Butterfly
Foundation for Eating Disorders

Submission to Select Committee into the Abbott Government's Commission of Audit

As the Commission is yet to report, this submission is (of necessity) focussed on the Commission of Audit's Terms of Reference (Committee's Term of Reference (b and g.). This submission deals with some of the main themes of the Committee's Terms of Reference, much of which was also included in a submission from Butterfly Foundation to the Commission itself on this issue.

Approximately 9% of the population will have an eating disorder at some point in their lives. This figure is increasing and will continue to rise. Eating disorders are serious psychiatric and medical illnesses which require multi-faceted treatment from a range of health professionals through primary, tertiary and allied health programs. Butterfly Foundation and its partners in the mental health, youth, wellbeing, medical and community sectors are working collaboratively to maximise efficiencies of prevention, early intervention, treatment and recovery programs to ensure that Australians increase their understanding of these illnesses, develop preventative approaches to the risk factors of eating disorders, and have a 'no wrong door' opportunity to early intervention and treatment programs.

The Australian Government recognises the seriousness of these illnesses and has begun to invest in key areas of prevention and awareness raising, support services and through the identification of models of care that can be delivered using current primary and tertiary health services in community.

Butterfly Foundation has outlined to the Commission of Audit the importance of the Government's current investment and the need to maintain or increase this investment to meet the socio-economic impact of eating disorders head on.

1. Executive Summary

In response to the Select Committee into the Abbott Government's Commission of Audit's call for submissions to inform its review of the activities of the Commission of Audit, the Butterfly Foundation would like to bring to the Committee's attention the Australian Government's leadership role in developing effective, nationally consistent responses to eating disorders.

Eating disorders are a group of serious and complex mental illnesses including anorexia nervosa, bulimia nervosa, binge eating disorder and other specified or unspecified feeding and eating disorders (OSFED & UFED).

The cost of an eating disorder to the Australian community is significant. The total socio economic cost of eating disorders in 2012 was estimated at $69.7 billion (Deloitte, 2012). This figure includes financial costs of $99.9 million per annum for health system costs, $15.1 billion per annum productivity costs and $56.2 billion per annum for burden of disease or the cost of the loss of healthy years of life.

And this burden continues to grow. The rate of eating disorders across the Australian population is increasing. It is estimated that over 913,000 Australians suffered from an eating disorder in 2012 while more than two million, based on current population figures, will experience these illnesses at some point in their lives. These are conservative estimates. Studies have indicated that eating disorders are under-reported and under-detected in the community.

Without intervention and continued investment from the Federal Government, the impact of these social and economic costs will continue to increase and represent a significant burden on the Australian population and its government. Contributing to this ongoing burden is the inequitable distribution of the cost of eating disorders treatment between government and private health sectors.

However, continued investment in current initiatives and improved efficiencies in health systems and their access could contribute to a decrease in the burden of these illnesses to individuals, their families, communities and government. The problem is solvable.

Since 2009 the Australian Government has provided support through the Department of Health (previously Department of Health and Ageing) for the development of nationally consistent responses to eating disorders. This support has included modest funding of:

- The National Eating Disorders Collaboration (NEDC)
- EDHope; the eating disorders Teleweb and e-health service
- Leadership in Mental Health Reform initiative - smaller one-off projects investigating opportunities to deliver eating disorders treatment within current funding initiatives.

Continued leadership by the Australian Government will contribute to the development of cost effective strategies for eating disorders that:

- Make eating disorders a priority for national and private health initiatives

- Promote eating disorder specific intervention early in the course of illness and in each episode of illness, reducing the risk of chronicity by a projected 40% based on current research figures (based on documented recovery rates from eating disorder specific early intervention)

- Coordinate state and territory responses to eating disorders to make cost effective use of existing resources, with particular reference to delivering services across traditional jurisdictions to meet the needs of people in rural and regional areas

- Integrate universal health initiatives in the area of healthy nutrition and eating taking both obesity and eating disorders into consideration

- Increase the effectiveness of other Australian Government health initiatives in the areas body image, youth early intervention and e-health strategies by supporting these initiatives with tertiary expertise in eating disorders

- Continue the work of currently funded initiatives in generating evidence through expertise and NEDC 'think tank', translating evidence to practice, supporting the implementation of nationally consistent best practice, and providing innovative access to support, information and services

- Address inefficiencies in the alignment of physical and mental health systems

- Creating equitable coverage of private health insurance systems for eating disorders related care.

2. Background

2.1. Eating Disorders in Australia

Eating disorders are a group of serious and complex mental illnesses that involve highly disturbed eating behaviours, weight control measures and a significant distortion of body image and its relationship to the person's self worth. According to the current Diagnostic Statistical Manual (DSM - 5) this includes anorexia nervosa, bulimia nervosa, binge eating disorder and other specified or unspecified feeding and eating disorders (OSFED & UFED).

Approximately 9% of the population will have an eating disorder at some point in their lives. This figure is increasing and will continue to rise. It is estimated that over 913,000 Australians suffered from an eating disorder in 2012 while more than two million, based on current population figures, will experience these illnesses at some point in their lives. These are conservative estimates. At least two studies have indicated that only about one tenth of the cases of bulimia in the community are detected. The true incidence has been estimated to be as high as 1 in 5 amongst students and women in Australia.

