Full Submission to the Select Committee on Mental Health
Eating Disorders – Core Business for Mental Health
[Focus on service needs for New South Wales]
NSW Centre for Eating & Dieting Disorders (CEDD)
May 2005

A: THE CURRENT SITUATION

1.0 Eating Disorders are not Rare Illnesses

1.1 Eating disorders are a common group of psychiatric disorders with significant levels of medical complications, morbidity and mortality (Hsu, 1988, 1990; Steinhausen, 2002).

1.2 Eating disorders exist on a spectrum of severity and according to current diagnostic systems (DSM-IV) are classified into three broad groups - anorexia nervosa (AN), bulimia nervosa (BN) and the heterogeneous group of Eating Disorders Not Otherwise Specified (EDNOS), the latter including the category of Binge Eating Disorder (BED).

1.3 **Lifetime risk** within the community for all of the eating disorders is difficult to estimate because of inadequacy in research funding in this area. However, best estimates extrapolated from epidemiological studies in Western countries including Australia place it at approximately **5%** of the population (Paxton, 2000; Patton et al., 2003) and for females at least double this - 8% lifetime risk for bulimic syndromes and 3% for anorexic syndromes (Kendler et al., 1991; Walters & Kendler, 1995; Patton et al., 1999).

1.4 Cross sectional surveys have confirmed that eating disorders are very common in adolescent women; around 0.5% have anorexia nervosa, 1% have bulimia nervosa, and 3% to 5% have subclinical syndromes (Johnson et al, 1988; Rastam et al., 1989; Patton et al., 1999).

1.5 There is frequently a progression from extreme dieting & disordered eating behaviours to more severe eating disorders (Franko & Omori, 1999; Hsu, 1990; Shissalak et al. 1995) and the levels of extreme dieting in the population, particularly amoung young females, are currently extremely high (Crawford & Worsley, 1988; Ben-Tovim, et al., 1989; Wertheim, Mee & Paxton, 1999; Grigg, Bowman & Redman, 1996; Patton et al. 1997; Martin, Wertheim et al., 2000; Wertheim et al., 1993).

2.0 Anorexia nervosa (AN)

2.1 AN is the least common of the disorders. However, after obesity and asthma, it is the most common chronic disease in adolescents and young women, and it is a much more deadly condition than either of the others. It is 5 times more common than IDDM in these persons (Lucas et al., 1991).

2.2 Extrapolating from epidemiological research, in NSW approximately 560 new cases are diagnosed each year, and about 4200 patients are affected by anorexia nervosa at any one time (see Hoek & Hoeken, 2003; Lucas et al., 1991).

2.3 The only Australian population based epidemiological study addressing anorexia nervosa is a survey-based study, with significant limitations, which found a one year prevalence of cases of anorexia nervosa, was 1.05 cases per thousand of the population studied (Ben Tovim & Morton, 1990). Other studies utilising diagnostic interviews have found a point prevalence of 0.5% in young women in the age group 15-19, and about half that in women aged 20-24 (Hoek & Hoeken, 2003). The prevalence rates should be compared with the lifetime risk of 1% for schizophrenia.

2.4 AN has the highest mortality rate of any psychiatric disorder (Harris & Barraclough, 1998). The most optimistic findings shows a mortality rate of 5% per decade of follow-up (Sullivan, 1995), the worst suggesting a mortality rate of almost 20% at 20 years (Ratnasurija et al., 1991). That the average age of onset is around 15 years means a significant and unacceptable number of Australians with anorexia nervosa die in their mid-thirties.

2.5 AN has the highest rate of suicide of any mental illness (Harris & Barraclough, 1998). A recent paper examining the prevalence of suicide attempts among sufferers of the different types of eating disorders found that 22.1% (or approximately 1 in 5) of anorexia nervosa patients assessed over the course of the study reported at least one suicide attempt (Franco, Keel, Dorer, Blais, Delinsky, Eddy, Charat, Renn & Herzog, 2004).

2.6 While suffered by both males and females the ratio of female to male in anorexia nervosa is between 10:1 and 20:1 in post-pubertal individuals (American Psychiatric Association, 1994) , however males suffer the condition more commonly while young the female to male ratio for pre-pubertal individuals is closer to 2:1 or 3:1 (Lask & Bryant-Waugh, 1995).

2.7 Anorexia nervosa has what is referred to as a bi-modal distribution of onset; there are two peak ages at which onset of the illness are most likely. They are age 14 and 18 (Halmi et al., 1979), although more generally the years from 12 to 20 are regarded as high risk.

2.8 AN was described long before the current societal pressures for thinness (more than 100 years ago), and AN patients commonly have more fundamental psychiatric problems (Gull, 1874; Lasegue, 1873).

