The Butterfly Foundation
Submission to the Senate Community Affairs Committee
Inquiry into Commonwealth Funding and Administration of Mental Health Services

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The Butterfly Foundation
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About The Butterfly Foundation

The Butterfly Foundation (Butterfly) is Australia’s largest national non-government organisation providing support to people who are affected by eating disorders.

Since 2002, Butterfly has been working closely with health professionals, academics, service providers, philanthropic foundations, funding bodies, schools, government and most importantly those who are suffering from eating disorders, their carers and families. Butterfly's activities aim to positively change the culture, policy and practice in the prevention, treatment and support of eating disorders to one that is accessible and available to all, multidisciplinary, holistic and non-punitive.

Butterfly also works to raise awareness of eating disorders and negative body image as serious social, medical and mental health issues and to provide support for intervention, prevention, research and treatment programs.

Butterfly is also currently coordinating the Government’s three year commitment to the National Eating Disorders Collaboration (NEDC): an initiative that is fully funded by the Department of Health and Ageing. The NEDC is overseeing the development of a national, evidence based and long-term approach to the promotion, prevention, early intervention and management of eating disorders. It is a collaboration of over 200 members across all states of Australia who are interested and experienced in eating disorders.

Eating Disorders and Mental Illness

An eating disorder is a serious mental illness that manifests itself as a total preoccupation with control over one’s body weight, shape, eating and exercising. While the psychiatric diagnostic criteria focus on the physical behaviours and impairment of someone suffering from an eating disorder, a sufferer will concurrently be grappling with severe psychological problems.

Eating disorders include Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Eating Disorders Not Otherwise Specified (EDNOS). They can affect anyone but occur most frequently in adolescence. Research has shown that a person can be genetically predisposed to develop an eating disorder, or influenced by environmental factors. In both cases, environmental triggers play a significant role in the onset of the illness.
An eating disorder is not a lifestyle choice and sufferers can be found at every age, of any socio-economic profile, of any race and be male or female. The incidence of eating disorders in the total population is estimated as being between 2-3% (450,000 – 680,000 people) and increasing, while the average age of onset is decreasing. Children as young as eight years old are being admitted as inpatients for serious eating disorders. Eating disorders affect more women than men, however eating disorders may be under-diagnosed in men due to them being less likely to seek help for an illness that is often seen to only be a ‘women’s issue’.

Eating disorders have the highest lifetime mortality rate of any psychiatric illness (up to 20%) and mortality rates are 12 times higher for women suffering from an eating disorder than for unaffected women.

Another disturbing trend is the apparent increase in early onset eating disorders. Analysis of The Children’s Hospital Westmead eating disorders unit data, specifically looking at eating disorders in the 5-13 year old age group has indicated the high rate of incidence in this age group. It appears that the illness is striking children at a younger age, and so severely that hospitalisation is usually required. This is analysed in greater detail in Annexure A.

It is important to note that treatment outcomes for adults suffering from eating disorders are poor. Less than 50% of adults recover within 5 years of diagnosis. Considering this, it stresses the importance of early identification and intervention. The Maudsley Family-Based Treatment (FBT) has shown improved recovery rates of 70% after 12 months and 90% after 5 years for children, prior to the development of potential chronicity in adult patients.

In most instances eating disorders are co-morbid with another psychiatric condition including anxiety, depression, obsessive-compulsive traits, self harm or social dysfunction with up to 86% of those suffering from an eating disorder having co-morbid depression, approximately 64% having a co-morbid anxiety disorder and approximately 58% with personality disorders.

Cost of Eating Disorders to Individual Health and the Community

The issues surrounding eating disorders are of national public health significance. Eating disorders carry one of the highest burdens of disease in Australia, involving high human, social and economic cost.