Eating disorders occur in both males and females; in children, adolescents, adults and older adults; across all socio-economic groups; and from all cultural backgrounds. Eating disorders are commonly perceived as being a disorder affecting adolescent girls but this belief masks the fact that they have a significant impact on boys and men and are increasing in both younger and older age groups.

People develop eating disorders because they carry vulnerabilities that are activated by various pressures in the environment. The most significant environmental trigger is dieting. As obesity and the related practice of dieting continue to be a focus of health initiatives it is imperative that eating disorders prevention and treatment are prioritized and that eating disorders expertise informs obesity prevention initiatives. Research suggests that approximately 30% of people who are obese are affected by binge eating.

Eating disorders have serious physical, social and psychological impairment consequences. Medical consequences include gastrointestinal disorders, infertility, high blood pressure, kidney failure, osteoporosis and Type II diabetes. Children and adolescents can experience additional physical consequences, such as arrested growth and development, and even after resolution of the eating disorder will, as adults, experience significantly higher levels of anxiety disorders, cardiovascular disease, chronic fatigue, depressive disorders, neurological symptoms, and suicide attempts (NEDC, 2010).

Eating disorders have unique characteristics that involve significant medical consequences and a high risk of chronicity. They are amongst the most difficult psychopathologies to treat. A person with an eating disorder requires treatment that is specific to their disorder, delivered by health professionals who have been trained in the delivery of evidence based approaches.

Without appropriate intervention as early as possible in the course of illness, eating disorders are likely to persist long term and lead to reduced quality of life and life expectancy. Eating disorders have an overall mortality rate of up to 20%. This increased risk of premature death exists for all types of eating disorders. The risk of premature death for women with anorexia nervosa is well documented, with estimates of risk at 6-12 times higher than the general population and much higher than other psychiatric disorders.

Cost of Eating Disorders

The cost of an eating disorder to the community is significant. The total socio economic cost of eating disorders in 2012 was estimated at $69.7 billion (Deloitte, 2012). This figure includes financial costs of $99.9 million per annum for health system costs, $15.1 billion per annum productivity costs and $56.2 billion per annum for burden of disease or the cost of the loss of healthy years of life. These productivity and burden of disease costs are similar to those for anxiety and depression.
Studies suggest that only 22% of people with eating disorders access specialist treatment for their illness and these estimates are unable to represent the high cost of health care related to treatment of the consequences of untreated or under-treated eating disorders.

The cost of untreated or inappropriately treated long term eating disorders is much greater for all those involved than the cost of adequate provision of treatment as early as possible in the progression of illness.

Accessing Treatment

Consultation conducted by the National Eating Disorders Collaboration (NEDC) on behalf of the Australian Government has identified that lack of knowledge about eating disorders, their identification, assessment and treatment, is prevalent amongst health professionals including general practitioners, emergency department personnel, dietitians, and psychologists. The lack of knowledge and confidence to treat eating disorders represents a significant barrier to gaining access to effective treatment.

There are significant gaps in the continuum of care available to patients with eating disorders in Australia. Most people have, at best, access to only one part of the continuum. There are too few services for the number of people experiencing eating disorders and at present no single Local Health District has been identified that delivers a full continuum of care for people with eating disorders. Investigation by the NEDC (National Eating Disorders Gap Analysis, 2013) indicates that 85% of people seeking treatment experience difficulty getting access to appropriate treatment and 60% of clinicians experience difficulty referring clients for eating disorders treatment. There are no specialist eating disorder inpatient services for adults in TAS, NT and WA and no specialist eating disorder services in regional areas.

While people with eating disorders are eligible for treatment under current mental health funding initiatives (e.g. BAMHS; ATAPS) no existing initiative supports an evidence based treatment dosage. Most treatment for eating disorders is provided through private practice and through private hospitals. This reliance on private health services and lack of recognition of eating disorders in private health insurance, contributes to difficulties in accessing treatment.

The most dangerous experiences of patients with eating disorders in health services have occurred because there was nowhere else for them to be referred to. Without skilled, purposeful eating disorders treatment the revolving door of hospital admission is going to continue.
Reference to eating disorders is largely absent from health policies and funding arrangements. Reliance on an understanding of other mental illnesses as the basis for policy development has led to initiatives that do not address the complexity and duration of eating disorders.

Disadvantaged Populations

Some vulnerable populations who are affected by eating disorders, such as Aboriginal and Torres Strait Islander communities, have no access to disorder specific treatment or support within their communities.

Research demonstrates that the prevalence of eating disorders, especially binge eating, is as high amongst Aboriginal and Torres Strait Islander people as other Australian populations. The findings are important as they highlight the relationship between eating disorder features such as disordered eating and body weight concerns, and obesity, substance abuse and related conditions that contribute to shortened lifespan and greater morbidity in Aboriginal and Torres Strait Islander people.

People with eating disorders generally may be categorized as a disadvantaged group due to their lack of access to services anywhere in Australia that adequately meet the evidence based standards for safe, effective treatment.