2.9 The average length of illness is 5-7 years; Approximately 20% suffer a chronic course of the illness (Hsu, 1988, 1990; Steinhausen, 2002)

2.10 Persistent psychiatric morbidity is common, especially dysthymia, major depression and obsessive-compulsive disorder (Beumont in Gaskill & Sanders, 2000)

2.11 AN leads to brain atrophy and a disorder of myelination. There is a propensity towards cardiac arrhythmias which are a common cause of sudden death in this illness. Long term physical morbidity is also common and serious. Growth retardation is present in some with an early onset of disease. Anovular infertility is common. Renal and hepatic function are frequently permanently impaired by anorexia nervosa, and a neutrogenic bowel with rectal prolapse is common, sometimes but not invariably associated with laxative abuse. (Beumont in Gaskill & Sanders, 2000).

2.12 One of the most serious medical complications of anorexia nervosa is profound osteopaenia. The presence of osteopaenia, osteoporosis, and their related medical consequences has been well-documented within the eating disorders literature. A considerable portion of the hospitalisation rate of chronic anorexic patients is due to the consequences of osteoporosis and related fractures. More women die as a result of a fractured femur than of breast cancer. (Beumont in Gaskill & Sanders, 2000) High rates of poor bone density have been reported in both anorexia nervosa and EDNOS (Joyce et al, 1990).

3.0 Bulimia nervosa (BN)

3.1 Epidemiological estimates of the prevalence of bulimia nervosa vary from study to study, however most place the lifetime prevalence of the disorder somewhere between 2 and 5% (Ben Tovim et al., 1989; Hoek & Hoeken, 2003).

3.2 An Australian epidemiological study found a point prevalence of 1-2% (Ben-Tovim et al., 1989), although this varied (upward) depending on the diagnostic criteria used. Thirteen (13%) of the sample in this study were found to engage in Bulimic binges (with or without purging).

3.3 Partial-syndrome bulimia nervosa is thought to have prevalence of about 5.4% among young females (Hoek & Hoeken, 2003)

3.4 Bulimia nervosa usually onsets in later adolescence or early adulthood. In the literature the age bracket 17 to 21 is identified as a high risk period, although younger onset cases are being increasingly reported. Pre-pubertal cases have been reported as have first onset cases in women in their sixties, albeit these are thought to be rare. Earlier onset bulimia nervosa (age 15 or below) has been associated with higher self-harm and familial depression (Schmidt, Hodes & Treasure, 1992).

3.5 10.9% of BN sufferers are reported to have made a suicide attempt. (Franco, Keel, Dorer, Blais, Delinsky, Eddy, Charat, Renn & Herzog, 2004).

3.6 Average length of illness is reported to be approximately 9 years; although more than one fifth (23.3%) remain ill after 12 years (Fichter & Quadflieg, 2004).

3.7 BN affects cardiovascular, gastrointestinal, renal, pulmonary, dermatologic and endocrine systems. With electrolyte abnormalities and a tendency to cardiac abnormalities a major cause of morbidity and mortality. Poor bone density is also prevalent in this illness group (Joyce et al., 1990).

3.8 Bulimia nervosa has a crude mortality rate of between 2.2% (Collings & King, 1994) and 2.3%, (Abraham, 1998).

4.0 Eating Disorders Not Otherwise Specified (EDNOS)

4.1 EDNOS is the most common eating disorder diagnosis seen in most outpatient settings both for adolescent and adult populations (Bunnell, Shenker, Nussbaum, Jacobsen & Cooper, 1990; van der Ham, Meulman, van Strien & van Engeland 2004; Martin et al., 2000; Ricca et al., 2001; Turner & Bryant-Waugh, 2004; Fairburn & Bohn, in press) and a number of studies have demonstrated that it is most likely the most common eating disorder in the general population (King, 1989, 1987; Meadows et al., 1986; Walters & Kendler, 1995; Kjelsas et al., 2004).

4.2 A number of studies have now demonstrated that the severity of psychopathology and degree of secondary psychosocial impairment in this group of eating disorders is comparable to that observed in anorexia and bulimia nervosa (Ricca et al, 2001; Turner & Bryant-Waugh, 2004).

4.3 Medical complications in EDNOS including osteoporosis and cardiac arrhythmias have been demonstrated to occur at similar levels observed in anorexia nervosa (Joyce et al., 1990; Birmingham & Beumont, 2004)

4.4 In some studies mortality in EDNOS has been found to be comparable with that of anorexia nervosa (Ben Tovim et al., 2001; Fairburn - personal communication).

