Establishing a National Strategy for The Prevention of Eating Disorders – A Staged Project Proposal

Commonwealth Funding Submission

Centre for Eating & Dieting Disorders NSW; Eating Disorders Outreach Service QLD; Centre for Excellence in Eating Disorders VIC; Eating Disorders Foundation of NSW Inc; Eating Disorders Foundation of VIC Inc; Eating Disorders Association of SA Inc; Eating Disorders Association of QLD Inc; The Butterfly Foundation; Australia & New Zealand Academy for Eating Disorders; Also, Throsby Centre ACT; Department of Nutrition, TAS; Eating Disorders Association WA; ISIS QLD;

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PROJECT SUMMARY

Eating Disorders (anorexia nervosa AN, bulimia nervosa BN and eating disorders not otherwise specified EDNOS) are serious mental illnesses affecting a significant proportion of Australians. The disorders exist on a spectrum from mild, to moderate and severe (AN has the highest mortality rate of any functional mental illness and a risk of suicide 32 times that expected for the general population[1] - greater even than major depression) and primarily affect adolescent girls and young women, although males and older people are not immune. Eating disorders have now been documented in children as young as 7 years old & the future impact of disordered eating & eating disorders must now be considered - particularly with regard to medical issues such as osteoporosis and other important factors including quality of life and long term mental health.

Eating Disorder organisations across Australia (both consumer organisations and Service coordination units) have varying roles and responsibilities – addressing health promotion, illness prevention, education and research, consumer support and service development. They each attract different levels of funding, with some State governments supporting both consumer organisations and service coordination units (VIC, QLD) and others operating primarily via donations, fundraising activities and the support of volunteers. Because of this variation in funding and resource allocation opportunities to develop and deliver eating disorder specific projects and programs are inconsistent across the States. As a result, despite collegial relationships existing between many of the individuals working in this field, Australia lacks a systematic approach to service development, prevention and health promotion.

This submission has been established using the recommended framework of the National Mental Health Strategy 2003-8, which identifies a focus on promoting mental health and preventing mental health problems and mental illness; increasing service responsiveness; strengthening quality; and fostering research, innovation and sustainability[2]. It is supported by all of the eating disorder organisations in Australia.

[1] Harris & Barraclough 1998 'Excess mortality of mental disorder' *British Journal of Psychiatry* 173:11-53
[2] Australian Health Ministers, National Mental Health Plan 2003-2008. Canberra, Australian Government 2003

Stage One of this project will see the establishment of a *National Eating Disorder Reference Group* and a *National Eating Disorder Clearinghouse (website).*

Stage Two of the project will be to research and propose a sustainable *National Framework and Service Development Strategy* for the management of eating disorders across the illness and age spectrum (from prevention and early intervention, to treatment and maintenance) upon which service development can be based.

A key component of the National Strategy will be **Stage Three** of the project – the development of a *National Eating Disorders Prevention Strategy* including recommendations from Australian specialists (both eating disorder and obesity), consumers and key stakeholders from health, education and sport & recreation departments.

Primary funding is sought from the Commonwealth Government and corporate partnership will also be sought via the Butterfly Foundation in Victoria for specific components of the proposal (namely the website).

INTRODUCTION

In Australia and overseas, eating disorders do not receive the systematic attention they require. A number of factors contribute to this, including the stigma of having a mental illness, a characteristic reluctance on the part of many sufferers to seek help, and the need for better coordination of care across health systems and other key stakeholder organisations.

There are differences in access and equity of services for people with eating disorders across Australia. In addition, there are varying levels of specialised services available in each State/Territory and within each area health region. Services range from minimal, to providing limited primary, secondary and tertiary level care. Where they exist at all, specialist outpatient, day patient and inpatient services are largely centered on metropolitan centres.

Consumer Organisations

The National Mental Health Strategy 2003-2008 (2003) recognises that consumer organisations provide access to support services that are essential to recovery and community participation and have a key role in mental health promotion and support. Only 3 State Eating Disorder Consumer Organisations receive funding from their relevant State government (QLD, VIC, SA). Others survive purely through membership drives, volunteer workers, donations and fundraising events and consequently, funding structures impact on every organisation's capacity to provide the service that communities want, need and deserve.

Service Coordination Units & Departmental Responsibility

Service coordination and Departmental responsibility for eating disorders is yet another area where States and Territories differ. The Victorian government funded a 'Centre for Excellence in Eating Disorders' (CEED) focusing on education, research & service development and employs 2FTE staff to coordinate it. In addition, the CEED funds 3 FTE clinical coordinators across the major health regions in Victoria.

In NSW a Statewide Service Plan has been developed and an Eating Disorder Service Development Officer for the State is appointed [at 1FTE on a grant through the NSW Centre for Mental Health 2004-2006] and operates the Centre for Eating & Dieting Disorders (CEDD) - which has a service development focus including training, education, clinical support and professional development.

The Eating Disorders Outreach Service (EDOS) in Brisbane has a Statewide coordination, education & clinical support mandate. It is staffed by a mental health clinical nurse consultant and part time medical and allied health staff.

Despite varying access to skilled services, South Australia, Western Australia, Tasmania, the ACT and the Northern Territory do not have eating disorder service development units/project officers operating within Health services.

A National Approach

While there are collegial relationships between the majority of eating disorder service providers, there is no systemic approach (i.e. a National Strategy) for managing, or preventing these serious mental illnesses. Australia also lacks a National forum where grass roots consumer and service development groups can meet, work towards common goals, share resources and efficiently & effectively plan activities, promotion/prevention events and service evaluation strategies. We lack an identified National website, where consumers, carers and health professionals can obtain information and be directed towards services in their local area.

The Royal Australia & New Zealand College of Psychiatrists have now released a consumer guideline for anorexia nervosa and are finalizing the process of the clinicians guideline – the first National Standards document for one of the eating disorders in Australia.