The human and economic burden of eating disorders is showing no sign of reducing in prominence, with recent Australian data suggesting the prevalence of disordered eating behaviours...
binge eating, purging, strict dieting, and fasting – increased over two-fold from the mid-1990s. Mission Australia’s 2010 national survey of more than 50,000 young people identified body image as the leading issue of concern for 11-14 and 15-19 year olds and for females. Almost one-in-two 20-24 year olds considered it a major concern. For young males, body image was the second highest concern behind alcohol - 27.4 per cent to 28.5 per cent. Every person who is diagnosed with an eating disorder has suffered from negative body image and this can be a serious trigger in the development of an eating disorder. Negative body image usually results in dieting behaviours and dieting is the highest risk pathway into a clinical eating disorder.

There is currently no hard economic data to determine the full cost impact of eating disorders, however Butterfly is currently examining options to commission a national economic impact study to examine this issue. There is no doubt that the full national economic impact of eating disorders is huge. This is not just because treating an eating disorder is expensive, but because of all the flow on effects an eating disorder has as a burden of disease. The consequences of an eating disorder are not limited to the acute phase of the illness but may also be long term, with the impact being felt in the young person’s arrested growth and development, relationships, and career prospects. Even if they recover from the eating disorder component, as adults they are likely to experience significantly higher levels of anxiety and depressive disorders, and long term medical complications including early onset of cardiovascular problems, renal difficulties, and osteoporosis.

Anorexia Nervosa and Bulimia Nervosa alone are the 10th and 8th leading causes, respectively, of burden of disease and injury for young women 15-24 years old, measured in disability adjusted life years. Both these conditions are classed as serious or severe mental health eating disorders, with Anorexia Nervosa having the highest mortality rate of any psychiatric disorder.

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Eating disorders are the 12th leading cause of hospitalisation costs for mental health in Australia\(^\text{10}\) and the expense of treatment of an episode of Anorexia Nervosa has been reported to come second only to the cost of cardiac artery bypass surgery in the private hospital sector in Australia\(^\text{11}\).

The imperative is for early intervention and to provide options other than hospitalisation for treatment of the illness. Early intervention improves the prospects of recovery and reduces the duration of the illness. Those suffering from an eating disorder that are identified and treated in its early stages have been shown to have an improved chance of recovery compared to those with a longer history of the illness. \(^\text{12, 13}\)

**The Impact of eating disorders on sufferers and their families**

Often people think that an eating disorder is a phase young people ‘go through’, that their dieting has gone a bit too far, however the reality is that an eating disorder is a serious mental illness. Once an eating disorder has its hold, with treatment the average time it takes for someone to recover is between 7 and 9 years. Whether the eating disorder is Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder or an Eating Disorder Not Otherwise Specified, it will take over the life of the sufferer – and of those who live with and care for the sufferer.

Like a drug addict who doesn’t know they are one until they take that first ‘hit’, a sufferer of an eating disorder will not know they are at risk until it is too late.

One of the most distressing things a person who has an eating disorder suffers is an incredibly low sense of self worth. That lack of self esteem is there when the disease strikes and it is there to undermine every step of the recovery process. This lack of self-esteem and self-worth is often present even when sufferers come from loving, supportive and functional families and having supportive and caring friends.

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Family and friends play a critical role in the treatment and recovery pathway for a sufferer of an eating disorder. They are often in step with them as they battle the challenges of the illness including their common urge to resist treatment if they have anorexia nervosa.

One of the most significant differences between a physical disease such as cancer and a mental illness is in the battle. With a physical disease the fight is to get better. With a mental illness your first hurdle is to want to get better.

When considering the impact of eating disorders on our community, it is important to consider the impact on the lives of those who are standing by – usually the friends and families of the sufferers. When a loved one is suffering from an eating disorder and is diagnosed but can’t find it within themselves the strength or perhaps even the willingness to fight, loved ones are often perplexed. This causes anguish and pain to those standing by. There are many elements to an eating disorder that are very difficult to understand from a loved one’s perspective and this can often add conflict and anxiety and heightened stress to all those who life the illness touches.

The impact of the family unit is extraordinary and it requires specialist care and treatment as often the family if heavily involved in supporting their ill loved one as they battle the illness. Part of the purpose of Family-Based Treatment in a modular treatment program is to support and help family members and include them as part of the treatment solution as their loved one battle the eating disorder.