5.0 Extreme Dieting & Disordered Eating in the Community

5.1 Dieting (over family history, psychiatric co-morbidity and a myriad of other factors) is the single biggest predictor of the onset of an eating disorder (Patton et al. 1999; Streigal-Moore et al., 1993; Lowe, 1996; Hill, 1996).

5.2 Dieting, like using alcohol, smoking tobacco and using drugs is a 'risk taking behaviour' and needs to be identified in the wider community as such, particularly in the 'at risk' age groups for eating disorders, namely between the ages of 12 and 20 years, and most particularly in the 'at risk' gender i.e. females.

5.3 Current research leaves little doubt that dieting in young people has reached epidemic proportions, especially in young women. Prevalence of weight loss behaviours in Australian studies of women (Crawford & Worsley, 1988; Ben-Tovim, et al., 1989; Wertheim, Mee & Paxton, 1999) 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%.

5.4 In Australian adolescents (Grigg, Bowman & Redman, 1996; Patton et al. 1997; Martin, Wertheim et al., 2000; Wertheim et al., 1993):

- 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%.

5.5 In an Australian community sample (Ben Tovim et al., 1989) binging at clinically significant levels was found in 13%.

5.6 The identification of risk factors and the definition of onset of illness are critical in respect to prevention. There are a few well-documented risk factors that influence the development of an eating disorder: being aged 15 to 25 years old, being female, being an athlete, dancer or a model, and having a personal or family history of psychiatric disorder (Garfinkel & Garner, 1982; Johnson et al., 2004; Ackard et al., 2004; Patton et al., 1999), and Australian data indicates that dieting is the most important predictor of new eating disorders (Patton et al., 1999). Female teenagers who diet at a severe level are 18 times more likely to develop an eating disorder within 6 months than those who do not diet, and moderate dieting has been associated with a 5-fold increased risk of developing an eating disorder. In addition, teenagers with psychiatric morbidity have an almost sevenfold increased risk of developing an eating disorder which is independent of dieting status. High stress reactivity, inability to label emotions and poor interoceptive awareness are also factors that are predictive of eating disorders. Girls who experience 2 developmental changes simultaneously (eg menstruating and dating) in addition to achievement threat (i.e. academic pressure) and slender body ideal are highly likely to display pathological eating behaviours and attitudes. In males eating disorders are more likely to be associated with a high use of exercise.

6.0 Terms of Reference Items B & C

Available Services*: *adequacy of modes of care, coordination and delivery.

6.1 The Royal College of Psychiatrists (2000) Eating Disorder Special Interest Group Report recommend six (6) high level treatment places per million of the population i.e. for NSW (6,680,000 Australian Bureau of Statistics) that would represent approximately 40 treatment places across the State. These recommendations relate only to adult patients and adolescents of 16 years or more. The survey recommends that child psychiatrists estimate the need and provide services for the younger age group; hence the total number if high-level treatment places required across the state is considerably greater.

6.2 In NSW there are a total of **7 adult** and **12 child/adolescent** dedicated eating disorder beds for the State. There are limited specialist outpatient treatment and assessment services across the Area Health Services which differ in their treatment capacity, staffing, referral criteria and available hours. Within the limited specialist services available understaffing is almost universal, with inadequate numbers of trained psychologists, family therapists, social workers, dietitians, nurses and psychiatrists.

6.3 The NSW Centre for Mental Health funds 1 FTE Service Development Officer for the State. This is the only fully-funded eating disorder position in the State of NSW and is provided on a short term grant until February 2006.

6.4 The Eating Disorders Foundation (EDF) is the peak consumer organisation for NSW. It provides a limited resource service, weekday crisis telephone line, public health initiatives (e.g. annual Youth Forum for 2000 students at Town Hall), moderated website chat room & consumer recovery groups/carer support groups. The EDF is a volunteer organisation which receives *no government funding*.

6.5 CAMHSNET (Child and Adolescent Statewide Mental Health Network) aims to ensure optimal inpatient management of children and adolescents with a mental illness (including eating disorders) within their local areas. While they provide no dedicated eating disorder service, inpatient admissions across the state can be supported by CAMHSNET, who provide clinical consultation, teleconferencing and education to regional or rural public inpatient facilities throughout NSW.