A professional organisation – the Australian & New Zealand Academy for Eating Disorders – was recently established to communicate information regarding all aspects of eating disorders to health professional members, develop a collegial culture of fellowship through the sharing and discussion of clinical experience, knowledge and

ideas and encourage contributions by all disciplines and respect for different theories and modalities of treatment. However, the Academy as a Professional organisation is not open to membership by consumer representatives or consumer organisations.

In addition, a framework is required for a coordinated National approach to the promotion of healthy body image and the prevention and early intervention of eating disorders and disordered eating. Minimum service standards should also be included in a National Strategy, to guide State health departments in service planning and development. However, before a National Strategy and Service Development Framework can be developed (Stage Two), it will be important that a National Eating Disorder Reference Group be established (Stage One) to share existing resources and information, collaborate where appropriate on common projects and establish a National discourse regarding the factors impacting on grass-roots service delivery (consumer organisations and service development) across each State.

With the 3rd National Mental Health Plan 2003-2008 (2003) focusing on service responsiveness, quality care, research, innovation and sustainability as its priority themes, articulated within a population health approach, it is an appropriate time to begin to address eating disorders, like other mental illnesses, from a National perspective.

This proposal is to develop a **National Eating Disorders Reference Group and National Eating Disorders Clearinghouse Website (Stage One); a National Eating Disorders Strategy and Service Development Framework (Stage Two) and a National Eating Disorders Prevention Strategy (Stage Three).**

WHAT ARE EATING DISORDERS?

Eating disorders are medical and psychological conditions that affect a sizeable minority of adolescents, young people and adults, severely disrupt family life, and cause distress and anxiety to friends, carers and partners. Depending on how strictly diagnostic criteria are applied, they may be seen either as high prevalence conditions, usually of only moderate severity, or low prevalence conditions of major severity[3]. Eating disorders contribute to nutritional problems, but that is not their essence. The term 'eating disorder' implies not simply that the person afflicted has a disordered pattern of eating, but also that their eating is the result of psychological factors, such as the inanition that characterizes anorexia nervosa or the obesity found in persons who "comfort eat". The abnormal patterns of eating found in persons with eating disorders may lead to serious medical and psychiatric illness.

'Eating disorders' constitute to a spectrum of illness and behaviours ranging from mild, to moderate and severe in respect to their psychiatric & medical presentation (see Figure 1).

At the mild end of the spectrum is **disordered eating,** which is relatively common and includes eating too much, too little or too imbalanced a diet.

- It has been estimated that up to 60% of girls and young women regularly engage in unhealthy weight loss behaviours.

- In Australian women - 47% of healthy weight women believe themselves to be overweight and only 24% of young healthy weight women are satisfied with their weight[4]

- 70 - 76% of adolescent girls would ideally prefer to be thinner - most of these girls are in the healthy weight range[5]

[3] Birmingham, CL & Beumont, PJV, The medical management of eating disorders: A textbook with manuals for health care professionals' Cambridge University Press [In Press]
[4] Cash, 1997; Kenardy, Brown & Vogt, in press; Maude, Wertheim, Paxton, et al., 1993; Paxton, Sculthorpe & Gibbons, 1994
[5] Maude, Wertheim, Paxton, et al., 1993; Schutz, et al., in press; Tiggemann & Pennington, 1990

- Prevalence of weight loss behaviours in Australian studies of women report Fasting in 6 -15% Crash dieting in 16% Vomiting to lose weight in 1 to 4% use of diet pills in 6% use of laxatives for weight loss in 3 to 11%[6]

- In Australian adolescents dieting occurs in over 50% (38% of 12-13 year olds); Experimenting with an extreme method (e.g., crash dieting, fasting, vomiting) in 47%; Occasional fasting in 26-28%; Fasting at least once a week in 6%; Vomiting at least once a week in 3%.[7]

- Binge eating episodes occur in 41 - 47%[8]

Overweight means that weight is higher than 'normal', where normal may relate to a population norm or to the likelihood of disease. **Obesity** on the other hand, means there is an excess of body fat. This excess usually results from a combination of increased caloric intake and decreased activity. Obesity is one of the major health problems of the developed world, and is becoming much more common in the developing nations. However, obesity is not considered a psychiatric disorder because it is not associated with consistent behavioural and psychological features[9]. As it is not defined as a mental illness or included in the classification of 'eating disorders' it is considered outside the scope of this proposal except in relation to primary prevention and health promotion – where a consistent health promotion approach to body image and nutrition is essential across the spectrum of weight-related illnesses.

EDNOS (eating disorders not otherwise specified) is a term used to describe mild, moderate and atypical presentations of eating disorder, which do not meet the strict criteria for anorexia or bulimia nervosa. Included in this group are those who are developing eating disorders or recovering from them, those whose eating problems relate to other psychiatric conditions (e.g. depression, anxiety, schizophrenia), those with binge eating disorder and those whose quality of life is impaired by their dissatisfaction with their body weight, shape and appearance.

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[6] Crawford & Worsley, 1988; Ben-Tovim, et al., 1989; Wertheim, Mee & Paxton, 1999
[7] Fear et al., 1996; Grigg, Bowman & Redman, 1996; Patton et al. 1997; Martin, Wertheim et al., 2000; Maude, Wertheim et al., 1993
[8] Wertheim, Paxton et al 1992
[9] Birmingham & Beumont ibid

Bulimia nervosa is a moderate to severe illness occurring in about 1% -3% of adolescent and young women with a larger number of people suffering less severe symptoms. People with bulimia nervosa are trapped in a vicious cycle of dietary restriction, binge eating and purging behaviour. In general, treatment in the community, with consultation from psychologists, GP's, dietitian and other health professionals will suffice and is appropriate.

In Australia, **anorexia nervosa** is the most serious chronic mental illness and physical disease of adolescent girls and young women. It leads to emaciation, physical dysfunction, an abnormal mental state, overvalued ideas concerning weight and shape, depression and obsessionality. It occurs in 0.5-1% of girls and young women (half the life-time risk of schizophrenia) and has by far the highest **risk of suicide** (**32 times** expected[10]) and **mortality rate** (**20% at 20 year follow-up**[11]) of all psychiatric illnesses. Anorexia nervosa causes a degree of handicap and family dysfunction comparable to that of schizophrenia.