2.2. Current federally funded programs and their outcomes

Since 2009 the Australian Government has provided support through the Department of Health (previously Department of Health and Ageing) for the development of nationally consistent responses to eating disorders. This support has included modest funding (approximately two million dollars in the current financial year).

The National Eating Disorders Collaboration (NEDC)

The NEDC brings together eating disorder stakeholders and experts in mental health, public health, health promotion, education, research, and the media to help develop a nationally consistent approach to the prevention and management of eating disorders.

The NEDC has a Steering Committee of 27 leading experts in eating disorders prevention, treatment and recovery support, including consumer and carer representatives, clinicians and academics. This group has acted as an expert ‘think tank’; having input to and oversight of all of the deliverables of the NEDC.

General membership of the NEDC now exceeds six hundred and sixty people and representation from all states and territories as well as all of the professional disciplines required to deliver prevention, early intervention, treatment and recovery support for people who have or are at risk of developing eating disorders. State governments and peak professional bodies have played an important role in the NEDC, contributing through an advisory group reporting to the COAG Mental Health group and through an Interdisciplinary Advisory Group.

The NEDC has drawn together the knowledge represented by this extensive collaboration to develop a number of publications including:

- An evidence review (2010); summarising current research in areas of prevention and treatment of eating disorders
- A National Framework including a national standards schema (2012); providing foundations and principles for an effective and consistent system to address eating disorders
- A Communication Strategy (2012); relevant to safe and effective messages around eating disorders, obesity and body image
- A Gap Analysis (2013); identifying opportunities for cost effective development of eating disorders services
- A Prevention and Early Intervention Report (2013); outlining opportunities to prevent key risks for eating disorders and to integrate eating disorders knowledge into other prevention initiatives.

The NEDC has developed an eating disorders specific website (www.nedc.com.au) which acts as the primary portal for dissemination of evidence based information for clinicians, other professionals, consumers and carers. The external evaluation of the NEDC in 2013 found that the NEDC has developed an identity as a credible source of information on eating disorders, with over 27,000 visits to the website in October, 2013

Dissemination of evidence based standards and resources has been supported through an annual National Workshop, professional development and consultation workshops in regional centres and through consultation with individual state governments and organisations such as headspace, Inspire, Mindframe, mindhealthconnect, Young and Well Cooperative Research Centre, ReachOut and beyondblue.

The collaborative approach taken by the NEDC is supported by the majority of stakeholders as essential to the success of the NEDC. Feedback to the evaluator indicates that those involved in the NEDC believe the outputs would not have been as effective or appropriate without implementing a model that focused on collaboration and consultation. Continued coordination of these diverse stakeholder responses to eating disorders will be an important element in developing a nationally consistent approach.

The NEDC has successfully introduced a level of national leadership and achieved a measure of consensus support for foundational principles of practice in eating disorders prevention and treatment. Feedback from members indicates that they see the NEDC having had an influence in several specific ways including developing leadership within the eating disorders sector, decreasing the isolation of service providers and promoting evidence-based approaches.
The NEDC purpose requires a long term, developmental approach to the prevention and management of eating disorders and the NEDC will need to adopt longer term strategies, supporting sustained engagement with the people and organisations required to deliver a nationally consistent approach to eating disorders. The identified long term needs include national leadership, coordination and the translation of research into practice. NEDC achievements so far have created a network of stakeholders and evidence based resources as a platform for this action.

EDHope – Eating Disorders Teleweb Service

Under the Australian Government's Teleweb program, the Butterfly Foundation has established a free telephone, email and web-based support and counselling service for those seeking help for eating disorders, including consumers, carers and families, and professionals who work with them.
This service aims to help people understand eating disorders and navigate the services and supports involved in the management of eating disorders by providing personalised information, support and strategies. It provides a safe, reliable and accessible point of entry to eating disorders prevention, treatment and support services including connecting people with appropriate services for improved health and social outcomes.

EDHope commenced in 2013 and over the year to date there has been a clear and continuing increase in number of contacts to the Teleweb service. This is consistent with the upward trend in requests for assistance observed by the Butterfly Foundation over the previous two years.

The eating disorders Teleweb service sits across a range of e-health strategies and may be considered unique in the position it occupies. In the eating disorders field service user needs cover a wide spectrum, from callers simply requiring a referral, to unwell individuals with complex needs; from non-urgent information enquiries to individuals entering a time of change and/or potential crisis. The standards for safe treatment of eating disorders, which require integration of physical health care and monitoring with psychological and nutritional care, mean that e-health services are not yet able to provide a full clinical treatment service for eating disorders. The Teleweb service is able however to engage in a high level of counselling, assessment and referral, bridging the gaps between consumers and health services, and supporting self management and help seeking.

At this stage in its development, EDHope has proved the concept that a dedicated e-health strategy for eating disorders will be utilized. Further refinement of the service will be required as evidence emerges on the most effective strategies to address the complexities of eating disorders through technology based services.