But it’s not only the emotional distress and intense treatment schedule that impacts on families. The costs associated with effective treatment add significant extra strain under circumstances that are already difficult. Medicare gap payments, travel to and from clinics (especially for those in remote communities), treatments associated with co-morbidities and many other costs mean that families caring for an eating disorder sufferer are often already at a financial breaking point. Any decrease in the financial assistance available will push many more families into situations where the only option is to join the waiting queue for public services, increasing the risk to the individual’s health, the health of the family unit, and increasing the cost to the community in the long term.

“When I was 17 I was extremely sick. My parents were beside themselves and we sat down and decided that I was going to travel to Melbourne every week from Canberra for treatment at a specialist treatment centre. My parents had to take a second mortgage on their house because there was no Medicare or private health fund subsidy for treatment. I had to stop treatment when the money ran out because my family were in financial stress and I had two baby brothers,” Noelle, an eating disorder sufferer.
The Government’s 2011-12 Budget changes relating to mental health

The 2011-12 Federal Budget introduced changes to the Better Access to Mental Health Care program that will have a negative impact on sufferers of eating disorders.

Under the current Better Access to Mental Health Care program, persons with serious or severe psychiatric illness can access up to a maximum of 18 Medicare-subsidised sessions with allied mental health professionals per calendar year. From 1 November 2011, under the revised Better Access program in this year’s budget, sufferers of eating disorders will only qualify for 10 subsidised sessions in a calendar year.

Based on current evidence, one of the most effective outpatient treatments for Anorexia Nervosa is Family-Based Treatment (based on the Maudsley model of care). For Bulimia Nervosa one of the most effective outpatient treatments is Cognitive Behaviour Therapy, appropriately adapted for eating disorders. There are recognised programs for both Family-Based Treatment and Cognitive Behaviour Therapy which are based on 20 sessions over a minimum period of 6-12 months. These treatment programs are shown to be effective. Under the current arrangements with Better Access, a patient who qualifies for 18 Medicare subsidised sessions will only need to find the additional funds for the remaining two sessions to receive the recommended treatment in a calendar year. Under the Better Access program arrangements commencing 1 November 2011 for the recommended treatment will be well beyond what will be affordable for many patients.

In the event a patient opts to only participate in treatment as long as it is subsidised, which is highly likely in the view of practitioners in this field, then this may actually do more harm than good. This premise that 10 sessions is far too few treatments, particularly for sufferers of Anorexia Nervosa, is supported by several credible studies, including one concluded by The Cochrane Collaboration based out of Monash University14.

The reality for many sufferers will be that they will not be able to afford completing the recommended treatment of twenty sessions in a calendar year once the government subsidies dry up after 10 sessions in a calendar year. Running half a recommended treatment cycle for eating disorder sufferers has been likened by leading psychologists in this field to ‘running half a course of antibiotics’. Whilst a patient may show signs of improvement during these sessions, those that don’t run the full course of Cognitive Behaviour Therapy and Family-Based Treatment sessions are at significantly greater risk of relapse. A ‘failure experience’ for eating disorders sufferers is very serious for a number of reasons. People suffering from eating disorders have a very low self worth and a failure at treatment will exacerbate these beliefs. A failure also makes future treatment delivery more difficult as patients are less likely to re-engage in treatment.

Patients who cannot afford to access the Family-Based Treatment and Cognitive Behaviour Therapy treatments that have been available, and affordable, over the last three years under the Better Access program will have no other option than to wait for treatment at public health psychology units. The waiting lists for these services are already long. Eating disorders that are left untreated become more and more entrenched within the patient’s psyche and make treatment much more difficult. There is a serious lack of publicly funded hospital beds for eating disorder patients. There is also a serious lack of qualified practitioners in the sector. The current membership of the Australian New Zealand Academy of Eating Disorders (ANZAED) is approximately 150 and that represents the majority of all practitioners across Australia in both private and public practice. An eating disorder left untreated is much more likely to require hospitalisation. Both the Family-Based Treatment and Cognitive Behaviour Therapy treatments are provided on an outpatient basis – a more cost and time effective option and one which has good prospects of being successful and keeping the patient out of hospital.