MILD	MODERATE		SEVERE
Disordered Eating	EDNOS	Bulimia Nervosa	Anorexia Nervosa
At the mild end of the spectrum is disordered eating, which is relatively common and includes eating too much, too little or too imbalanced a diet. It has been estimated that up to 60% of girls and young women regularly engage in unhealthy weight loss behaviours. On the other hand, obesity, the result of over-nutrition and insufficient activity, is reaching epidemic proportions in most developed countries, and is a major cause of serious physical disease later in life.	EDNOS (eating disorders not otherwise specified) is a term used to describe mild-moderate or severe, but atypical presentations of eating disorder, which do not meet the strict criteria for anorexia or bulimia nervosa. Included in this group are those who are developing eating disorders or recovering from them, those whose eating problems relate to other psychiatric conditions (e.g. depression, anxiety, schizophrenia), those with binge eating disorder and those whose quality of life is impaired by their dissatisfaction with their body weight, shape and appearance.	Bulimia nervosa is a moderately severe illness occurring in about 4% of women. People with bulimia nervosa are trapped in a vicious cycle of dietary restriction, binge eating, vomiting and purging behaviour.	Anorexia nervosa is a low prevalence illness which occurs in only 0.2-0.5% of women, less in men. It's severity is well documented, it may result in life-long physical and psychiatric morbidity and has the highest mortality rate of any functional psychiatric illness. Anorexia nervosa is characterised by reduction in weight through extreme dietary restriction, over activity and frequently, vomiting and purging.

Figure 1: Eating Disorders exist on a continuum[12].

[10] Harris & Barraclough (1998) Excess mortality of mental disorder BJP 173:11-53
[11] Ratnisurya R.H., Eisler, L., Szmukler, G.I., & Russell G,F., (1991) Anorexia Nervosa: Outcome and prognostic factors after 20 years. *British Journal of Psychiatry* Vol 18: 392-502
[12] Marks, P., Beumont, P., Birmingham, C.L., 2003 GPs managing patients with eating disorders: A tiered approach.

WHO IS AFFECTED?

- 95% of people with eating disorders are female, though the incidence of eating disorders in men and boys is said to be more common than had previously been thought[13]
- Many psychiatric illness (e.g. depression, anxiety, obsessive-compulsive disorder, schizophrenia) and physical diseases (e.g. diabetes mellitus, osteoporosis, infertility, malabsorption), substance abuse and other self-harming behaviours have a high co-morbidity with eating disorders, requiring complex treatment planning.
- Families, carers, partners and friends are all affected.
- Research in Australia on the epidemiology of eating disorders is inconclusive to date, but work is continuing, including an ambitious and comprehensive study currently being undertaken in the ACT.

WHO IS AT RISK?

- Dieting is the most important predictor of eating disorders[14], with females who diet severely being 18 times more likely to develop an eating disorder[15]. In those who diet extremely, psychiatric morbidity appears to be a major factor associated with significantly greater risk of progression to eating disorder over time. This suggests that both the behaviour of dieting as well as psychiatric morbidity is important in the development of new eating disorders. 68% of 15-year-old females are on a diet, of these, 8% are severely dieting. Included in this risk group are those who engage in other risk taking behaviours such as purging, drug use and smoking to suppress appetite.
- Those with a family history of eating disorder, family dieting, and/or adverse comments from family members about eating, appearance or weight[16]are more at risk. There is a strong familial association with these illnesses[17] [18]. Some suggest

[13] Woodside, D.B., 2004 'Assessing and treating men with eating disorders' *Psychiatric Times* XXI(3)
[14] Huon G F, Gunewardene A, Hayne A, Sankey M, Lim J, Piera T and Walton C (2002) Empirical support for a model of dieting: findings from structural equations modelling. International Journal of Eating Disorders (in press).
[15] Centre for Adolescent Health, Melbourne
[16] Attie I and Brooks-Gunn J. Developmental issues in the study of eating problems and disorders. In The Etiology of Bulimia Nervosa: the individual and familial context. Crowther J H, Tannenbaum D I, Hobfoll S E and Stevens M A (Eds), Hemisphere, New York, 35-58.
[17] Griffiths R, Beumont PJV, Beumont D, Touyz S W, Williams H and Lowinger K (1995) Anorexie a deux: an ominous sign for recovery. European Eating Disorders Review 3(1):2-14.

that there may be a causative genetic component[19] Also at risk are those with childhood obesity, obese parents, early menstruation or exposure to (or concurrent presentation of) mood disorder, substance abuse and obsessive-compulsive disorder.

- Girls between 14-19 years (for anorexia nervosa) and between 19-25 years (bulimia nervosa) are most at risk, although disordered eating and eating disorders have been reported in children as young as 7 years old.

- People considering a career in an industry where low weight is considered a pre-requisite, such as modeling, acting and dancing, or where 'weight categories' are specified regardless of height such as boxing, should be considered 'at risk'[20] [21] as should elite athletes, sports people and 'gym junkies'[22]

- Peer group pressure (where a group leader is 'successfully' engaged in a dieting disorder) and pressure to conform to a thin stereotype. People who feel insecure about themselves, those who experience difficulty communicating their needs and emotions and those who do not feel 'in control' of their lives. Those with a poor body image and/or negative self-evaluation. Those who are prone to perfectionism, depression, obsessionality or social anxiety and those with a past psychiatric history[23].

- Childhood sexual assault is related to heightened levels of psychiatric comorbidity in individuals with eating disorders, particularly in those with bulimia nervosa[24] [25].