6.5 Northern Sydney/Central Coast Area Health Service

- **Prevention**: Nil
- **Early Intervention:** Part-time Early Intervention Service Wyong (Servicing those with AN less than 12 months and those with BN less than 3 years) (3 days/week only)
- **Acute Care:** Nil
- **Community Care:** Nil
- **After hours crisis services:** Nil
- **Respite Care**: Nil

6.6 Sydney South West Area Health Service

- **Prevention:** Nil
- **Early Intervention:** Nil
- **Acute Care:** 4 dedicated adult beds in acute psychiatric unit (‘de facto’ tertiary unit), VMO (director) funded for only 10 hours per week
- **Community Care:**
  - RPAH Eating Disorder Outpatient Assessment Clinic ½ day per week; non-funded; psychiatrist, dietitian, psychologist.
  - GP Shared Care program 1999-2001
- **After hours crisis services:** Nil
- **Respite Care:** Nil

6.7 Sydney West Area Health Service

- **Prevention:** Nil
- **Early Intervention:** Nil
- **Acute Care:**
  - 3 dedicated adult beds in acute psychiatric unit (Westmead Hospital) (SWAHS residents only);
  - 8 adolescent beds in adolescent medical ward (‘de facto’ tertiary unit) (Westmead Hospital);
  - Children’s Hospital Westmead (CHW) 4 child & adolescent beds (tertiary referrals accepted)
- **Community Care:**
  - Nepean Eating Disorder Outpatient Clinic; psychologist, dietitian; no access to inpatient beds.
  - Child & Adolescent Outpatient Clinics at Children’s Hospital Westmead (CHW) & Westmead Hospital Adolescent Unit;
  - Westmead Hospital Adult Outpatient Clinic;
  - Westmead Hospital Adult Day Program (SWAHS residents only)
- **After hours crisis services:** Nil
- **Respite Care:** Nil

6.8 South Eastern Sydney/Illawarra Area Health Service

- **Prevention:** Nil
- **Early Intervention:** Nil
- **Acute Care:** Nil
  (children/adolescents with severe eating disorders are currently accepted for treatment on the medical/mental health unit (tertiary referrals accepted, maximum 4 at any time) Sydney Children’s Hospital (SCH))

- **Community Care:**
    - Illawarra Eating & Behaviour Service;
    - Bulli CHC Eating Disorder Clinic;
    - SCH Randwick Outpatient Clinic;
- **After hours crisis services:** Nil
- **Respite Care:** Nil

6.9 Greater Southern Area Health Service

- Nil Services

6.10 North Coast Area Health Service

- **Prevention:** Nil
- **Early Intervention:** Nil
- **Acute Care:** Nil
- **Community Care:**
    - Lismore Women's Health Service ED Coordinator 3 days per week; assessment and referral clinic only
- **After hours crisis services:** Nil
- **Respite Care:** Nil

6.11 Hunter/New England Area Health Service

- **Prevention:** Nil
- **Early Intervention:** Nil
- **Acute Care:** Nil allocated services
    - NEXUS adolescent mental health unit takes non-specific number of clients with eating disorder (need based admission)
- **Community Care:** Nil
    - Centre for Psychotherapy, James Fletcher Hospital: limited adult outpatient treatment for the spectrum of eating disorders
    - Community Adolescent Team: limited adolescent outpatient treatment for the spectrum of eating disorders
- **After hours crisis services:** Nil
- **Respite Care:** Nil

6.12 Greater Western Area Health Service

- Nil Services

7.0 Terms of Reference Item D

The role of the private and non-government sectors

7.1 In NSW the private sector provides services to clients with eating disorder across the service spectrum – comprehensive outpatient, specialist day patient and inpatient services.

7.2 In NSW the private beds dedicated to eating disorder patients are in excess of 24. In addition, two of the private services offer day programs (10 places) and outpatient programs. Those 34 places are fully subscribed year round with persons with varying stages of illness and recovery from eating disorders and with associated co-morbid conditions, and both services have extensive waiting lists.

7.3 Approximately only one quarter of the population is adequately insured and sufficiently wealthy to access private treatment for eating disorders.

8.0 Terms of Reference Item F

The Special needs of children & adolescents

8.1 Children and adolescents struggling with anorexia nervosa face a number of medical complications that are different from those experienced in adulthood, due to the particular developmental aspects of youth. A better understanding of nuances of the physiological processes involved in linear growth and pubertal development during the adolescent years may alleviate some of the irreversible long-term effects. The effects of malnutrition on the developing body have been well documented, and are clearly associated with the increase in morbidity seen in this patient population.

8.2 Pre-pubertal children and pubertal adolescents are faced with the possibility of stunted growth and delayed pubertal maturation, with the possibility of irreversible and long-term effects on bone accretion, and structural and morphological changes of different organ systems, such as the brain.

8.3 For the younger adolescent, acute medical complications may pose a particular risk, based on lack of adaptation to the major changes associated with abnormal eating behaviours seen in adults.

8.4 Because it usually occurs at the crucial stage of a girl or boy’s physical, psychological and social development, it causes serious impairment of functioning and interferes with quality of life, education, work training, adaptation to peer relationships, sexual relationships and separation from the family of origin (Beumont in Gaskill & Sanders 2000).