The reduction of access to the Better Access program for eating disorder sufferers increases the risk of significant personal, social and economic costs than the savings made. The immediate and long term consequences for the Government and the sufferer is a prolonged and more acute period of suffering from the eating disorder and a higher financial burden on their family, the public health and welfare system and the community.

The following diagrams highlight where the Better Access subsidised Cognitive Behaviour Therapy and Family-Based Treatment treatments fit into the spectrum of treatments available to sufferers of eating disorders. These diagrams are designed to highlight that:

- Significant impact will be felt on the other services listed when sufferers who are unable to afford to pay the full amount for treatment they once accessed under the Better Access program; and
- How Cognitive Behaviour Therapy and Family-Based Treatment treatments are a crucial and central part of therapy for an eating disorder sufferer and that its inaccessibility for sufferers may render the remaining treatments ineffective.
Importance of Better Access to treatment of eating disorders

Anorexia nervosa under 18 years

Note: Better Access subsidizes CBT and FBT therapies. Without CBT and FBT modular treatment programs an AN patient will not recover.
The Clinical Sector

The Australian and New Zealand Academy for Eating Disorders (ANZAED) provides the leading national forum for clinicians who work with eating disorder sufferers. In July 2011, ANZAED conducted a survey of its members, seeking their professional input on how the changes to the Better Access program would affect sufferers of eating disorders, from a treatment perspective and from the perspective of the impact the changes could have on the ability of clinicians to provide services from a business perspective. The results were confronting and are of grave concern to Butterfly from its perspective as being representative of all persons affected by eating disorders.

Three-quarters of the respondents of the survey were clinical psychologists, with the remaining quarter made up of psychiatrists, general practitioners and paediatricians. The majority of those who responded to the survey were 100% private practitioner members, with only 10% of those who responded practising in the public sector only. This is likely an indication that it is those in private practice who will be impacted the most as a result of the changes to the Better Access program.

The total number of eating disorder patients represented by the respondents was 599 and the average number of sessions the respondents saw these patients was 23 times in a calendar year. These same respondent clinicians were asked why 10 treatment sessions in a calendar year was inadequate for patients with eating disorders. The reasons cited were:

- Complexity of treatment required for patients with eating disorders
- Chronicity at presentation
- Co-morbidity associated with eating disorders
- Poor motivation for treatment
- Evidence Based Treatment standards (Cognitive Behaviour Therapy-Enhanced; Family-Based Treatment) requiring a minimum of 20 session per calendar year

Access to Allied Psychological Services - ATAPS

The Access to Allied Psychological Services scheme (ATAPS) enables general practitioners to refer consumers to allied health professionals who deliver focused psychological strategies, including psychologists, social workers, mental health nurses, occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications.

Through ATAPS, patients are eligible for a maximum of 12 sessions per calendar year – an initial six sessions with an option for a further six sessions following a mental health review by the referring GP. Sessions can be individual and/or group therapy sessions. ATAPS provides patients
with assistance for short-term intervention. If further sessions are required it may mean that the patient needs a longer term program to meet his/her needs.

Under the ATAPS program the patient does not pay fees to the allied health practitioner – their fees are paid by the GP Networks currently which will transfer to Medicare Locals through funding from the Commonwealth Department of Health & Ageing. The ATAPS agreement with allied health practitioner prevents any co-payment or gap fees being charged to the patient.

If clinicians could only provide subsidised treatment under an ATAPS style arrangement to meet the shortfall in subsidised treatment as a result of changes to the Better Access Program, they generally would not participate in treatment at all for sufferers of eating disorders as this would not be viable for a full recommended course of Cognitive Behaviour Therapy or Family-Based Treatment – ie. The cost of the service exceeds the amount that they can charge.

