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Submission to the Senate Community Affairs Committee - Inquiry into Mental Health Services in Australia 2007

Overview – Eating Disorders

Eating disorders need to be recognised as an urgent and critical issue impacting on the mental health of over **600,000** Australians by the Federal Government.

The peculiarities of symptoms of eating disorders require discrete services that address issues of shame, isolation, stigmatisation and accessibility, specifically the lack of discrete public health services for adult patients.

Funding is required for both community based and tertiary services including a dedicated adult inpatient facility in Western Australia. The Federal Government has a responsibility to advocate for discrete services for eating disorders with the State Governments.

Recognition by the Federal Government of this area of mental health as a priority would be demonstrated with the availability of funding to support the evidence based preventative approaches which have been developed to respond to the increasing prevalence of risk factors that often preface an eating disorder. These preventative approaches need to be adequately resourced and prioritised in a national response to the increasing numbers of people affected by these disorders and a recognition by the Federal Government of this issue as an urgent and critical concern for many Australians.

Gaps/Short Falls in the Western Australian Mental Health Sector – Eating Disorders

- **15.5% of Western Australians will have an eating disorder during their lifetime – that is, 92,400 people. Of these, 7% will have a current eating disorder – that is, 6,468.**
- Approximately 1 in 100 adolescent girls develop Anorexia Nervosa.
- Anorexia Nervosa is the third most common chronic illness for adolescent girls in Australia (after obesity and asthma).
- The incidence of Bulimia Nervosa in the Australian population is 5 in 100 but the true incidence of bulimia is estimated to be as high as 1 in 5 in the student population.
- Using the available statistics, it can be estimated that over 500,000 women in Australia are affected by eating disorders

These alarming statistics point to an urgent challenge to the health sector in WA and do not account for those people affected by eating disorders such as binge eating or the clinical classification of 'eating disorders not otherwise specified (EDNOS)'.

The chronicity of symptoms and ingrained behaviours of people presenting with eating disorders to the Centre for Clinical Interventions, the specialized adult therapeutic service in WA indicates the urgency and severity of this insidious disorder for people in this State.

Further to this, body image, a key risk factor for eating disorders, is a significant concern for close to 30% of young Australians according to the 2006 National Survey of Young Australians compiled by Mission Australia. This is consistent for both males and females and is particularly important for those aged 11 to 19 years and for Indigenous young people. Research shows that 75% of people diagnosed with anorexia are under the age of 16 years and bulimia most commonly manifests in young people aged from 16 – 24 years.

Currently in WA, a person suffering from an eating disorder has very little choice unless they have expensive private health cover. If they become very ill and are under the age of 16 years, they will be able to access the services of Princess Margaret Hospital, however if they are an adult, there are no specific inpatient specialist services. If they can wait, they may be able to access some clinical intervention. If they have the esteem and confidence, they may find supportive friends to help them through their recovery journey. If they have the resources and support, they might find other treatment options around Australia, but how will they afford to travel to them? This has been the reality for many families from Western Australia. Recovery from an eating disorder generally involves a journey of two to five years. How will they provide for themselves during this time?

The Eating Disorders Sector in WA

WOMEN'S Healthworks (WHW) has established a reputation as the leading community based organisation offering assistance for women suffering from an eating disorder in Western Australia. The organisation has developed The Body Esteem Program that offers self help groups for women suffering from anorexia nervosa-type and bulimia nervosa-type eating disorders. WHW has led the collaboration between service providers and interested stakeholders of the small eating disorders sector in Western Australia to pursue a joined up approach to prevention, early intervention and treatment for people in WA. WHW continues to advocate for public funding for eating disorders and a community wide recognition of eating disorders as an urgent and critical issue for the young women of Western Australia.

The eating disorders sector in WA is very small. There are 5 main organisations, including WHW across the private and public health systems that provide support or services to people suffering from eating disorders.

WOMEN'S Healthworks is a community based women's health centre who developed the Body Esteem Program, offering self help groups for women over the age of 18 years with anorexia – type and bulimia-type eating disorders. This program closed in August 2007 due to lack of funding. Negotiations for future funding with the WA Health Department are continuing.

Princess Margaret Hospital (PMH) is the only specialised inpatient service for adolescents and also offers some limited outpatient services to adolescents who have previously been admitted to PMH before the age of 16 years.

The Centre for Clinical Interventions (CCI) offers clinical outpatient intervention for adults and can cater for adolescents of 16 and 17 years. The waiting list for this public service can be as long as 12 months and does not address the need for a service to provide on-going clinical and complementary care across the journey of recovery from the disorder that can last as long as 2 to 5 years.

Hollywood Clinic is the main private provider of specialised inpatient care for those affected by eating disorders. This service can cost as much as \$4000 per week with an average admission of approximately 3 weeks with the high likelihood of multiple admissions across the recovery journey. This is prohibitive for those without private health insurance.

Bridges Association was launched at the Eating Disorders conference held in Perth on 4 and 5 September 2006. The committee consists of professionals and people affected by eating disorders including family members. The committee positions are voluntary.

Western Australia – A Unique Collaborative Model in the Eating Disorders Sector

WHW strives to provide a community based service delivery model that complements the services of Princess Margaret Hospital for Children, the Centre for Clinical Intervention and other existing private services thereby establishing WA as the leader in the fight against eating disorders.

