LAQON 1323

Government of Western Australia
Department of Health

Youth Eating Disorders

Inpatient Service

A Staged Approach to Developing an Integrated Service

Delivering a Healthy WA

Contents

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1.0 Executive Summary

This project aims to develop a specialist youth inpatient service for patients with eating disorders in the age range of 16-25 in line with 'A Better Deal for Youth Mental Health: Prevention Meets Recovery' (WA Health Department, 2011) **Recommendation 19;**

"Develop a specific inpatient unit for treatment of severe Eating Disorders for 16-25 year olds due to the highly specialised medical and psychological treatments required."

At the request of the Chief Executive of the Child and Adolescent Health Service and the Executive Director of the Sir Charles Gairdner Group, North Metropolitan Area Health Service, this document outlines a staged approach to an inpatient eating disorders service for youth.

This request is timely given the current National and State strategic interest in youth mental health and the relocation of PMH to the New Children's Hospital at the QE II site.

Patients with eating disorders are an extremely high risk group

- Eating disorders have the highest mortality rate of any mental illness. In Western Australia since 2006, approximately 28 individuals who have been treated for eating disorders have died, some without having any access to life saving medical inpatient treatment.
- Anorexia Nervosa and Bulimia Nervosa fall within the top 10 contributors to burden of disease in Australia between the ages of 16-24.
- Eating disorders are the 12th leading cause of hospitalisation within Australia and the cost of each admission is second only to the cost of cardiac bypass surgery in the private hospital sector.

Youth with eating disorders

- Approximately 55% of individuals treated for eating disorders in WA public hospitals are aged 16-25. The majority of these patients are currently treated in Adult Mental Health Units. These services are ill-equipped to persevere with treatment resistant eating disorders and their medical complications.
- The window of opportunity for a successful outcome of treatment of an individual with an eating disorder begins to fade after 3-4 years (NEDC 2010), making it very important to invest in effective services for the years following the onset of the disorder – i.e. adolescence and youth.
- Australian and international best practice guidelines recommend that inpatient treatment of youth with eating disorders is in age appropriate facilities that are equipped to meet the complex medical, psychological and developmental needs of these patients.

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The WA Public Health system is not meeting the inpatient needs of youth with eating disorders

- Consultation with consumers and relevant stakeholders reveals common experiences of inappropriate and inadequate inpatient care for patients with eating disorders in the public health system.

- Regional youth and families are without adequate assistance as services struggle to provide appropriate in-patient treatment.

- Western Australian families are travelling interstate and internationally to receive adequate inpatient care for their young people with eating disorders.

- Youth and adults with eating disorders are able to receive specialist psychological outpatient care at the statewide specialist youth and adult Centre for Clinical Interventions (CCI) service. However, no specialist inpatient care is available for patients once they are no longer eligible for care at PMH.

Public Specialist Eating Disorders Services in WA

Age	Specialist Inpatient	Specialist Outpatient
0-17*	✓	✓
18-25*		✓
>25		✓

*NB: If patients with eating disorders are diagnosed above the age of 16 and require inpatient treatment, they are seen by the adult health system and no specialist inpatient eating disorders service is available.

- Western Australia is the only Australian state to not formally address the inpatient treatment of eating disorders in Adult Health Services. Other states have either dedicated eating disorders services or state-wide treatment protocols for patients who present with an eating disorder.

The development of a specialist inpatient service for patients with eating disorders is recommended

- Youth with mental health disorders often require periods of acute intervention, followed by periods of low level continuing care. A specialist youth inpatient eating disorders service is an essential part of the continuum of care to ensure patients receive the best available treatment during these periods of acute need.

- The role of this service is threefold:
    - Facilitate excellent inpatient care to youth with eating disorders
    - Promote linkages within and between services
    - Develop treatment protocols to ensure treatment of patients with eating disorders is evidence based and consistent.

2.0 Key Recommendations

Recommendation 1: The service is estimated to require 4 beds utilised by youth with eating disorders at any one time.

- Currently the WA Activity Based Funding Schedule suggests an average LOS for an inpatient stay for an eating disorders is 21 days (ABF Inpatient Weighted Activity Schedule 2011-2012)
- Current inpatient activity in WA suggests that a youth inpatient service would see approximately 70 patients a year resulting in160 separations.
- These estimates suggest 4 beds will be utilised by youth with eating disorders at any one time.

Recommendation 2: The service requires staff who are competent in the treatment of youth and are able to provide developmentally appropriate treatment and activities.

- Consumers report frequent experiences of developmentally inappropriate treatment in adult inpatient settings. E.g. enforced nap times during days and lack of access to education support.

Recommendation 3: Improved protocols for the transition from Child and Adolescent Services to Adult Services are recommended to be developed.

- Consumers report the transition between child and adolescent services and adult services is difficult to navigate, resulting in a period of service avoidance and increased risk.

Recommendation 4: Families/Carers are recommended to play an important role in the planning and implementation of treatment of youth with eating disorders.