8.5 Periods of transition across the services – from child and adolescent to adult – are particularly difficult and care is required to plan the transition appropriately over time. Increased ‘double-up’ resources may be required at this time.

8.6 New research indicates that children and adolescents with eating disorders of mild to moderate severity may be best treated within the family using a Family Therapy Approach (Le Grange et al., 1992; Eisler et al., 1997; 2000; Lock et al., 2001), meaning that they do not need to be removed from the family with its inherent disruptions, there is only one service in NSW which has minimal funding for Family Therapy (2 FT positions) (CHW).

9.0 Terms of Reference Item G

The role and adequacy of training and support for primary carers in treatment, recovery and support of people with eating disorders

9.1 Many generalist and mental health professionals express concern at their lack of knowledge and skills with relation to the management of clients with eating disorders and as a result are unwilling to work with them. Given that eating disorders almost always involves the intervention of a number of health professionals (psychologist, psychiatrist, dietitian, general practitioner and family therapist) this is completely unacceptable.

9.2 Patients suffering from eating disorders have the same rights to treatment as do patients suffering from any other illness: no less and no more. It is completely unjustified to refuse treatment because the illness is perceived as "self-induced". First, this apportionment of blame is only partially true: persons suffering eating disorder patients are caught in a vicious circle of unhealthy behaviours over which they have only partial control. Second, there is an increasing emphasis on the patient's responsibility in many other areas of medicine: the effect of unhealthy lifestyles on cardiovascular disease and diabetes; irresponsible sexual behaviour and the use of illicit drugs in the HIV-AIDS complex; excessive exposure to the sun in melanoma; cigarette smoking in emphysema and several forms of neoplasia, especially lung carcinoma. The recognition of these relationships should not be used to excuse the denial of treatment, although they must be carefully considered in acquiring the patients' families' and the community's optimal co-operation in treatment.

9.3 Most community mental health services do not employ dietitians.

9.4 All specialist services for eating disorders in NSW report a lack of adequately trained and educated staff across the allied health spectrum.

9.5 Funding for child & adolescent psychiatry fellowships in Eating Disorders and dedicated Adult Psychiatry Advanced trainees in eating disorders are sorely lacking.

9.6 From 1999-2001 a successful Eating Disorder Shared Care Project was piloted in NSW. This was a 12 month program that included clinical support and supervision, a weekend workshop, follow-up education sessions and formal evaluation of clinical skills, knowledge and attitude.

9.7 From 2005 GPs will have access to the NSW Institute of Psychiatry’s Graduate Diploma in Mental Health. An eating disorders elective subject will be offered from July 2005.

10.0 Terms of Reference Item H

The role of Primary health care in promotion, prevention, early detection and chronic care management

10.1 Up to 5% of women presenting to (or registered with) a general practitioner has an eating disorder (Hay, 1999). And patients with eating disorders are known to attend general practitioners significantly more frequently, in the five years prior to diagnosis, than controls (Ogg et al, 1997).

10.2 Because eating disorders are frequently concealed or denied, up to 50% of cases go unrecognised in a clinical setting (Becker et al 1999). However, ultimately 90% of eating disorder patients present to their general practitioner with associated complaints, frequently hoping that the doctor will pick up on a small hint and probe further about dieting behaviour (Noordenbos, 1998).

10.3 An essential component of every general practitioner’s role is the identification of the disorder as it presents in various developmental or formative stages.

10.4 On a practical level, secondary prevention has been associated with improved outcome and reduced chronicity (as a result of reduction in social handicap and fewer deaths) (Touyz, Russell & Beumont 1993 p116).

10.5 For patients with partial- and full-syndrome disorders, the most effective role that a general practitioner can be the role of care coordinator or case manager, ensuring that the individual has access to the multi-disciplinary team required for successful treatment. Although it is acknowledged that GP's, especially in rural areas in NSW, often have such high case loads that they are able to do little more than monitor medical parameters.

10.6 Recovery from an eating disorder requires intervention from multiple disciplines, including at minimum dietetics, psychology and psychiatry and often social work, nursing and family therapy. Due to the denial present in these illnesses, the lack of motivation often present (Vitousek, 1998) and the significant physical risks the disorders poses to the individual, clinicians treating the eating disorders have to be highly trained and educated.

10.7 Due to the increased prevalence of this group of disorders in the young, youth workers, community mental health workers, school counsellors and other generic health workers within the community are often the first point of contact for persons with eating disorders. Education enabling accurate identification and appropriate referral is lacking.

