

# Brief 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

### BRIEF VERSION (please refer to Appendix 1 – THE FULL SUBMISSION for details)

#### A: THE CURRENT SITUATION

#### **Eating Disorders are not Rare Illnesses**

- Eating disorders (ED's) are common psychiatric disorders with significant medical complications, morbidity and mortality. They exist on a spectrum of severity and include anorexia nervosa, bulimia nervosa, eating disorders not otherwise specified.
- The combined **lifetime prevalence** within the community for all of the eating disorders is at least 5% of the population.

#### Anorexia nervosa (AN)

- AN is the most common chronic disease in adolescents and young women.
- In NSW approximately 560 new cases are diagnosed each year, and about 4200 patients are affected by anorexia nervosa at any one time
- For AN there is a point prevalence of 0.5% in young women in the age group 15-19, and about half that in women aged 20-24. Prevalence rates should be compared with the lifetime risk of 1% of schizophrenia.
- AN has the highest mortality rate of any psychiatric disorder.
- AN has the highest rate of suicide of any mental illness

#### Bulimia nervosa (BN)

- The prevalence of bulimia nervosa is higher than for AN at between 2-5% for the general population
- Partial-syndrome bulimia nervosa is thought to have prevalence of about 5.4%
- Bulimia nervosa usually onsets in later adolescence or early adulthood
- 10.9% of BN sufferers are reported to have made a suicide attempt.
- Bulimia nervosa has a crude mortality rate of between 2.2% and 2.3%

#### **Eating Disorders Not Otherwise Specified (EDNOS)**

- EDNOS is the most common eating disorder diagnosis and the most common ED diagnosis seen in most outpatient settings both for adolescent and adult populations
- The severity of psychopathology and degree of secondary psychosocial impairment is comparable to that observed in anorexia and bulimia nervosa.
- Mortality in EDNOS is comparable with that of anorexia nervosa.

#### **Extreme Dieting & Disordered Eating in the Community**

- Dieting is the single biggest predictor of the onset of an eating disorder
- Dieting is a 'risk taking behaviour' and needs to be identified as such, particularly in the 'at risk' age groups for eating disorders and most particularly in the 'at risk' gender i.e. females.
- Dieting in young people has reached epidemic proportions, especially in young women.
- The identification of risk factors and the definition of onset of illness are critical in respect to prevention.

#### Item B & C

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

- The Royal College of Psychiatrists recommend six (6) high level treatment places per million of the population i.e. for NSW (6,680,000 AusBureauStatistics) representing approximately 40 treatment places across the state.
- 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. Most area health services in NSW have none.
- 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.
- The Eating Disorders Foundation (EDF) is the peak consumer organisation for NSW, offering a crisis-line, support groups and referral centre. It is a volunteer organisation which receives *no government funding*.

#### Item F

#### The Special needs of children & adolescents

- ED's usually onset in childhood and adolescence, and have their highest rates in this age group.
- ED's cause serious impairment of functioning, psychological and physiological development, and interfere with quality of life, education, work training, adaptation to peer relationships, sexual relationships and separation from the family of origin
- Transition across the services from child and adolescent to adult is a particularly difficult time of transition and requires appropriate planning and resourcing.
- Recent research suggests outpatient Family Therapy can be effective in mild-moderate cases in this age group but is yet to be implemented in NSW due to a lack of funding.

#### Item G

#### Training and support for primary carers

 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.

- From 1999-2001 a successful Eating Disorder Shared Care Project was piloted in NSW.
- 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.

#### Item H

#### The role of primary health care

- Up to 5% of women presenting to GPs have an eating disorder.
- Patients with eating disorders attend GPs significantly more frequently.
- Recovery form an ED involves multi-disciplinary intervention: adequate education & training programs for all allied health professionals, especially dietitians, psychologists and community/youth workers are lacking.
- Up to 50% of cases go unrecognised in a clinical setting.
- An essential component of every general practitioner's role is the identification of the disorder as it presents in various developmental or formative stages.
- GPs offer affordable access to comprehensive care and are well placed to provide continuing care.

#### Item N

#### Research

- Research limitations are not confined to research conducted in Australia. Very few methodologically sound studies of the epidemiology of eating disorders and effective treatments for them have been conducted worldwide.
- Lack of research into epidemiology, treatment and outcome directly reflects the lack of funding in this area.
- Australian researchers in a Cochrane Database Review have identified research into effective treatments for ED's, particularly AN, as an urgent National research priority.