In general the evaluation has found to date that most callers perceive their needs to be met by the service. Feedback shows that service users are using the support, counselling and information received to reduce psycho- social distress, improve their knowledge and understanding of eating disorders, help them engage in appropriate care strategies, and identify further professional resources available to them. A significant percentage of service users are clinicians, teachers and family members who require information to assist them to support people with eating disorders.

Strengthening other health initiatives

Many existing initiatives, such as Access to Allied Psychological Services (ATAPS), the Mental Health Nurse Incentive Program, mindhealthconnect and headspace centres, have the potential to support evidence based and effective responses to eating disorders. Medicare Locals have a demonstrated opportunity to coordinate the development of community based responses to eating disorders.

All of these services have the potential to provide access portals for people with mild eating disorders, if they are applied to that purpose but only when implemented in ways that are focussed on the specific characteristics and treatment needs of eating disorders. There is a significant gap in the knowledge and expertise to treat eating disorders at all levels and within all health professions and this impacts on the cost effectiveness of treatment options for people with eating disorders. Investigation by the NEDC has identified that half of health professionals receive no training in eating disorders and an additional 47% receive training they believe is inadequate to equip them to treat eating disorders. A lack of confidence to treat eating disorders amongst health professionals results in many people being refused access to treatment.

Investigation conducted by the Butterfly Foundation during 2013 (Exploration of treatment options for eating disorder sufferers; Leadership in Mental Health Reform) is demonstrating that there are opportunities to develop community based responses for bulimia nervosa and binge eating disorder within current funding initiatives, including ATAPS and the MHNIS. There are however considerable challenges to extending these responses for people with anorexia nervosa. People with anorexia nervosa typically require intensive treatment over a longer time period than is currently supported by government or private health insurance schemes; there is a lack of confidence amongst health professionals to address these complex and life threatening disorders and, particularly in regional areas, there is insufficient access to psychiatrists.

3. The case for continued involvement of the Australian Government

3.1 National leadership: collaboration between state and federal eating disorders initiatives

The effective prevention and treatment of eating disorders require a 'whole of community' and 'whole of Government' approach. A nationally consistent approach to eating disorders can only be achieved with national leadership that has the capacity to bring together state and territory governments and key stakeholders. The Australian Government has a clearly articulated leadership role in mental health, supported by The Council of Australian Governments (COAG) Working Group on Mental Health Reform.

Each state and territory has taken a different approach to the development of eating disorders services. Responses have developed in an ad-hoc fashion in response to local opportunities. No state or territory currently provides a full continuum of care for eating disorders. With a relatively small population some elements of the continuum may be beyond the scope of some state and territory health systems but could potentially be delivered nationally (e.g. intensive specialist treatment in residential settings).

Each state is currently responsible for developing its own information and resources to support eating disorders treatment. There is considerable duplication of effort and cost. Effective collaboration at a national level can reduce the overall costs and improve efficiency, extending the impact of limited resources.

The complexity of eating disorders makes it essential that expert tertiary consultation is accessible at all levels of treatment from early intervention to recovery support for consultation, supervision, guidance, training and referral if required. The delivery of safe, effective, and therefore cost effective treatment requires safe and flexible treatment options that address all of the aspects of illness: physical, behavioural and psychological and are delivered by staff specifically trained in eating disorders treatment.

State and territory governments have addressed access to tertiary support in different ways however at this point no state or territory is able to provide the breadth of tertiary consultation necessary to ensure that everyone with an eating disorder can be treated in their own community.

It is essential for safe treatment of eating disorders that medical and nutritional treatment is integrated into psychiatric care. This presents challenges to the traditional segmented organisation of prevention and treatment that can only be effectively addressed through national leadership and national standards.

For effective treatment, integration and collaboration is required between physical and mental health services; public and private health services; and between professional disciplines. For effective prevention and early identification, integration and collaboration is required between the eating disorders sector and education, physical activity instruction, community services, frontline health professionals, and with health promotion initiatives addressing weight and appearance related issues.

The NEDC concluded in the national standards schema (National Eating Disorders Framework, 2011) that systems that support integration, collaboration and on-going development between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and community services and between professional disciplines is essential for the delivery of effective responses to eating disorders.

The key gap identified in the NEDC gap analysis is the lack of a systematic approach that embeds eating disorders treatment into mainstream health systems and ensures that the majority of people with eating disorders have access to evidence based care. Evidence for the lack of a systematic approach can be found in the inconsistencies between states and territories and between regions in the implementation of prevention programs, specialist treatment programs and community based recovery support programs. The absence of systematic implementation of eating disorders initiatives can be identified at all levels in the continuum of care from prevention to recovery support and at all levels of administration from policies to data collection.

Systems are required to support integration of services provided at different levels of care, in different settings from community services to tertiary services, and potentially in different health regions or even different states. This level of integration is essential to address gaps in workforce capacity and specialist service provision and requires collaboration between state and territory governments, led by the Australian Government.

3.2 Collaboration for prevention: obesity and eating disorders

Obesity and eating disorders are often seen as separate problems and yet eating disorders, weight and shape preoccupation and obesity often co-occur over time and share common risk and protective factors. Disordered eating and overweight may perpetuate each other's development. The overlap between obesity, binge eating disorder and bulimia nervosa impacts on the cost effectiveness of obesity prevention strategies and subsequent health care costs.