11.0 Terms of Reference Item N

Research into the Eating Disorders

11.1 Early epidemiological studies in Australia attempted a broad approach by examining the prevalence of component behaviours of disordered eating among girls and women in Sydney, Adelaide and Melbourne (Abraham et al., 1983; Crawford & Worsely, 1988; Hay, 1998; Maude et al., 1993). They are studies of disordered eating rather than attempts to estimate the prevalence of clinical or sub-clinical eating disorders, i.e. of behaviour, rather than illness. They are useful in that they give an impression of the magnitude of the problem, and consequently of its mental health implications, but unfortunately they are too varied in their approaches to allow firm conclusions to be drawn.

11.2 Seven Australian studies were identified that have attempted to examine the prevalence of eating disorders *per se*, and/or its association with dieting and extreme dieting (Paxton et al., 1991; Ben Tovim, 1988; Ben Tovim & Moprton, 1990; Patton et al., 1999; Wade et al., 1996; Clayer et al., 1998, 1995). Their findings are generally similar to overseas studies, but they are all subject to stringent criticism of methodology, including unrepresentative samples, low response rates and poor definition of "caseness".

11.3 These limitations are not confined to research conducted in Australia. Very few methodologically sound studies of the epidemiology of eating-disordered behaviour have been conducted overseas either, and it cannot be assumed that prevalence rates and risk factors are the same across geographical boundaries.

11.4 Lack of research into effective treatments for the eating disorders in both child/adolescent and adult groups, in particular anorexia nervosa and EDNOS, is a national and international problem which has been well identified and documented in the literature (Hay et al., 2003; Ben Tovim et al., 1999; Wilson et al., 2000; Vitiello & Lederhendle, 2000; McIntosh et al., 2005; Gowers & Bryant-Waugh, 2004). There is a reasonably good evidence base in the literature for treatment of Bulimia Nervosa (Fairburn et al., 1991; Fairburn et al., 1993: Hay et al., 2004) with cognitive-behavioural therapy, although more controlled trials are needed, especially for the binge eating disorder diagnosis. There have been few randomised control trials of interventions for the anorexia nervosa and even fewer conducted in Australia (Hay et al., 2003). Research and development for effective treatments for anorexia nervosa, and the EDNOS variants, is identified as an urgent research priority for both Australia and the rest of the international community, particularly given the high morbidity and mortality in this illness group (Hay et al., 2003).

11.5 Existing treatment services within the NSW public system for eating disorders do not routinely collect data to monitor their outcomes. This is a direct result of lack of research funding within the budgets.

11.6 Lack of research into epidemiology, treatment and outcome directly reflects the lack of funding in this area both at a government level and through the National research funding bodies.

B. RECOMMENDATIONS - What is needed?

1.0 Recommendations: Terms of Reference Item B

1.1 The adequacy of various modes of care

- The current modes of care are inadequate for meeting the needs of this significant mental health issue and the development of future services requires a coordinated approach.
- The eating disorder patient has the same right to treatment as do patients with any other illness.
- Eating disorders must be considered core business for National Mental Health Services.
- High level treatment places in NSW, servicing children, adolescents and adults, should be provided and funded in accordance with the Royal College of Psychiatrist (2000) recommendations.
- Service Models for rural areas need to be considered.

1.2 Prevention

- Given the epidemic proportions of extreme dieting & disordered eating in the wider community and the link between these behaviours and the onset of serious eating disorders, it is essential that prevention & early intervention form an important component of any strategy aimed at addressing eating disorders.

- A comprehensive funding submission entitled ‘Establishing A National Strategy for the Prevention of Eating Disorders: A Staged Project Proposal’ was submitted to the Federal Minister for Health December 2004 (See Appendix 3) by the Centre for Eating & Dieting Disorders on behalf of a consortium of eating disorder organisations around Australia. This document should be endorsed and funded as a matter of urgency.

1.3 Early Intervention

- Funded research into effective targeted early interventions for at risk populations is required.

- The subsequent development and implementation of evidence based interventions for those at risk populations is essential.

- The Central Coast Health Eating Disorders Early Intervention and Outpatient Service offers the only model for targeted early intervention in the early stages of eating disorders, and should be considered for funding and development by other area health services.

1.4 Acute Care and Community Care

- People with eating disorders in NSW need access to treatment regardless of their socio-economic status or place of residence.

- Given the high morbidity and mortality rates in this illness group the funding of services offering high level care are mandatory.

- Specialist services offering high level care (inpatient, partial hospitalisation and comprehensive outpatient) for both adult and child and adolescent persons should be available in each of the four Metropolitan Area Health Services in NSW (by both funding and development where they do not exist and through expansion of services where they do exist) and access pathways to specialist services must be identified in the Service Plans of each of the four Rural Area Health Services.

