experience, inclusion of lived experience input across all eating disorder services, and to support introduction of appropriately skilled and supported peer workforce initiatives.

Funding Arrangements

Can you provide specific examples of sub-optimal policy outcomes that result from any problems with existing funding arrangements?

The November 2019 access to a dedicated MBS eating disorders item code will impact the cost to patient of eating disorders however with a watch out that a problem may be deemed to be solved whereas barriers to access will remain e.g. MBS funding provision limited to 'severe or complex', remaining out of pocket costs, not all required services covered, workforce may not be available under Medicare.

In a 2018 Butterfly consultative survey *Cost of Eating Disorders* (5) 600 people responded to an anonymous online survey, used to gather their experiences in paying for treatment and the impact these costs had on their day to day lives.

The average respondent to the survey was aged between 18 and 35, and identified as female. They had their own experience of an eating disorder, most commonly Anorexia Nervosa.

Access to Treatment

Most commonly people saw a Psychologist or Counsellor/Therapist and GP on a regular basis as part of their treatment. 58% of respondents said they had had a hospital inpatient admission at some stage during their treatment and 51.5% had accessed a specialist eating disorders service.

Almost two thirds of respondents indicated that they had experienced some form of financial barrier to care, with some respondents noting multiple barriers. Most commonly this related to not being able to afford treatment as frequently as needed.

The Cost of Treatment

Most commonly, people spent a total of approximately \$4500 per year on treatment and associated costs after reimbursement from Medicare and private health insurances. Cost experience varied greatly, from no out of pocket expenses, to \$50,000 annually for treatment and \$60,000 annually for other expenses.

People payed for treatment using a mixed approach, with most using some combination of Medicare, self-funding, and then private insurance. Other funding avenues commonly reflected that family members, usually parents, had paid for the treatment.

More than 1 in 3 respondents (34.4%) indicated that they had to go in to debt to pay for their treatment.

The Impact of Treatment Costs

72% of respondents indicated that their well-being, welfare or relationships had been negatively impacted by the cost of their eating disorders treatment.

Many respondents found other areas of their life negatively impacted by the focus on eating disorders treatment and recovery. Almost half (44.7%) saw their family or social activity impacted, while 1 in 4 had to forgo health care (e.g. for another family member or ailment) or food/essentials (e.g. becoming behind in utilities payment) to be able to pay for treatment.

The results of this consultation show that the financial cost of eating disorders treatment in Australia has a significant, negative impact on:

- The quantity and quality of treatment a person can access, including whether or not a person can access treatment at all
- Financial distress and debt
- the ability for individuals and families to afford other life needs
- Family dynamics and relationships
- Psychological function and capacity for recovery.

The cost of eating disorders treatment, as part of the broader experience of having an eating disorder or caring for someone with an eating disorder, can result in sustained disadvantage across a person's lifetime.

When discussing the impact of the cost of eating disorder financially, experiences were complex, and factored in not only the high cost of private treatment, but also the loss of income resulting from decreased capacity to work, for both those with their own experience, and carers.

Respondents shared common experiences of the difficulty and distress that this financial burden caused them and the impact that had on their quality of relationships, social connections and economic status.

A significant proportion of respondents had missed work or education opportunities due to their illness, impacting on their quality of life and future employment opportunities. More than half of those with their own experience said they had missed work or study hours, and approximately 40% said they had missed out on completing studies or gaining a qualification because of their illness.

While not directly related to the payment of treatment, these **opportunity costs** have a direct and sustained impact on a person's capacity to work and earn in to the future. The following examples are illustrative of many respondents' experience:

- "I have fully withdrawn from university studies three times now and cannot work more than two days per week"
- "I went from a 40+ hours per week job to part time hours and reduced days. Then to not working at all"

- “This has been a hugely impacted area of my life - causing me to drop out of university and reduced my capacity to work. My whole life trajectory was halted”
- “For us the biggest expense was having to forgo income as 2 professionals who have had to give up work to look after our son full time. This means forgoing about 0.5 FTE of income.”
- “ I have to forgo a day a week (at least) to obtain treatment”
- “ I have had to give up work and go on Disability Pension”
- ‘Finishing school was so hard. I'd missed so much school and it felt like I had much bigger things going on.’

Butterfly recommends the establishment of further studies, e.g. a follow up to Deloitte’s Paying the Price to track the totality of costs including societal associated with eating disorders.

How does the way the MBS operates impact on the delivery of mental health services? What changes might deliver improved mental health outcomes?

In 2018 the Governments announced November 2019 implementation of a dedicated single Medicare Benefits Scheme item number for eating disorder treatment for those with severe and complex illness, delivering up to 60 Medicare funded sessions of treatment – 40 psychotherapeutic and 20 dietetic across the range of eating disorders – anorexia nervosa, bulimia nervosa, binge eating disorder and atypical presentations. This initiative represents a significant advance however with impact to be determined in terms of understanding those who will qualify and take up plus the timely availability of providers.

Out of pocket expenses will likely remain an issue and with early intervention potentially not covered by ‘severe and complex’.

Butterfly recommends ongoing review of the take up of the new MBS code and research into remaining barriers to access so as to guide future investment.

Are decision-making forums for mental health receiving high quality and timely information on which to base strategic decisions?

Decision makers do not receive high quality or timely information on which to base strategic decisions due to lack of recording of eating disorders. Data availability is very poor to the extent that some service providers indicate no evidence of eating disorders within their catchment. There is a need to understand and focus on physical recording and information analysis plus qualitative issues driving willingness for data to be recorded (by health care provider or patients).



What does improved participation, productivity and economic growth mean for consumers and carers? What outcomes should be measured and reported on?

Given eating disorders commonly occur in School and University aged persons it is suggested that time lost from the educational system by measured as a surrogate for lost productivity and economic growth.

References

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3. The National Agenda for Eating Disorders 2017-2022. Butterfly Foundation.
4. Developing a Skilled Workforce: A Consultation Paper, 2013. National Eating Disorders Collaboration.
5. NEDC personal communication in anticipation of Guide to Peer Workforce, 2019. National Eating Disorders Collaboration.
6. Cost of Eating Disorders, 2018. Information available from the Butterfly Foundation.