The development of comorbid obesity with eating disorder behaviours has increased at a faster rate than that of either obesity or eating disorders alone over the last thirty years. Australian research has found that one in five people suffering obesity also suffered from disordered eating and that there was an increase in incidence in binge eating disorder and atypical presentations of eating disorders in the ten years to 2008.

Overweight adolescents are at higher risk than their healthy-weight peers for disordered weight-control behaviours and binge eating, behaviours. Unhealthy weight loss dieting is associated with other eating disorders and other health concerns including depression, anxiety, nutritional and metabolic problems, and, contrary to expectation, with an increase in weight. Adolescents who diet and develop disordered eating behaviours carry these unhealthy practices into young adulthood and beyond influencing their long term health.

It is not possible to fully address obesity prevention without also addressing eating disorders prevention. An integrated approach to prevention based on the shared risk factors for obesity, body dissatisfaction and disordered eating may provide the best opportunity to reduce the impact of all of these conditions on the health of Australians.

4. Options for greater efficiencies in the Australian Government approaches to eating disorders

4.1 Consolidating eating disorders initiatives for stronger and cost effective impact

Australia is fortunate to have a mental health policy, plan and standards that promote recovery, early intervention, evidence based treatment and consumer participation. The current policy environment offers a framework to develop an eating disorders system of care that is able to intervene early and provide integrated services across health and social domains.

The Australian Government has already invested in developing a knowledge base and national collaboration including representatives of state governments and all the health disciplines involved in the treatment of eating disorders. Information and service models that address priority gaps in responses to eating disorders are already available in Australia. Training resources already exist, national standards and service models are emerging from the work of the NEDC; innovative pilot programs are being implemented to suit the Australian context; evidence based prevention and early intervention programs are available to be implemented.

This provides a cost effective platform for future action. Standards and resources must now be assertively promoted to governments, public and private health service providers and insurers in order to support the implementation of evidence based and cost effective treatment.

Australian Government investment to date in the development of the NEDC website and the Teleweb also provide cost effective technology for the delivery of tertiary support to all states and territories including rural and regional areas. There is an opportunity to develop a credible national centre for eating disorders using technology rather than the development of hard infrastructure that can link people to services which provide consistent, evidence-based care at a state and local level and provide innovative digital solutions which transcend geographic and service availability barriers.

By combining current projects for eating disorders into one initiative (National Eating Disorders Collaboration; Eating Disorders Teleweb and the Treatment Options consultation and service

development process) and focussing these activities on addressing key gaps it will be possible to deliver a coordinated national response to eating disorders that draws on and enhances state initiatives for the most cost effective solutions and reduces the administrative costs associated with smaller contracts. This approach ensures the input of eating disorders expertise across projects, providing for one expert advisory ‘think tank’ to inform all initiatives relevant to eating disorders.
In the long term, since the productivity costs of eating disorders largely fall to the federal government, this ongoing funding would ensure return for investment in the original outlay for the NEDC and Teleweb, and reduction in other burdens placed on health, welfare and economy systems in Australia.

4.2 Making eating disorders a priority for national and private health initiatives

Medicare Locals

Medicare Locals are explicitly tasked with identifying and responding to gaps in community health services and improving the patient’s experience of navigating the health system. Medicare Locals are well placed to support the development of local responses to eating disorders, informed by tertiary expertise in eating disorders treatment. The current focus on preventive health, particularly in relation to diabetes, is relevant to this role given the interface between binge eating disorder, obesity and diabetes. Early intervention for people with eating disorders is paramount. Informed and supported by the information and resources of the NEDC and Teleweb, Medicare Locals are well positioned to help primary providers to respond with early, disorder specific treatment to minimize the impact of eating disorders.

Increase private health insurance coverage.

Private health insurance coverage of treatment for eating disorders is essential but currently insufficient, particularly in the areas of primary care and community based eating disorders programs (e.g. counselling, dietitians, recovery support, and day programs). As eating disorders services are enhanced nationally, it is imperative that private insurers take an appropriate component of the health care burden.

The Council of Australian Governments (COAG)

The COAG Mental Health Reform group has been actively involved in the second phase of the NEDC. Engaging more broadly across the various health areas of interest to COAG, including physical health, and particularly obesity related initiatives, would provide the collaborative national leadership required to address the need for service development for eating disorders with integration of physical and mental health services.

4.3 Strengthening health strategy - Outcome 11: Mental Health

To enhance the effectiveness of the Australian Government's mental health initiatives as described in outcome 11 of the Department of Health's budget statement, the Butterfly Foundation respectfully recommends that:

- People with eating disorders are recognised as a disadvantaged group to ensure that services actually target the needs of this group in a cost effective manner.
- Early intervention, early in each episode of illness for adults be included to the qualitative deliverables
- Development of community based recovery support services is identified as a qualitative deliverable.