- The expansion of existing specialist services to provide for the spectrum of illness i.e. both inpatient, partial hospitalisation and comprehensive outpatient facilities are required. Existing specialist services also have a role in providing tertiary services, clinical support, supervision and education to non-specialist providers and this should be addressed appropriately with regard to funding so that specialist services can develop these services.

- Each of the very few existing specialist services lacks adequate staffing: adequately trained psychologist, psychiatrists, dietitians, family therapists social workers and nurses are lacking and additional positions need to be funded.

1.5Crisis Services

- A National Eating Disorder Support line, staffed by people with expertise in eating disorders, such as that which exists (albeit in a voluntary and necessarily time limited capacity) at the Eating Disorders Foundation, must be funded.

- Support services, including recovery groups, family and friends support groups and resource & information services should be established for families in each Area Health Service.

1.6 Continuing/Respite Care

- Eating disorders, like several other severe psychiatric illnesses, are seldom simply ‘cured’. Relapses and need for further treatment is common (Beumont et al., 2004). Continued care and ongoing treatments that are lengthy and expensive are usually necessary for those with more chronic illness. Such services should be made available to those who require them.

- Support services should be established for families and carers of people with eating disorders. Particular attention should be given to families burdened by chronic illness.

2.0 Recommendations: Terms of Reference Item C

Coordination, Delivery and Funding of Services

- Given the severity of psychiatric and medical complications, the significant mortality rates associated with eating disorders and the varying levels of illness severity, illness duration and chronicity, the eating disorders require multiple modes of treatment and coordination of these services.

- The NSW Health Department must approve the Draft Service Plan for Eating Disorders in NSW (Appendix 2) and discrete funding must be directed towards development of appropriate services as outlined in that document.

- Coordination of service development should be provided at a State-wide level.

- It is essential a coordinator be appointed in each Area Health Service in NSW.

- For the reasons stated in bullet point 1 of this section, Centres for Excellence in NSW are mandatory in the field of eating disorders so that experts may liase with service providers within the various Area Health Services, particularly in rural areas, to provide case management, benchmarking, supervision and consultation to less experienced workers dealing with this potentially deadly group of illnesses. Two centres within NSW have the capacity to develop such a service – RPA and Westmead. Appropriate funding to develop the services associated with a Centre of Excellence needs to be administered.

3.0 Recommendations: Terms of Reference Item D

The appropriate role of the private and non-government sectors

- Well resourced specialist outpatient, inpatient and partial hospitalisation exist in NSW. The opportunity exists for collaboration across public, private and non-government organisations. Private service providers have expressed interest in collaborating with public health services to provide treatment.

- The appropriateness and feasibility of such an arrangement should be investigated as a matter of priority.

4.0 Recommendations: Terms of Reference Item F

The special needs of children and adolescents, the socially and geographically isolated and people with complex and co-morbid conditions and drug and alcohol dependence;

- Establishing and funding prevention and early intervention programs that work are a priority. These should be delivered to children, adolescents and parents.
- Care pathways from rural and remote areas, to specialist eating disorder services should be established.
- To this end every Area Health Service must comprehensively address the issue of eating disorders in their Service Plans.
- Prompt funding if the Draft Service Plan for Eating Disorders in NSW (currently with the NSW Centre for Mental Health; NSW Department of Health) would go some way to addressing the above issues.
- Funding for out-patient Family Therapy programs throughout the state needs to be considered.
- Co-morbidity in this population group is high & frequently crosses medical, psychiatric and drug & alcohol conditions. Research into the specific needs of clients with co-morbid diagnoses requires urgent attention.

5.0 Recommendations: Terms of Reference Item G

Education, Training and Support for Primary Carers/Health Professionals

- Funding should be provided for GPs to access the elective eating disorder component of the NSW Institute of Psychiatry’s Graduate Diploma in Mental Health.
- Funding should also be provided to develop brief ‘Better Outcomes’ training modules for GPs and other health professionals.
- Funding should be provided for specialist practitioners to provide clinical support to novice practitioners – i.e. Through case conferencing, clinical supervision and care planning; via telephone and telepsychiatry.
- Education programs that address issues of stigma, stereotype and attitude (as well as the physical and mental health issues) should be included in under-graduate health professional programs.
- Education programs for allied health professionals need to be developed addressing the needs of, at minimum, psychologists, dietitians, psychiatrists, youth workers and school counsellors.
- The general public and the professions need to be educated about how common and serious these illnesses are. Their importance should not be underestimated, nor should it be exaggerated. Extreme weight-losing activities should be acknowledged as dangerous risk-taking behaviours, similar to the abuse of narcotic drugs, unprotected sex, and drink-driving.

- Funding of the Draft Service Plan for Eating Disorders in NSW would go someway to addressing all of the above educational needs.

6.0 Recommendations: Terms of Reference Item H

The Role of Primary Health Care in promotion, prevention, early detection and chronic care management.