Respondents to the survey question regarding this issue said:

“I would probably not see clients with eating disorders as it would not be financially viable, due to the high level of liaison with other professionals and families involved. I would definitely not see young people. I may even stop my private practice entirely.” Clinical Psychologist; 20 patients; Perth.

“I would no longer do this work. I would close my private practice and find alternative work. I have spent more than 7 years doing university training to become a specialist; I have lived away from my family for large chunks of time in order to get hospital (Inpatient and outpatient) supervised clinical experience and I have transferred my knowledge to a rural area, including practices in the public system. I spend huge amounts of money to maintain my skills. It would be a great loss to this rural community if I quit.” Clinical Psychologist; 18 patients; (rural).

“If the fee were set at $110 I would be forced to seriously consider closing my business altogether, and looking at alternative avenues for my career... “

This fee of $110 would not cover the costs I require to run my business and my life, nor would it cover the costs involved in yearly professional development that I must engage in to maintain memberships with professional representatives. For example, per year I spend approximately $3000 on attending workshops and seminars that are directly related to working with patients with eating disorders. This does not include how much income I forego to attend the workshops. ... It would significantly reduce my capacity to provide services to sufferers of eating disorders, to the point of 100%” Clinical Psychologist, 20 patients, Sydney.

“I fear that that would make it even more difficult for patients to find specialist clinicians trained in the provision of ED treatment - already a difficult task, given the difficulty of the population. At a professional level, I fear this would discourage training psychologists to pursue work in the field of ED’s and greatly deplete the field. At a personal/financial level this would have an impact on my ability to provide services for such patients. It would also have a roll-on effect to my ability to
afford to attend continuing professional development training, supervision etc, and I believe would therefore have an impact on best practice in a very global way.” Clinical Psychologist; 32 patients; Sydney

“Our specialist private practice in Sydney employs a number of highly trained clinical psychologists who specialise in a very difficult area of treatment. We would not be able to see people under ATAPS. If ATAPS was the primary method to get people with an eating disorder seen, highly trained and experienced psychologists would not be able to see them. This means that less experienced and less trained psychologists would see these people, and poor results are inevitable.” Clinical Psychologist; 56 patients; Sydney.

If the reduction in private services were to be realised under the new funding arrangements, this would put much greater pressure on the public sector to “pick up the slack”. Reflecting this, ANZAED members who work in the public sector made the following comments:

“Very few of the families that I see could cope with that extra cost and all our patients would then be referred back to CAMHS.” Paediatrician, Tasmania, 90% Public Sector; 80 patients (CAMHS – Child and Adolescent Mental Health Service, Department of Health and Human Services, Tasmania).

“it would increase waiting list times at our service as patients would not be being seen for long by private practitioners.” Clinical Psychologist; 100% Public Sector; WA

The need for workforce development – NOW

The threat that clinicians in the private sector may walk away from this space due to the changes in the budget, along with the evidence that public facilities are already at breaking point in dealing with eating disorder sufferers, means that the sector is facing a situation where an existing shortfall is exacerbated, exactly at the time when it is crucial for workforce development and growth in this area.

Butterfly works to educate the community on eating disorders and to ‘de-stigmatising’ eating disorders in an attempt to get more sufferers to present for treatment – ideally at early stages. This is a key part of Butterfly’s strategy and is also integral to the strategy of the federally funded National Eating Disorders Collaboration.