The current deliverables focus on the very early stages of risk for mental illness in children and young people, and on the severe and chronic experience of illness for those who do not have access to or do not respond to treatment (e.g. Partners in Recovery). Between these extremes there are the majority of people with eating disorders who cope with their illness but experience a high level of need for medical services to manage the consequences and a high degree of impact on their health related quality of life and therefore on their economic contribution to society. Deliverables are required that ensure that adults with moderate to severe illness have access to the treatment that they need early in each episode of illness to reduce the need for hospitalization for either physical or psychiatric treatment and reduce the economic impact of presenteeism/absenteeism.

5. Conclusions

Recognition of eating disorders in policy and data collection is an essential first step towards reducing the impact of these disorders in Australia. Effective responses to eating disorders require national leadership and collaboration across jurisdictions and departments, an approach which can provide a basis for streamlining responses for cost effectiveness.

Community based treatment, support and coordination services and e-health services have the potential to reduce the need for inpatient treatment and reduce the impact of the chronic physical and psychiatric consequences of eating disorders on individuals and on the health system. Prioritizing access to evidence based treatment specific to eating disorders early in the course of illness would reduce the long term burden of disease.

Building on the policies and expertise that we already have will require a commitment of resources. The alternative however is for individuals, families, communities and governments to continue to bear ever increasing costs associated with not providing access to effective treatment.

The Butterfly Foundation respectfully requests that the Australian Government continue its commitment to national leadership of responses to eating disorders.

Attachments – following within this document.

To support this submission the Butterfly Foundation also provides the following as an attachment:

- An introduction to the work of the Butterfly Foundation.
- The Executive Summary from the Butterfly Foundation Paying the Price Report on the economic and social impact of eating disorders in Australia, prepared by Deloitte Access Economics (Deloitte 2012)

References and NEDC reports may be found at www.nedc.com.au .

Butterfly
Foundation for Eating Disorders

The Butterfly Foundation is Australia's only national charity supporting those affected by eating disorders and negative body image. Services span prevention, early intervention and support, including the provision of the federally funded national Teleweb service, staffed by trained counsellors experienced in dealing with eating disorders.

Butterfly's philosophy is based on recognizing the need for greater respect for sufferers and carers and involving them in treatment; increased choices and access to effective treatment within the public health sector; greater awareness in the community of the seriousness of negative body image and eating disorders, which have incredibly high mortality rates, and the need to change the culture around 'thin' as a perfect ideal.

Butterfly works in collaboration with a range of partners, believing this is the most effective way to bring about sustainable cultural change. Butterfly has extensive networks among eating disorder professionals, not for profit consumer organisations, researchers and academics, corporate, fashion, and media. Butterfly seeks to bring people together to improve knowledge, awareness and capacity in the sector. Our collaborative approach has seen Butterfly successfully coordinate the National Eating Disorders Collaboration (NEDC) for the Australian Department of Health, as well as manage multiple projects with state health services and other non-government organisations.

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There are more than 913,000 people in Australia with eating disorders in 2012. The total socio economic cost of eating disorders in 2012 is $69.7 billion.

In 2012 Deloitte Access Economics was commissioned by the Butterfly Foundation to examine the economic and social costs of eating disorders in Australia. This review was supported by an advisory panel of experts in eating disorders, mental health, and population health.

Prevalence of eating disorders and associated mortality

The last official estimate by the Australian Institute for Health and Welfare (AIHW) suggested that there were 23,464 people with eating disorders in Australia in 2003 (Begg et al, 2007).

- This estimate was not based on Australian data, but mainly on a relatively small survey of Swiss schoolgirls in the mid-1990s.
- The AIHW estimate also only covers two eating disorders, anorexia nervosa (AN) (male and female) and bulimia nervosa (BN) (only female estimates). No estimates were made for Binge Eating Disorder (BED) or Eating Disorder Not Otherwise Specified (EDNOS), which have higher prevalence than AN and BN.
- As the Australian Bureau of Statistics (ABS) does not appear to have ever collected data on eating disorders, the AIHW figure remains the only official Australian estimate.

Recent population based surveys in South Australia, New Zealand and the United States yield far higher (although widely varying) estimates. Taking an average of these studies, Deloitte Access Economics estimates that there are 913,986 people in Australia with eating disorders in 2012, or around 4% of the population (Table i). Of these people, 3% have AN, 12% BN, 47% binge eating disorder and 38% other eating disorders. Females comprise around 64% of the total.

- This estimate may be conservative, as it is lower than the only Australian study (Hay et al, 2008), which also found that the rate of disordered eating behaviour had doubled in the ten years to 2005.

The imbalance between reported estimates of mortality from eating disorders and evidence from scientific studies is also substantial. The ABS (2012) indicates a total of 14 deaths from eating disorders in 2010. However, the latest meta-analysis of epidemiological studies from the published literature (the gold standard of health research) indicates that mortality rates are almost twice as high for people with eating disorders and 5.86 times higher for people with AN (Arcelus et al, 2011), compared to those without the conditions. On this basis there were an estimated 1,829 deaths from eating disorders in 2012.

Cost impacts of eating disorders

The AIHW reports health system expenditure for eating disorders of $80.4 million in 2008-09. Inflating this to allow for subsequent prevalence increase and health cost inflation suggest expenditure of $99.9 million by 2012.