- All doctors (GPs, psychiatrists, psychiatric registrars) and mental health professionals should know how to recognize and take appropriate action with patients presenting with diagnosable eating disorders. They should also be alert to the risk factors associated with their development as well as the early signs and symptoms.
- Funding should be provided for the expansion of the successful GP Shared Care program piloted from 1999-2001 by the Centre for Eating & Dieting Disorders. The program should be broadened to include community mental health workers and generalist community health workers (including dietitians).
- More dietitians/nutritionists should be employed in Mental Health services. Not only for treatment of people with eating disorders but to provide dietary advice for people with a mental illness whose medication has specific drug/nutrient interactions or whose illness affects their nutritional status and health by affecting their ability to shop for, store and cook healthy meals. This can also affect the nutritional and health status of families and children's learning of these same life skills.

7.0 Recommendations: Terms of Reference Item I

Opportunities for reducing the effects of iatrogenesis and promoting recovery-focused care through consumer involvement, peer support and education of the mental health workforce, and for services to be consumer-operated.

- Consumer organisations/representatives must be involved in service development, planning, delivery and evaluation.
- In NSW, the EDF is actively involved in government working parties and all of the educational programs delivered by the Centre for Eating & Dieting Disorders. This process should be formalised and funding provided for (usually) volunteer participants to attend meetings and workshops.
- Consumer support groups should be included as part of service planning.
- Providing appropriate funding training for group leaders and telephone counsellors is required.

8.0 Recommendations: Terms of Reference L

De-stigmatising eating disorders and providing support service information to people affected by eating disorders, their families and carers.

- The Eating Disorders Foundation in NSW, and other consumer organisations like it around Australia, must be provided with supportive funding, in order that they can provide support services to the community at the grass roots level.

  - Because eating disorder sufferers have a right to treatment, they should receive the same sympathy and courtesy as other patients. A health professional has no more right to decline involvement with this illness than with any other. If the professional feels incompetent in treating eating disorder patients, he or she should seek out ways to gain that competence. Medical educationalists need to teach students about eating disorders in the same way as they teach about other illnesses. The patient and her carers have a right to expect both empathy and skill from their medical advisers and other health professionals in dealing with this illness.

9.0 Recommendations: Terms of Reference H

Research

- Resources should be devoted to eating disorder treatment and research in direct proportion to its importance as a health problem. Unfortunately, this is not done, perhaps because eating disorders have not received strong advocacy from health professionals or in the community. The reasons for this, and ways to overcome the problem, need to be addressed.

- For unknown reasons funding for research into eating disorders is not a priority for the National research funding bodies, and it is the regular experience of researchers working in the field that the are unable to gain funding for research through these well-established routes. The reasons for this need to be examined and rectified.

- National research funding bodies and governments need to identify research into effective treatments for eating disorders, in particular anorexia nervosa, as a research priority.

- The development of effective preventative interventions for eating disorders will depend on distinguishing unambiguous risk and protective factors. An important guideline for researchers to consider is that prevention programs need to be tailored to the risk status of the group selected for intervention. An intervention developed for those individuals who are at risk because of personality or developmental variables will be quite different from an intervention designed for individuals who are entangled in disordered eating attitudes and practices.

- Funding must be dedicated towards research into the epidemiology, prevention, early intervention and treatment outcome across the illness and age spectrums.

10.0 Recommendations: Terms of Reference O & P

Data collection, outcome measures and quality control for monitoring and evaluating eating disorder services and opportunities to link funding with compliance with national standards. The potential for new modes of delivery including e-technology.

- The RANZCP has published Clinical Practice Guidelines for Anorexia Nervosa (Beumont et al., 2004) as has the National Institute for Clinical Excellence (NICE)

(Wilson & Shafran, 2005) in the U.K. These should be adapted to provide a set of minimum standards for practice and distributed Nationally.

- The Minimum Data Set identified as mandatory for collection by all treatment services for eating disorders in the Clinical Practise Guidelines for Anorexia Nervosa (RANZCP) needs to be implemented at all treatment services in NSW; appropriate funding must be directed to existing services to systematically document their treatment outcomes as a matter of urgent priority.
- Eating disorders form a relatively discrete population. Therefore the opportunity to capture service utilisation and outcome data, as services are developed, is unique.
- Telepsychiatry was used extremely successfully during the NSW GP Shared Care Project for clinical supervision and training, and with funding could be expanded to include other health and mental health practitioners throughout the state of NSW.
- The Kids Help Line reports that eating disorders and body image issues are one of the primary reasons for accessing their email-based counselling service. This should be considered, particularly with regard to establishing and funding consumer support and crisis services.

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