- Families and carers are often the primary influence in a young person's life and are the most important resource. They report feeling excluded from the treatment process by the adult inpatient system.

Recommendation 5: A key priority for the service will be to ensure continuity of care through the continued development of effective linkages between services to facilitate transition, mutual support between services, and consistent treatment protocols.

- An inpatient service is only one part of a continuum of care. Inpatient, outpatient, and community services in both the private and public sectors need strong relationships and consistent protocols to provide excellence in continuity of care for patients and to support staff in demanding environments.

Recommendation 6: Training will be an integral activity of the new service. The new inpatient service is recommended to collaborate with existing community and inpatient eating disorders training programs to deliver comprehensive training options to inpatient, outpatient and community services

- The treatment of eating disorders spans several specialist areas. Utilisation of currently available training reflects a need for increased education and support for services providing treatment to patients with eating disorders.

Recommendation 7: A hub and spoke model specialist inpatient eating disorders service is recommended for youth with eating disorders.

- The National Eating Disorder Collaboration National Framework recommends the development of Hub and Spoke models of care for eating disorders services:

  "Major population centres need specialist Eating Disorder units providing excellence in care and resourced to provide support for the development of peripheries of competence." (pg 42, NEDC 2010) *see 5.2.2 for description of hub and spoke model

Recommendation 8: The service is recommended to be developed in several stages to allow the utilisation of currently available resources, followed by an expansion of the service to meet the inpatient needs of youth with eating disorders.

- This service will initially focus on assessment and medical stabilisation followed by transition to appropriate psychiatric or community care settings.

- The proposed stages towards the development of a Hub and Spoke inpatient service for youth eating disorders patients are:

- **Stage 1:** Provide medical and psychiatric funding to support consultation liaison and training already conducted by clinicians at SCGH. Develop treatment protocols and training resources for treatment of eating disorders within the SCGH.

- **Stage 2:** Develop multidisciplinary team capable of providing specialist assessments, liaison services and Community Services support.

- **Stage 3:** Expand team to increase treatment options for inpatients and provide training and research components.

Recommendation 9: Stage one funding to be promptly made available to support **c**urrent work by Psychiatric and Medical consultants at SCGH with patients with eating disorders.

- Significant time is being invested in the treatment of eating disorders by consultants at SCGH. Protocols and procedures are currently being developed for treatment of patients with eating disorders at SCGH. This momentum can be maintained through medical funding for the treatment of eating disorders at SCGH.

3.0 Background

3.1 Aim

Aim of the project:
The aim of this project is to establish an inpatient service in a staged manner which is capable of meeting the complex medical, psychological and developmental needs of patients with eating disorders aged 16-25 in a sustainable manner.

Expected outcomes and objectives:

The project will comprise of four stages:

- **Stage 1:** Provide medical and psychiatric funding to support consultation liaison and training already conducted by clinicians at SCGH. Develop treatment protocols and training resources for treatment of eating disorders.

- **Stage 2:** Develop multidisciplinary team capable of providing assessments, liaison services and Community Services support.

- **Stage 3:** Expand team to increase treatment options for inpatients and provide training and research components.

3.2 Strategic Context

The development of the service will be aligned with key strategic planning documents at a service, state, and national level. Key documents that this service will align with are:

- National Standards for Mental Health Services 2010
- The Western Australian Mental Health Commission - Mental Health 2020: Making it Everybody's Business
- Health Department of Western Australia – A Better Deal for Youth Mental Health: Prevention Meets Recovery
- Eating Disorders – The Way Forward: An Australian National Framework. The National Eating Disorders Collaboration
- Australia New Zealand Academy for Eating Disorders Position Statement: Inpatient Services for Eating Disorders.
- National Institute for Clinical Excellence (NICE): Eating Disorders – Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders.

These documents all specifically recommend youth specific services. Those that relate explicitly to eating disorders all recommend that inpatient treatment of patients with eating disorders is in age appropriate facilities that are equipped to meet the complex needs of these patients.

3.3 Overview of Eating Disorders

3.3.1 Body Dissatisfaction

Body dissatisfaction has become a cultural norm in Western society (The National Eating Disorders Collaboration, 2010a). Mission Australia surveyed 48,000 youth in 2009 and found that body image is one of the biggest concerns for Australian adolescents (Mission Australia, 2007, 2009). Body dissatisfaction develops when an individual experiences negative feelings about their body which impact on their wellbeing (Commonwealth of Australia, 2009). Body image dissatisfaction is typically more prevalent among females however research suggests that body dissatisfaction amongst boys and men is increasing (The National Eating Disorders Collaboration, 2010a). A South Australian study found that the prevalence of disordered eating behaviours doubled between 1995-2005 among males and females aged 15 years or older (Hay, Mond, & Darby, 2008).

Recent evidence suggests that the prevalence of eating disorders is rising in youth and the age of onset is falling (Brunner & Resch, 2006).