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[18] Bulik C M, Sullivan P F, Wade T D and Kendler (2000) Twin studies of eating disorders: a review. International Journal of Eating Disorders 27, 1-20.
[19] Halmi K (1999) Eating disorders: defining the phenotype and reinventing the treatment. Editorial. American Journal of Psychiatry 156:1673-1674.
[20] Huon et al ibid
[21] Abraham S F, Beumont PJV, Fraser I S and Llewellyn-Jones D (1982). Body weight, exercise and menstrual status among ballet dancers in training. British Journal of Obstetrics and Gynaecology 89, 507-510.
[22] Smolak, L., Murnen, S., Ruble, A., (2000), Female athletes and eating problems: A Meta-analysis. International Journal of Eating Disorders 27:371-380.
[23] Beumont PJV, Abraham S F, Argall W J, George GCW and Glaun D E (1978). The onset of anorexia nervosa. Australian and New Zealand Journal of Psychiatry 12, 145-149.
[24] Brown L, Russell J, Thornton C and Dunn S (1997) Experiences of physical and sexual abuse in Australian general practice attenders and an eating disorders population. Australian and New Zealand Journal of Psychiatry 31:398-404.
[25] Wonderlich S A, Brewerton T D, Jocic A, Dansky B S and Abbott D W (1997) Relationship of childhood sexual abuse and eating disorders. Journal of American Academy of Child and Adolescent Psychiatry 36:8.

THE CURRENT SITUATION AROUND AUSTRALIA

As briefly discussed in the introduction, the situation across Australia with regards to specialist services, service coordination units, Departmental responsibility and community/consumer organisations is patchy. The following table outlines the major public services & organisations where these exist.

New South Wales	
Specialist Services	**Adults:** there are 7 'de facto' tertiary beds for eating disorders in NSW (located in Central and Western Sydney AHS) and the only publicly funded day program for adults is in Western Sydney AHS. There are two tertiary-level outpatient clinics (Central and Western AHS) and 4 secondary-level outpatient clinic sessions (South Western Sydney, Nepean Hospital, Hunter and Illawarra AHS). An early intervention program in the Central Coast AHS began taking clients in January 2004. **Children & Adolescents:** there are a small number of 'de facto' tertiary beds located at the Children's Hospital Westmead and the Westmead Adolescent Unit – both of which have an outpatient service and access to a limited day program. The Children's Hospital Randwick also accepts inpatients with eating disorders. Outpatient treatment is offered for adolescents in Central Sydney. NEXUS Unit in the Hunter AHS is the only adolescent mental health unit which accepts people with eating disorders.
Community Organisation	The Eating Disorder Foundation NSW Inc is a volunteer consumer organisation, operating without government funding, which provides the community with free telephone and group support, holds educative public forums and has developed a resource centre. EDF of NSW Inc. aims to provide sufferers of eating disorders and the families and friends with up to date information about the various eating disorders and about services and resources to assist recovery.
Service Coordination & Divisional Responsibility	The NSW Centre for Mental Health (CMH) has accepted overall responsibility for eating disorders and has developed a Statewide Service plan. It appointed a Service Development Officer for NSW on a short-term grant [2004-2006] who operates the Centre for Eating & Dieting Disorders [which has a service development focus including training, education and professional development]. A local coordinator has been appointed in one rural region funded by the Area Mental Health Service (Northern Rivers).

Australian Capital Territory	
Specialist Services	Throsby Place Eating Disorders Program is a government funded service which provides a day program service for people with anorexia or bulimia, some of whom are inpatients in a medical unit at the Canberra Hospital. A support group for family and friends meets monthly at the community-based centre. A psychiatrist from Sydney consults weekly to the program.

Queensland	
Specialist Services	The Royal Brisbane Hospital accepts a limited number of clients with eating disorder on a tertiary referral basis.
Consumer Organisations	The Eating Disorders Association Inc (Qld) is a non-discriminatory, non-profit organisation. The Eating Disorders Association is funded by the Statewide Health and Non-Government Services Unit of Queensland Health, to provide information, support and referral services for the state of Queensland, Australia. Isis – Centre for Women's Action on Eating Issues Inc is a community based organisation funded by Queensland Health (Mental Health). ISIS was funded in July 1996 to develop a model of feminist group work practice with women who idenfiy as having serious eating issues, such as bulimia, anorexia and compulsive eating.
Service Coordination & Divisional Responsibility	The Eating Disorders Outreach Service (EDOS) runs through the Division of Mental Health Services at Royal Brisbane Hospital. EDOS is concerned primarily with service coordination, education & clinical support of health professionals from within mental health services all around Queensland. It is staffed by a full-time mental health Clinical Nurse Consultant and part time medical and allied health staff.

Victoria	
Specialist Services	**Adults** Banksia House (Austin & Repatriation Medical Centre) has inpatient and outpatient services for clients aged 16+. ARMC caters for North/North-East Victoria. Royal Melbourne Hospital has inpatient, day patient and outpatient services for people 16+ - taking clients from Western Victoria. This is the only publicly funded eating disorders day program in Victoria. **Children / Adolescents** Monash Medical Centre- Department of Child Psychiatry and Adolescent Health has inpatient and outpatient services for clients up to 18 years. Royal Children's Hospital –inpatient and outpatient service for up to 16 years old with a catchment area covering Victoria.
Community Organisations	The Eating Disorders Foundation of Victoria is a non-profit organisation which aims to support those affected by eating disorders, and to better inform the community about disordered eating. The Foundation was established in the early 1980s by health professionals who recognised the need for information and support related to eating disorders. The Butterfly Foundation provides financial assistance for the direct relief of sufferers of eating disorders and for the prevention of disease by supporting education and early intervention programs. The Butterfly Foundation is neither a service provider nor a referral service. Funds raised are directed at the Board's discretion on the basis of an income and assets test, to disadvantaged sufferers of eating disorders in order that they may access suitable, ongoing treatment options of their choice, and to providers of prevention, early intervention and support activities for the purposes of supporting their activities.
Service Coordination & Divisional Responsibility	The Victorian Centre of Excellence in Eating Disorders (CEED) was launched in January 2002 as part of the Victorian government's commitment to improving health care for people with eating disorders. CEED aims to reduce the risk, duration and impact of eating disorders in people of all ages by building Victoria's capacity to undertake effective prevention, early intervention and clinical care.