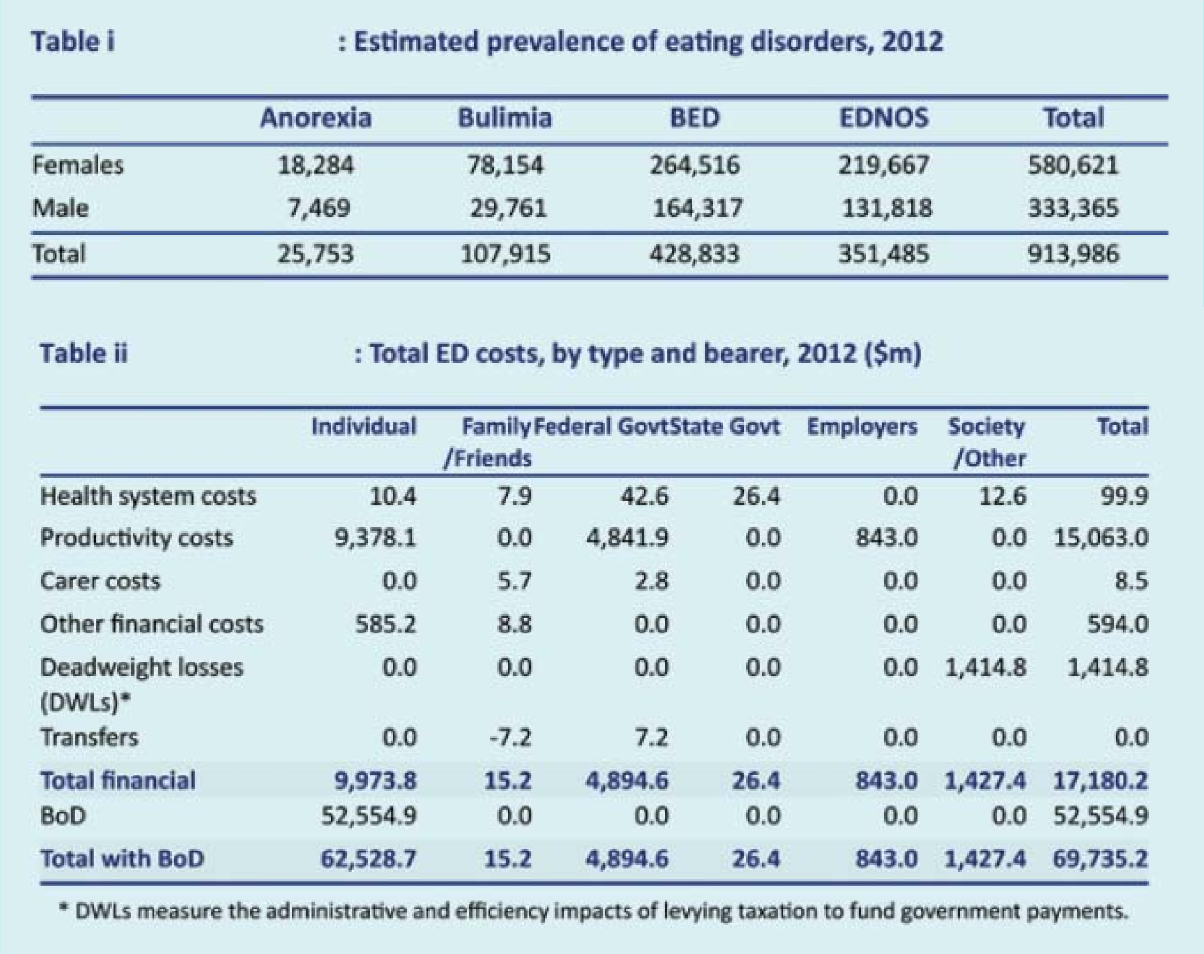

Table i : Estimated prevalence of eating disorders, 2012

	Anorexia	Bulimia	BED	EDNOS	Total
Females	18,284	78,154	264,516	219,667	580,621
Male	7,469	29,761	164,317	131,818	333,365
Total	25,753	107,915	428,833	351,485	913,986

Table ii : Total ED costs, by type and bearer, 2012 ($m)

	Individual	Family /Friends	Federal Govt	State Govt	Employers	Society /Other	Total
Health system costs	10.4	7.9	42.6	26.4	0.0	12.6	99.9
Productivity costs	9,378.1	0.0	4,841.9	0.0	843.0	0.0	15,063.0
Carer costs	0.0	5.7	2.8	0.0	0.0	0.0	8.5
Other financial costs	585.2	8.8	0.0	0.0	0.0	0.0	594.0
Deadweight losses (DWLs)*	0.0	0.0	0.0	0.0	0.0	1,414.8	1,414.8
Transfers	0.0	-7.2	7.2	0.0	0.0	0.0	0.0
Total financial	**9,973.8**	**15.2**	**4,894.6**	**26.4**	**843.0**	**1,427.4**	**17,180.2**
BoD	52,554.9	0.0	0.0	0.0	0.0	0.0	52,554.9
Total with BoD	**62,528.7**	**15.2**	**4,894.6**	**26.4**	**843.0**	**1,427.4**	**69,735.2**

* DWLs measure the administrative and efficiency impacts of levying taxation to fund government payments.