In establishing the pilot of the Body Esteem Program, WHW collaborated with the existing public health services in the eating disorders sector. This included Joondalup Community Mental Health, and Princess Margaret Hospital for Children and the Centre for Clinical Interventions. Consumers, both parents and sufferers have also been instrumental in developing this program. WHW is a key stakeholder in both the Bridges Association Management Committee and the Bridges Association Reference Group – the body that incorporates service providers of the sector.

WHW considers working collaboratively and developing partnerships as an important mechanism for building and sustaining capacity in the delivery of services. WHW's commitment to this method of practice has been evidenced by the organisation's ongoing collaborative activities to strengthen the Bridges Association as the peak body for eating disorders in Western Australia. WHW has driven the sector wide approach to strengthening this peak organisation by providing staff time and expertise to facilitate the formal processes associated with inviting the organisations of the sector to collaborate. This has included hosting sector wide forums and providing project management consultation and expertise to the Bridges Association. This approach has ensured that all members of the eating disorders sector are supportive of the community based approach of WHW.

WHW is aware of the many organisations in other states that are offering a diverse range of services for those affected by an eating disorder. This organisation strives to maintain communication with these organisations, including the Butterfly Foundation in Victoria, with the view to build a national coalition of service providers which could further strengthen the community's support for this important issue. Additional to this, we would expect that with a strong national voice we will be able to garner both private and public support at both the state and national levels.

Co-morbid Mental Health Conditions of People with Eating Disorders

Further insight to the challenges those affected by eating disorders face can be seen when considering the co-morbid conditions often present for individuals affected by an eating disorder. Not only are they struggling on a daily basis with the obsessive thoughts around food and weight, they also struggle with the difficulties of restriction or bingeing and purging, use of appetite suppressants and/or laxatives and excessive exercise. Other health issues reported at assessment by participants for the Body Esteem Program self help groups included;

- 70% reported depression
- 60% using medication (all mood related drugs)
- 40% reported physical complaints all related to weight, eating and exercise
- 90% reported other concerns such as sleep disturbance and anxiety/feeling down
- 20% reported excessive alcohol intake
- 10% drug use
- 30% self harm
- 40% identified other problems such as bowel problems, harming ideation, anxiety and panic around work .

It is the position of WOMEN'S Healthworks and the Body Esteem Program that the challenges associated with eating disorders need to be publicly acknowledged as a priority area of concern within the provision of mental health services for Western Australia. This acknowledgement will model the individual processes required for positive change and recovery by directly addressing the restraints experienced by individuals that form barriers to recovery. These include social isolation, shame, low self esteem and a reluctance to ask for help due to feelings of low self worth.

WOMEN'S Healthworks advocates an holistic approach to effectively support the recovery process for both the individuals, families and service providers involved with tertiary intervention. Funding to ensure the continuation of the proven Body Esteem self help group model and parent education and support group interventions will reduce the impact, severity and trauma of eating disorders for individuals and their families and carers. Mentoring programs would increase the resilience and capacity of carers to support the recovery journey. School based prevention will increase awareness and understanding of known risk factors related to eating disorders to reduce the prevalence of these risk factors in the school communities targeted.

It is acknowledged by service providers in this sector that there are unique challenges both professionally and personally when working with these target groups. This necessitates high level professional infrastructure, consultation, supervision and support for service providers to ensure their own resilience and professional capacity. It is the position of WOMEN'S Healthworks that funding must reflect these best practice principles and adequately provide for this service infrastructure to ensure the sustainability and efficacy of support and services provided.

History demonstrates that there have been numerous self-help and support groups established by sufferers over the years in Western Australia. These include BANG-Bulimia and Anorexia Nervosa Group, Bulimic Group – Body Bliss for Bulimics, Parents & Partner's Group for help with Anorexia & Bulimia, Eating Disorder Support Group, SEAL, and Eat to Live. Discussion with sufferers and ex sufferers indicates that the lack of support and infrastructure is a common reason for the lack of sustainability of these voluntary organisations.

As a direct result of this under-resourcing, in August 2003 after seven years of operation, the Eating Disorders Association WA - a voluntary agency - discontinued its services due

to individual "burnout". EDAWA, like many other groups that have been established by sufferers in their attempt to support one another, was not sustainable as more demands for support services was not matched by funding opportunities or professional support and infrastructure.

For the community sector to respond to the needs of these individuals and families, professionals must be employed to supervise, train and support any voluntary commitment to the work being undertaken.

Supervision and peer reviews have been paramount to supporting facilitators delivering the Self help groups.

The National Action Plan presents a unique opportunity to support people to manage their mental illness and make best use of services that will work for them, their families and carers in a more integrated way.

People with eating disorders often feel intense shame and guilt. Research highlights that sufferers live in denial and may hide their disorder at great cost to their health and emotional wellbeing for many years.

The impact on families is considerable.

The Mental health Plan aims to improve mental health and facilitate recovery from illness through a greater focus on promotion, prevention and early intervention with improved access to mental health services. It is critical that we work together to ensure that investment is coordinated, efficient and effective.

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