Tasmania	
Community Organisations	The Community Nutrition Unit conducts a range of nutrition promotion programs including providing support and training to communities and health workers. Support includes assistance with planning, implementation and evaluation of community nutrition programs. The unit also has extensive collection of nutrition education materials including kits, posters, pamphlets, videos etc. The unit offers a free telephone nutrition advisory service to the public.

South Australia	
Community Organisations	The Eating Disorders Association of South Australia Inc is a consumer organisation which provides information & support to the people of South Australia who have eating disorders. In addition, the organisation is supported by a Board of Directors and a small number of volunteer project officers who are involved in developing specific projects. Core funding is from Mental Health unit branch of Department of Human Services.
Specialist Services	Flinders Medical Centre has 6 beds on the weight disorder unit which is in the context of a 20 bed acute psychiatric unit.

Western Australia	
Community Organisations	The Eating Disorders Association of WA Inc

Stage One Part One:
National Eating Disorders Reference Group

There is no formal capacity for networking and sharing information between eating disorder community groups and service development units. Part One of this proposal is to develop a National Eating Disorder Reference Group with representation from eating disorder community organisations and service coordination units (or services) across Australia. An additional component of this process will be the development and maintenance of a National Eating Disorder Website (see part two), which will assist consumers and carers by providing them with information about eating disorders, about prevention and early intervention and direct them to eating disorder service providers and treatment centres in their local area. Corporate funding/sponsorship will be sought for this component of the project (part two).

Aim: To establish a National Eating Disorder Reference Group which meets three times per year and works within the framework of the National Mental Health Plan 2003-2008 i.e. with a focus on promoting mental health and preventing mental health problems and mental illnesses such as anorexia and bulimia nervosa; increase service responsiveness; strengthening quality; and fostering research, innovation and sustainability[26].

Objectives

1. Develop a structure whereby National collaboration on health promotion and illness prevention projects is a focus. Providing an opportunity to develop health promotion / illness prevention programs which provide consistent health messages across all States (and across the weight-disorder spectrum – from obesity to anorexia nervosa).

2. Increase access to appropriate resources (including training & education, information, consumer support and clinical services) for people across Australia, primarily through the promulgation of resources which exist in individual organisations (e.g. EDFV has recently completed a VIC Health accredited early

[26] Australian Health Ministers, National Mental Health Plan 2003-2008. Canberra, Australian Government 2003

identification training program for fitness instructors. This type of program could be utilized by organisations in each State, if opportunities for 'Train-The Trainer' seminars existed.) Ultimately, responsiveness to the needs of the community will be increased by this type of collegial sharing of resources.

3. Strengthen and improve the quality of services and the research and training capacity of each organisation, through collaboration, cross-fertilisation of ideas and networking and develop a Resource Network whereby service development strategies and best practice documents can be disseminated.

4. Enable the development of timely and appropriate research, avoiding duplication and resource wastage thereby ensuring funding handed down by State Health Organisations and obtained from other granting bodies is utilized as effectively and efficiently as possible.

5. Improving sustainability of individual organisations, particularly by supporting those who do not receive any government funding, by establishing a National approach towards the prevention, identification and treatment of eating disorders.

Outcomes

1. All organisations will be represented at the National Eating Disorder Reference Group meetings
2. A National Website and resource list will be established and available on line to all Australians
3. 'Train the Trainer' seminars will be held enabling projects developed by one organisation to be utilized across the services.
4. Promotion/prevention materials, information & resources will be re-branded and utilized across the services.
5. Where possible and appropriate, joint projects will be established involving two or more organisations from within the Reference Group.
6. The group will act as a resource for the development of a National Strategy for Eating Disorders Service Development [Stage Two of this proposal] and for the development of a National Strategy for the Prevention of Eating Disorders [Stage Three of this proposal].

MEMBERSHIP

The group (listed below in alphabetical order) would be made up of:

a) A representative from each State Consumer Organisation, or where these do not exist, a consumer or carer representative.

b) A representative from each State Service Coordination Unit, or where these do not exist, a representative from the specialist service provider, or where these do not exist, from the State Health Department

c) A representative from the National professional body – the Australian & New Zealand Academy for Eating Disorders

	State	Organisation Name	Type of Organisation
1	NSW	Centre for Eating & Dieting Disorders	Service Coordination Unit
2	VIC	Centre for Excellence in Eating Disorders	Service Coordination Unit
3	QLD	Eating Disorder Association Inc Queensland	Consumer Organisation
4	QLD	Eating Disorder Outreach Service	Service Coordination Unit
5	SA	Eating Disorders Association of South Australia Inc	Consumer Organisation
6	WA	Eating Disorders Association of Western Australia Inc	Consumer Organisation
7	NSW	Eating Disorders Foundation of New South Wales Inc	Consumer Organisation
8	VIC	Eating Disorders Foundation of Victoria Inc	Consumer Organisation
9	QLD	ISIS	Consumer Organisation
10	VIC	The Butterfly Foundation Inc	Consumer Organisation
11	TAS	The Community Nutrition Unit	Consumer Organisation
12	ACT	Throsby Place Eating Disorders Program	Specialist Service Provider
13		Australia & New Zealand Eating Disorders Academy	National Professional Body
14	WA	Department of Health – Mental Health	Service Provider
15	ACT	Nominated Consumer Representative	Consumer Representative
16	NT	Nominated Consumer Representative	Consumer Representative
17	NT	Department of Health – Women's Health	Service Provider
18	TAS	Department of Health	Service Provider

CO-ORDINATION

It is proposed that the group meetings are coordinated through the Centre for Eating & Dieting Disorders [CEDD] by the Eating Disorder Service Development Officer for NSW and that the Commonwealth Grant and additional corporate funding obtained be administered through the Eating Disorders Foundation of NSW Inc. All organisations involved in the development of this funding submission agree with this process.