#### **B. RECOMMENDATIONS - What is needed?**

#### Item B: The adequacy of various modes of care

- The current modes of care are inadequate
- 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.
- People with eating disorders in NSW need access to treatment regardless of their socio-economic status or place of residence.
- High level treatment places in both the inpatient and partial-hospitalisation setting, servicing children, adolescents and adults, should be provided / funded in accordance with the Royal College of Psychiatrist (2000) recommendations.
- Specialist services should be developed in each of the four Metropolitan Area Health Services in NSW and, at minimum, 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 is required. Increased staffing at all existing specialist services is needed.

- 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.
- A National Eating Disorder Support line, staffed by people with expertise in eating disorders, must be funded.
- Support services should be established for families in each Area Health Service.
- Relapses and need for further treatment is common. Continued care and ongoing should be made available to those who require them.

#### Item C: Coordination, Delivery and Funding of Services

- The NSW Health Department must approve as a matter of urgency 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. This measure alone would go some way to addressing some of the recommendations for items B, G, H and I.
- Coordination of service development should be provided at a State-wide level; ongoing funding for the Service Development Officer for NSW needs to be established immediately.
- It is essential a coordinator be appointed in each Area Health Service in NSW.

#### Item D: The appropriate role of the private and non-government sectors

- The appropriateness and feasibility of purchasing services from the private sector should be investigated as a matter of priority.
- The private sector cannot bear the main responsibility for treating this illness group; all Australian's with ED's need equal access to care.

# 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;

- More high level treatment places for this age group across the state are essential.
- Establishing and funding prevention and early intervention programs that work are a priority.
- Care pathways from rural and remote areas, to specialist eating disorder services should be established.
- Every Area Health Service must comprehensively address the issue of eating disorders in their Service Plans.
- The funding of the submission 'Establishing a National Strategy for the Prevention of Eating Disorders: A Staged Project Proposal' (recommended in item B) (Appendix 3) would go some way to addressing all of the above and is a logical first step.
- 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.

#### 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 NSWIOP Graduate Diploma in Mental Health.
- Funding should be provided to develop brief 'Better Outcomes' training for GPs and other allied and general 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 should be included in under-graduate courses.
- The general public and the professions need to be educated about how common and serious these illnesses are.

#### Item H: The Role of Primary Health Care

- All doctors should know how to recognize and take appropriate action with patients presenting with 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. It 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.

# Item 1: 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.
- Consumer support groups should be included as part of service planning.
- Providing appropriate funding training for group leaders and telephone counsellors is required.
- Funding for a Resource Centre to be run by consumer's forms part of the Draft Service Plan for NSW (Appendix 2), to be funded as a matter of urgency.

### Item 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. 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.

#### Item N: Research

- Resources should be devoted to eating disorder treatment and research in direct proportion to its importance as a health problem.
- The development of effective preventive interventions for eating disorders will depend on distinguishing unambiguous risk and protective factors.

• Funding must be dedicated towards research into the epidemiology, prevention, early intervention and treatment outcome across the illness and age spectrums at both a governmental and National research funding body level.

Items 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. These should be operationalised into a set of minimum standards for practice and distributed nationally.
- In particular the
- 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 could be expanded to include other health and mental health practitioners.
- 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.

#### **Summary of Recommendations**

- The Draft Service Plan for Eating Disorders for NSW (Appendix 2) must be funded as a matter of urgency.
- The submission 'Establishing a National Strategy for the Prevention of Eating Disorders: A Staged Project Proposal' (Appendix 3) must be funded as a matter of urgency.
- High level treatment places (inpatient and partial-hospitalisation) need to be available in all four Metropolitan Area Health Services in NSW this will require funding for expansion of existing services and new services.
- All four Rural Area Health Services in NSW need to consider service models and at minimum develop access pathways to specialist services.
- More dietitians/nutritionists should be employed in mental health services.
- The Eating Disorder Foundation (EDF) consumer organisation requires urgent funding from the government.
- Part of any funding package to services for eating disorders must comprise a budget element dedicated to data collection for monitoring outcomes & research

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