Anecdotal evidence suggests that Butterfly’s various campaigns and activities through the media and other outlets have led to an increase in referrals and help seeking activity; however there is no easy way to scientifically measure this across the sector at this point of time. Butterfly has requested data from the Department of Health and Ageing that would indicate how many people in Australia were accessing funded health services for the treatment of eating disorders, however this data has not been available.
Recommendations

The Butterfly Foundation recommends that:

1. The governments of Australia invest in programs that develop and grow the workforce of clinicians that specialise in the treatment of eating disorders, to correspond to the investment made to increase early intervention;

2. A separate and dedicated funding program be created which is complimentary and annexed to the Better Access program to be accessed by those who are sufferers of eating disorders and require the minimum clinical treatment of 20 Cognitive Behaviour Therapy and Family-Based Treatment sessions per year. It is proposed that sufferers of eating disorders would switch over to this new program once they had exhausted their annual allocation of treatment under the proposed changes to the Better Access program as at 1 November 2011. The proposed scheme would include an additional 10 Medicare subsidised Cognitive Behaviour Therapy and Family-Based Treatment treatments in a calendar year. Not only would this take the number of subsidised treatments to the recommended minimum of 20 sessions per calendar year for sufferers of eating disorders, but would allow for more accurate data collection regarding Commonwealth support to sufferers of eating disorders to facilitate good future policy around eating disorders treatment funding; and

3. That DOHA and Human Services conduct research to determine how much Commonwealth funded access to clinical services has been sought by sufferers of eating disorders in the past 5 years and that the outcomes of this research be made publicly available so that policy and funding for eating disorders can be more appropriately allocated.

Submitted by

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ANNEXURE A

Eating Disorder Admission statistics – The Children’s Hospital Westmead (NSW)

Scope of the problem
Anorexia Nervosa is the third most common chronic disorder affecting adolescent girls (Beaumont, et al., 1993) with a lifetime mortality rate of up to 20%\(^\text{15}\), a rate higher than for any other psychiatric disorder and 12 times greater than that of death from all causes in women aged 15-24 years\(^\text{16}\).

Lifetime prevalence rates in women are 2.9% for Anorexia Nervosa and 4.3% for partial Anorexia Nervosa (excluding amenorrhea as a diagnostic criteria\(^\text{17}\)) with onset primarily in adolescence\(^\text{16}\). Anorexia Nervosa prevalence in adolescents has increased over the past 50 years\(^\text{19}\) while the age of onset decreased\(^\text{20}\).

Young people with Anorexia Nervosa are at risk for developing serious and chronic health and mental health concerns and other complications from malnutrition associated with Anorexia Nervosa including growth retardation, osteoporosis, infertility and changes in brain structure as well as psychological complications including depression, anxiety, obsessive compulsive disorder and cognitive impairment\(^\text{21}\).

Effective treatment is particularly critical in the child and adolescent patient group where early intervention reduces length of illness and improves recovery rates. Recent randomised controlled trials and research has demonstrated an average length of illness in children and adolescents provided with an evidence based treatment called Family Based Treatment of between 12 and 18 months with a 80 - 90% 5 year recovery rate compared with an average length of illness of 7 years and a recovery rate of less than 50% in patients treated as adults.

\(^{19}\) Lucas AR, Crowson CS, O’Fallon WM, Melton III. The ups and downs of anorexia nervosa. Int J Eat Disord 1999; 26: 397-405.
The Eating Disorder Team at The Children’s Hospital has been leading the development of Family-Based Treatment for children and adolescents with Anorexia Nervosa in Australia since 2003. Family-Based Treatment is now widely recognised as the treatment of choice for this age group.

**Increased demand for service**

The Children’s Hospital at Westmead Eating Disorder Service is the largest eating disorder service in NSW. It has a State-wide mandate for the treatment of children and adolescents with eating disorders and plays leading roles in research, teaching, training and supervising clinicians throughout NSW and Australia.

Since the commencement of the eating disorder service there has been a significant increase in demand for services with a 270% increase in inpatient admissions since 2000 (30 inpatient admissions in 2000 increasing to 81 admissions on 2009) and a 1000% increase in outpatient occasions of service since 2003 (298 outpatient appointments in 2003 increasing to 3157 appointments in 2009).

These increases in demand have occurred despite a statistically significant reduction in readmission rates between 2002 and 2006 from 2.08 admissions per patient to 1.26 admissions per patient per year and a reduction in length of illness through the introduction of family based treatment.

**The statistical breakdown of admission by age and sex**

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