FREQUENCY AND LOCATION OF MEETINGS

Because Brisbane, Sydney and Melbourne are the sites where the majority of group members reside, it would be cost effective if the meetings were held variously in each of these locations. It would be reasonable for the group to meet three times per year - once in Brisbane, once in Sydney and once in Melbourne.

COSTING ESTIMATES

For 3 meetings per year, one in Brisbane, one in Sydney, one in Melbourne, for 18 members, for two years.

Total Costing Estimate for National ED Reference Group

[See Appendix One for Breakdown of Costs]

a) Flights	**$36,088.00**
b) Catering	**$7,081.20**
c) Accommodation	**$17,100.00**
Total	**$60,269.20+ GST = $66,296**

Stage One Part Two: National Eating Disorder Website

At present, there is no nationally identifiable point of contact for people struggling with eating disorders, their carers, families or health professionals. A recent UK evaluation of web-based information about eating disorders[27] highlighted the fact that there was a lack of quality information about the treatment of eating disorders available on the web. It also noted that eating disorders are probably a key source of information for people with eating disorders – particularly because they are predominantly in the age group where internet literacy is extremely high, but also because of the intrinsic factors associated with the illnesses themselves. Eating disorders are associated with high levels of secrecy, shame and stigma and sufferers are typically reluctant to seek help.

Websites exist for the following organisations community and service development organisations:

Centre for Eating & Dieting Disorders www.cedd.org.au NSW
Eating Disorders Foundation Inc www.edf.org.au NSW
Centre for Excellence in Eating Disorders www.ceed.org.au VIC
Eating Disorders Foundation VIC Inc www.eatingdisorders.org.au VIC
Eating Disorders Resource Centre (EDA) QLD www.eatingdisorders.org.au QLD
ISIS Centre for Women's Action on Eating Issues QLD http://www.isis.org.au/ QLD

Each of these sites focuses on different aspects regarding eating disorders – some particularly on women's issues, others on available services, some with information about eating disorders, others with comprehensive program information and research. A national clearinghouse - 'Eating Disorders Australia' - would enable consumers and health professionals from every State in Australia to access up to date clinical practice guidelines and benchmarking tools, information about treatment types including issues surrounding outcome, State and National policies relating to eating disorders, promotion and prevention tools and of course links to local services and service providers. Collaborative projects run by members of the Eating Disorder Reference

[27] Murphy, R., Frost, S., Webster, P., Schmidt, U., (2004) An Evaluation of Web-Based Information, *International Journal of Eating Disorders* 35:145-154

Group would also be available, as would programs run by each of the individual organisations (consumer & service development units) with links to their various sites.

An additional component which would be important from the perspective of child and adolescent help-seeking would be a moderated chat room, where young people who suspect that they, or one of their friends, might have, or be developing an eating disorder, could ask questions in a 'safe' and anonymous environment.

NOTE: Funding for this component of the proposal will be sourced through corporate sponsorship and does not form part of this funding submission.

COSTING ESTIMATES per year

[See appendix for breakdown of costing estimates]

YEAR ONE

Initial Website Development	**$6,000.00**
Maintenance per annum	**$5200.00**
Moderated online sessions	**$15,600.00**
Total	**$26,800.00** **GST inclusive**

Year TWO/Thereafter

Maintenance per annum	**$5200.00**
Moderated online sessions	**$15,600.00**
Total	**$20,800.00** **GST inclusive**

Stage Two: National Strategy for Eating Disorders & Framework for Service Development

At present there is no national strategy or framework for service development for eating disorders in Australia. Indeed, NSW is the only State where policy relating specifically to eating disorders has been developed - over the past 2 years the NSW State Health Department (Centre for Mental Health) has established a draft Eating Disorders Service Development Plan for NSW. This plan is awaiting ratification by the Minister but has 'in-principle' support from the Director for Mental Health Services who is chairing a working party and has begun operationalisation of the plan.

In Victoria, a parliamentary inquiry into the impact of negative body image on young people has been commissioned and is currently seeking submissions.

A national strategy for eating disorders is required for a number of reasons.

1) There has been uncertainty about which clinical system should be primarily responsible for care of people with eating disorders – they frequently require the input of multiple disciplines, which has resulted in their care being isolated in a super-specialist area of psychiatry, or pediatric or adolescent medicine. Unfortunately this has meant that neither mental health nor general medicine has taken overall responsibility for providing care to people with eating disorders and has resulted in eating disorder services existing only where there are interested and dedicated clinicians.

2) Because care for clients with eating disorders has not been widely accepted by the mental health or generalist medical community, there is a lack of knowledge and expertise amongst the majority of general practitioners, community health and community mental health workers, generalist and mental health inpatient treatment services, private and public psychiatrists, psychologists, dietitians, social workers and OTs. In accordance with the process of mainstreaming mental health services, it will be essential to address the education & training needs of health professionals with regards

to working with clients who have eating disorders in order to ensure clients are receiving appropriate care.

3) As the need for treatments and services for eating disorders grows, it will be important that established clinical benchmarks are promulgated in order that services are developed in line with available EBM and best practice.

COSTING ESTIMATE

Item	Salary/Cost p/a or p/h	Oncosts	Total
Project Director Overseeing Stages 1, 2, 3 1 x FTE 1.5 years	$150,000 p/a	25% = $37500	$187,500 x 1.5 years = $281,250
National Strategy (Stage 2) Project Coordinator 1 x FTE 1 year	$100,000 p/a	25% = $25000	$125,000
Researcher 1 x FTE 1 year	$45,000 p/a	25% = $11250	$56,250
Expert Consultants 10 consultants x 10 hours	$100 p/hr	X 20 hours	$10,000
Secretarial Service 1 x FTE 1.5 years	$35,000	25% = $8750	$43,750 x 1.5 years = $65,625
National Strategy Key Stakeholders Summit			$30,000
Office & Utilities (See Appendix 3)			$43,400.00 x 1.5 years = $65,100
Travel Allowance Project Director (1.5 years) & Stage 2 Coordinator (1 year)	$10,000 each p/a		$25,000
Total			**$658,225**

Stage 3: National Eating Disorder Prevention Strategy

Eating disorders, because they are so clearly related to motivated behaviour, would seem an ideal area for preventative approaches. In addition, it is simply unacceptable that these often chronic illnesses which primarily affect young Australians are responsible for such alarming morbidity and mortality rates. Unfortunately, those preventative measures that have been directly aimed at decreasing inappropriate dieting behaviour have proved to be at best ineffectual, and at worst perhaps even harmful: they have glamorized dieting and eating disorders. For this reason a new approach to prevention is necessary. Work both in Australia and overseas suggests that a far more beneficial approach is to devote preventative programs to enhancing self-esteem, especially in school children[28, 29, 30]. This has the added advantage that it is possibly also of value in preventing the development of other mental health problems as well.