The productivity impacts of eating disorders were estimated as $15.1 billion in 2012, similar to the productivity impacts of anxiety and depression which were $17.9 billion in 2010 (Access Economics, 2010). Of this cost, $2.0 billion is due to lost lifetime earnings for young people who die. Eating disorders also have lengthy duration – an average of around 15 years in survey respondents – which can mean long lasting productivity impacts for those living with eating disorders, such as lower employment participation (costing $6.0 billion) and greater absenteeism ($1.8 billion) and presenteeism ($5.3 billion). Productivity costs are borne largely by individuals, but also by Federal Government (in the form of less taxation revenue) and by employers (sick leave and lower productivity from presenteeism). Table ii also provides estimates of the cost of informal care for people with eating disorders, totalling $8.5 million, based on data from the Federal Department of Human Services, and other financial costs of $594 million, based on survey data for out-of-pocket expenses borne by people with eating disorders and their families and carers.

The "burden of disease" from eating disorders is estimated as $52.6 billion, calculated by multiplying the years of healthy life lost (measured in disability adjusted life years or DALYS), by the value of a statistical life year (VSLY) as recommended by the Department of Finance and Deregulation. The estimate is comparable, although slightly larger, than the estimated value of the burden of disease for anxiety and depression of $41.2 billion (Access Economics, 2010).

Recommendations – data and monitoring

A pressing need in relation to eating disorders is collecting better information, particularly in relation to tracking prevalence, mortality and health system costs, and better defining less well known eating disorders. While AN and BN are well defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), EDNOS is composed of disparate criteria. One of these – BED– is the most common single ED, and in early 2013 will be classified independently in the DSM 5. Almost half (44%) of people with BED are severely obese (Spitzer et al, 1993), and it is probable that many of these people may currently have their treatment classified as "consequences of obesity" rather than BED.

Deloitte Access Economics makes the following recommendations regarding information.

- **Include eating disorder questions in the Australian Health Survey.** New Zealand and the United States include validated questions about eating disorders in their equivalent to our Australian Health Survey. It would be relatively simple and inexpensive to do the same. However, self-reported data are not as reliable as epidemiological data, and an Australian epidemiological study would be very valuable to better understand eating disorders and their impacts nationally. EDs should be recognised as a serious psychiatric disorder.
- **Reassess mortality data.** The AIHW (2012) notes that most people have three causes of death, and as many have five causes of death (20%) as have only one. If eating disorders have the mortality rates that the literature suggests it is important to verify this, which would also be assisted by funding a national epidemiological study.
- **Include BED as a condition in the International Classification of Primary Care.** The ICPC 2 Plus is an Australian categorisation system used by the AIHW to measure non-hospital treatment by disease type. At present, it contains categories for AN and BN, but not for BED. Once the DSM 5 has been released, there may be merit in reviewing the inclusion of BED in the ICPC2. It is possible that the small reported non-hospital costs for eating disorders other than AN and BN may be partly due to general practitioners (GPs) having limited awareness of BED and classify it by its frequent impact (overweight and obesity) instead.
- **Include eating disorders in welfare data.** At present, there is no information on eating disorders as a cause for unemployment benefits, sickness benefits or disability support pension. Given the high prevalence of eating disorders, this should be revisited.

Treatment recommendations

Relative to prevalence, there appears a lack of focus on treatment for eating disorders across acute and community care settings. The reports from survey participants of not being able to access appropriate treatment when needed are harrowing.

- **Make eating disorders a priority for Medicare Locals.** Medicare Locals are a commendable recent initiative by Council of Australian Governments (COAG) to better coordinate primary health care. They have been explicitly tasked with improving the patient journey, mapping population health needs and identifying services gaps. Medicare Locals have somewhat of an initial focus on preventative health and diabetes, which is relevant given the interface between BED, obesity and diabetes. Early intervention for people with eating disorders is paramount. Medicare Locals may be able to help primary providers enhance identification of people with early symptoms of eating disorders, and conduits for appropriate care.
- **Increase Medicare psychology coverage and/ or Partners In Recovery (PIR) referral.** Many survey respondents noted that they often require psychiatric visits

on a weekly basis, but noted that Medicare coverage is capped at ten visits per year, when the literature suggests a minimum of twenty visits per annum is required to be effective. Given the high productivity costs of eating disorders – and thus lost taxation revenue – it is possible that increasing the visit cap may have little adverse impact on the net Commonwealth budget position. Alternatively, if the cap is approached, referral into the PIR program may be appropriate for those where symptoms are severe and persistent.

- **Increase private health insurance coverage.** Judging from survey participant feedback, private health insurance appeared to be necessary but insufficient. Participants were grateful that their insurance covered most of their hospital costs, but also noted that it failed to cover a majority of their other costs, or left large out-of-pocket 'cost gaps' between what was reimbursed and actual fees (GPs, counselling, dietitians, etc). Given eating disorders are long-lasting and complex to treat, it would help people if such multidisciplinary costs could be covered by insurance, although it is acknowledged premiums may have to increase to cover this.