Almost all adolescent girls in our society diet, many also over-exercise to control weight, or more dangerously use vomiting and purgation for this purpose. There are several factors that have enforced this trend[31, 32, 33, 34, 35]:

(a) Health promotion to prevent obesity which has been interpreted too literally and inappropriately, extolling restriction and exercise;

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[28] O'Dea J (2000) School-based interventions to prevent eating problems: First do no harm. Eating Disorders: the Journal of Treatment and Prevention 8(2):123-130.

[29] Buddeberg-Fischer B, Klaghofer R, Gnam G and Buddeberg C (1998) Prevention of disturbed eating behaviour: a prospective intervention study in 14- to 19-year old Swiss students. Acta Psychiatrica Scandanavica 98:146-155.

[30] O'Dea J and Abraham S (2000) Improving body image, eating attitudes, and behaviours of young male and female adolescents: A new educational approach that focuses on self esteem. International Journal of Eating Disorders 28:43-57.

[31] Women's Health Australia. What do we know? What do we need to know?: Progress on the Australian longitudinal study on women's health 1995-2000, Brisbane 2001.

[32] Huon G (1994) Dieting and binge eating, and some of their correlates among secondary school girls. In national Health and Medical Research Centre (NHMRC) 1995, Acting on Australia's Weight, p146. Huon G F and Walton C (2000) Initiation of dieting among adolescent females. International Journal of Eating Disorders 28, 226-230.

[33] Hay P (1998) The epidemiology of eating disorder behaviours: an Australian community-based survey. International Journal of Eating Disorders 23, 371-382.

[34] Sawyer M G, Arney F M, Baghurst P A, Clark J J, Graetz B W, Kosky R J, Nurcombe B, Patton G C, Prior M R, Raphael B, Rey J, Whaites L C and Zubrick S R (2000) The Mental Health of Young People in Australia. Child and Adolescent component of the National Survey of Mental Health and Wellbeing. Commonwealth Department of Health and Aged Care. See also current letters in the Australian and New Zealand Journal of Psychiatry.

[35] Huon G F, Gunewardene A, Hayne A, Sankey M, Lim J, Piera T and Walton C (2002) Empirical support for a model of dieting: findings from structural equations modelling. International Journal of Eating Disorders (in press).

(b) Social pressures, exerted largely through the media, and directed at young persons, that promote the thinness ideal for women (more so than for men) and inappropriately equate slenderness with beauty;

(c) A general perception within society of women's worth being judged on their appearance rather than who they are or what they do;

(d) Other factors within our society that impair the self-esteem of women, and which stigmatize obese persons;

(e) Inappropriate pressure from family, teachers, and other persons in authority for girls and young women to comply with societal expectations that are unreasonable, and often self-contradictory (a large bust with a diminutive waist; an active contributor to the community through hard work and effort, but at the same time a full-time mother and a sex object);

(f) Perhaps most important of all, competition within the peer group of adolescent girls and young women as to who can be the most slender, closest to the ideal;

(g) The mistaken belief that being slender means being happy.

At present, Australia faces a problem in respect to obesity of epidemic proportions. It is assumed that most obese people will be able to accept and act on education and advice about healthy eating and exercising and thus improve their health, but this optimistic expectation is yet to be proved. The extent of psychological problems that contribute to over-eating among obese persons, and whether these problems are causative of, or the result of, the abnormal eating (or both) are unknown. At the same time there has been an increased awareness (and probably also an increased occurrence) of eating disorders that lead to chaotic eating behaviours in normal weight persons (eg bulimia nervosa) or to self-induced undernutrition and starvation (anorexia nervosa). Although these disorders are not considered to be of epidemic proportions, they are nevertheless significant health problems that must be properly addressed by better understanding their causation, by taking appropriate preventative measures in the community, by offering effective and accessible diagnostic and treatment facilities, by ensuring that

treatment is affordable and easy to reach for all people in the State, and to provide rehabilitation and long-term care. It is important to ensure that attention to eating disorders is not at the expense of disordered eating, particularly that resulting in obesity, and hence it is necessary that a common approach is adopted in our response to these problems. To do so, healthy eating and life-styles must by promoted, but both excessive restriction and irresponsible eating discouraged[36,37].

COSTING ESTIMATE

Item	Salary/Cost p/a or p/hr	Oncosts	Total
Project Director Overseeing Stages 1, 2, 3 1 x FTE 1.5 years	$150,000 p/a	25% = $37500	$187,500 x 1.5 years = $281,250
National Prevention Strategy (Stage 3) Project Coordinator 1 x FTE 1 year	$100,000 p/a	25% = $25000	$125,000
Expert Consultants 10 consultants x 10 hours	$100 p/hr	X 20 hours	$10,000
Research Coordinator 1 x FTE 1 year	$45,000 p/a	25% = $11250	$56,250
Secretarial Service 1 x FTE 1.5 years	$35,000 p/a	25% = $8750	$43,750 x 1.5 years = $65,625
National Prevention Strategy Key Stakeholders Summit			$30,000
Office & Utilities (See Appendix 3)			$43,400.00 x 1.5 years = $65,100
Travel Allowance Project Director (1.5 years) & Stage 3 Coordinator (1 year)	$10,000 each p/a		$25,000
Total			**$658,225**

[36] National Task Force on the Prevention and Treatment of Obesity (2002) Dieting and the development of eating disorders in overweight and obese adults: a review. Archives of Internal Medicine 25, 2581-2589.
[37] Gaskill D and Sanders F (2000) The Encultured Body: Policy implications for healthy body image and disordered eating behaviours. Queensland University of Technology.

Project Details

This 3 stage project submission has been developed by the **Eating Disorder Service Development Officer for NSW** from the **NSW Centre for Eating & Dieting Disorders [CEDD – Funded by NSW Centre for Mental Health]** in collaboration with a Consortium all of the Eating Disorder Organisations in Australia (as listed). It is anticipated that any submission funding received will be administered through the **Eating Disorders Foundation NSW Inc**. All organisations involved in the development of this funding submission agree with this process.

The **Eating Disorders Foundation NSW Inc** is the leading community based volunteer run organisation in NSW which supports, educates and advocates for those affected by eating disorders. They play a unique role in understanding and responding to the personal and social impact of eating disorders and aim to improve the mental and physical health of everyone affected. They also address issues of prevention, promoting a healthy body image and acceptance of diversity. The Foundation provides support and recovery groups, a resource centre and a support and information line. In addition they hold health promotion activities and education forums - the biggest of which is the annual Youth Forum attended by 2000 students. The Executive Officer and the volunteers of EDF are accountable to a Board of Management. The first Board was inducted at the 2002 Annual General Meeting and comprises men and women with a diverse range of experiences and professional skills. They span careers of accountancy, psychology, teaching, social work, human resources, marketing, medicine and psychiatry.

The **Project Director** will hold overall responsibility for the delivery of this 3 stage project and will oversee, support and direct the Project Coordinators (National Strategy Coordinator & National Prevention Strategy Coordinator) regarding planning, development, consultation, preparation and evaluation of Stage 2 and Stage 3 components. In collaboration with the Coordinators, s/he will arrange the 2 Key Stakeholder Summits (National Strategy Summit & National Prevention Strategy Summit) and ensure that there is a consistent approach taken across the Stages to ensure complimentary strategies are developed. The Project Director will be responsible to the Board of the Eating Disorders Foundation NSW Inc, who will act on behalf of the consortium of Eating Disorder Organisations listed above.

CONCLUSION

Eating disorders are serious mental illnesses with significant morbidity and the highest mortality rate of any functional psychiatric illness.

This submission is to develop a comprehensive national strategy for the prevention and treatment of eating disorders; including establishing a National Eating Disorder Reference Group; a National Strategy for Service Development; A website clearinghouse for information dissemination and a National Strategy for Preventing Eating Disorders.

This submission is supported by every eating disorder community organisation and service coordination unit in the Country.

Total Funding Requested:

[Excluding funding for website which will be obtained via corporate sponsorship]

Stage 1: National ED Reference Group	**$66,296**
Stage 2: National Strategy for Eating Disorders & Framework for Service Development	**$658,225**
Stage 3: National Eating Disorder Prevention Strategy	**$658,225**
GRAND TOTAL	**$1,382,746**

Appendix 1: Breakdown of Costing Estimates for National Reference Group

Origin	Destination	$ one way	No	Total Cost
Darwin	Brisbane	440.00	2	1760.00
Darwin	Sydney	324.00	2	1296.00
Darwin	Melbourne	479.00	2	1916.00
Perth	Brisbane	300.00	2	1200.00
Perth	Sydney	374.00	2	1496.00
Perth	Melbourne	307.00	2	1228.00
Adelaide	Brisbane	279.00	2	1116.00
Adelaide	Sydney	176.00	2	704.00
Adelaide	Melbourne	139.00	2	556.00
Melbourne	Brisbane	142.00	3	852.00
Melbourne	Sydney	139.00	3	834.00
Sydney	Brisbane	132.00	2	528.00
Sydney	Melbourne	135.00	2	540.00
Brisbane	Sydney	174.00	3	1044.00
Brisbane	Melbourne	185.00	3	1110.00
Canberra	Brisbane	199.00	2	796.00
Canberra	Sydney	95.00	2	380.00
Canberra	Melbourne	172.00	2	688.00
	Sub Total One Year			*$18044.00*
	a) Total Estimate Two Years			**$36088.00**

Meal	Price per person	No.	Days per meeting	Cost per meeting	Cost over 3 meetings
Morning Tea	$6.95	18	2	250.20	750.60
Lunch	$20.00	18	2	720.00	2250.00
Afternoon Tea	$5.00	18	2	180.00	540.00
Total Estimate per year					*$3540.60*
b)Total Estimate two years					**$7081.20**

Accommodation Location	Cost per person	No.	Nights	Total Estimate
Brisbane Metro Hotel Tower Mill	$89.00	15	2	2670.00
Sydney The Haven Inn Glebe	$106.00	16	2	3180.00
Melbourne Arrow on Swanston	$90.00	15	2	2700.00
Total Estimate per year				*$8550.00*
c) Total Estimate two years				**$17100.00**

Note: Venue & Equipment hire for meetings will be covered by the Host Organisation [i.e. CEDD NSW; CEED VIC; EDOS QLD]

Appendix 2: Website Development & Maintenance Estimate Breakdown

Item	Cost
Project Management	**$5500 including GST**
Design & Development – including live chat room facilities for client Question/Answer sessions	
Content preparation	
Production	
Implementation	
Domain Name Registration	**$200**
Site hosting	**$300 per annum**
Site maintenance at 2 hours per week @ $100 p.h.	**$5200 per annum**
Moderated chat facility for client Q&A about eating disorders – staffing for 1 hour per day M-F @ $60p.h.	**$15,600 per annum**
TOTAL	

Appendix 3: Office Utilities Breakdown

Item	Amount per week	Annual
Rent	$500	$26,000
Internet Access	$20	$1,040
Telephone	$100	$5,200
Insurance	$50	$2,600
Equipment		$3,000
Maintenance		$1,000
Electricity	$30	$1,560
Stationery & Postage		$3,000
Total		**$43,400**