3.3.2 Anorexia Nervosa

Anorexia Nervosa is characterised by a severe restriction of food intake, body weight 15% lower than is considered normal, loss of menstrual periods, an intense fear of gaining weight and/or losing control of eating, relentless pursuit of thinness and disturbed perception of personal body weight and shape (The Victorian Centre of Excellence in Eating Disorders, 2005). Evidence suggests that Anorexia Nervosa has a bimodal peak onset at 12-14 years and 17-18 years (The National Eating Disorders Collaboration, 2010a), meaning one of the peak onset periods falls within the age range covered by the current proposal. The average duration of the illness is 5-7 years (Marks & Maguire, 2005).

Anorexia Nervosa is the third most common chronic illness that affects adolescent females, following obesity and asthma, and is five times more common than insulin dependant diabetes mellitus (Marks & Maguire, 2005). The lifetime prevalence of Anorexia Nervosa in women is estimated between 0.3% and 1.5% (The National Eating Disorders Collaboration, 2010a). The rates of anorexia in males are one tenth of these estimates (The National Eating Disorders Collaboration, 2010b).

Anorexia Nervosa causes numerous medical complications such as electrolyte imbalances, muscle wasting, elevated cholesterol, and fluid depletion (Fisher, Golden, & Katzman, 1995). Long-term consequences of Anorexia Nervosa include kidney failure, heart failure, osteoporosis, infertility and cardiac arrest (Fisher et al., 1995). Complications remain following recovery with rates of depression, anxiety, and suicide significantly higher in individuals who have recovered from Anorexia Nervosa compared to the general population (The National Eating Disorders Collaboration, 2010a). Studies have shown that the all-cause standardised mortality ratio is three times higher for Anorexia Nervosa than any other psychiatric illness and is 12 times higher compared to women without mental illness (The National Eating Disorders Collaboration, 2010b).

3.3.3 Bulimia Nervosa

Bulimia nervosa is characterised by recurrent episodes of eating an abnormally large amount of food in a short period of time, accompanied by a sense of loss of control (Gaskill & Sanders, 2000). These periods of binge eating are followed by inappropriate compensatory behaviours to prevent weight gain, such as purging (Gaskill & Sanders, 2000). The average age of onset for Bulimia Nervosa is 16-18 years (The National Eating Disorders Collaboration, 2010a) – within the age range covered by the current business case.

Bulimia Nervosa is more prevalent than Anorexia Nervosa. Studies suggest that 0.9%-2.1% of females and 0.1%-1.1% of males experience Bulimia Nervosa in their lifetime (The National Eating Disorders Collaboration, 2010b).

Physical and medical side effects of Bulimia Nervosa include dental erosion, gum disease, gastrointestinal bleeding, inflammation of the lining of the gastrointestinal tract, electrolyte imbalances and cardiac arrest (The National Eating Disorders Collaboration, 2010a).

3.3.4 Atypical Presentations of Eating Disorders

Disordered eating behaviours that are severe, but do not fit the diagnostic criteria for Anorexia Nervosa or Bulimia Nervosa are classified as Eating Disorders Not Otherwise Specified (EDNOS). Examples include Binge Eating Disorder or conditions in which the patient has developed chronic maladaptive eating patterns that place them at severe risk but do not qualify them for a diagnosis of Anorexia or Bulimia (The Victorian Centre of Excellence in Eating Disorders, 2005). It is important to recognise that eating disorders in this category are as medically and psychologically severe as eating disorders that fit the diagnostic criteria for Anorexia or Bulimia Nervosa (The National Eating Disorders Collaboration, 2010a).

Atypical eating disorders are the most common of the Eating Disorder Diagnoses. The prevalence of Binge Eating Disorder in Australia is around 2.3% and the prevalence of other atypical eating disorders is around 1.9% (Hay et al., 2008). Atypical presentations are the most common diagnoses in clinical settings (Fairburn & Harrison, 2003).

4.0 Health Service Profile & Activity

4.1 Current Service Profile

4.1.1 Burden of Disease

The financial and social burden caused by eating disorders in Australia is difficult to measure due to the lack of studies conducted in an Australian context (The National Eating Disorders Collaboration, 2010b). As a result, the impact of poor body image and eating disorders is likely to be underestimated (The National Eating Disorders Collaboration, 2010a).

Studies indicate that eating disorders are the 12th leading cause of hospitalisation within Australia and the cost of each admission is second only to the cost of cardiac bypass surgery in the private hospital sector (The National Eating Disorders Collaboration, 2010a).

The standardised mortality rate for Anorexia Nervosa is 12 times higher than the annual death rate for all causes in females aged 15-24 years, and suicide rates for people living with eating disorders is significantly higher than suicide rates in the general community (The National Eating Disorders Collaboration, 2010b).

Other unquantified social costs associated with eating disorders include the devastating effect the illness has on the social, mental and physical development of the sufferer, and the detrimental financial and emotional effect on family and friends (The National Eating Disorders Collaboration, 2010b).

Western Australian Deaths

The number of recorded deaths of individuals in Western Australia who had been treated for an eating disorder in an inpatient setting from 2006-2011 was less than 5.

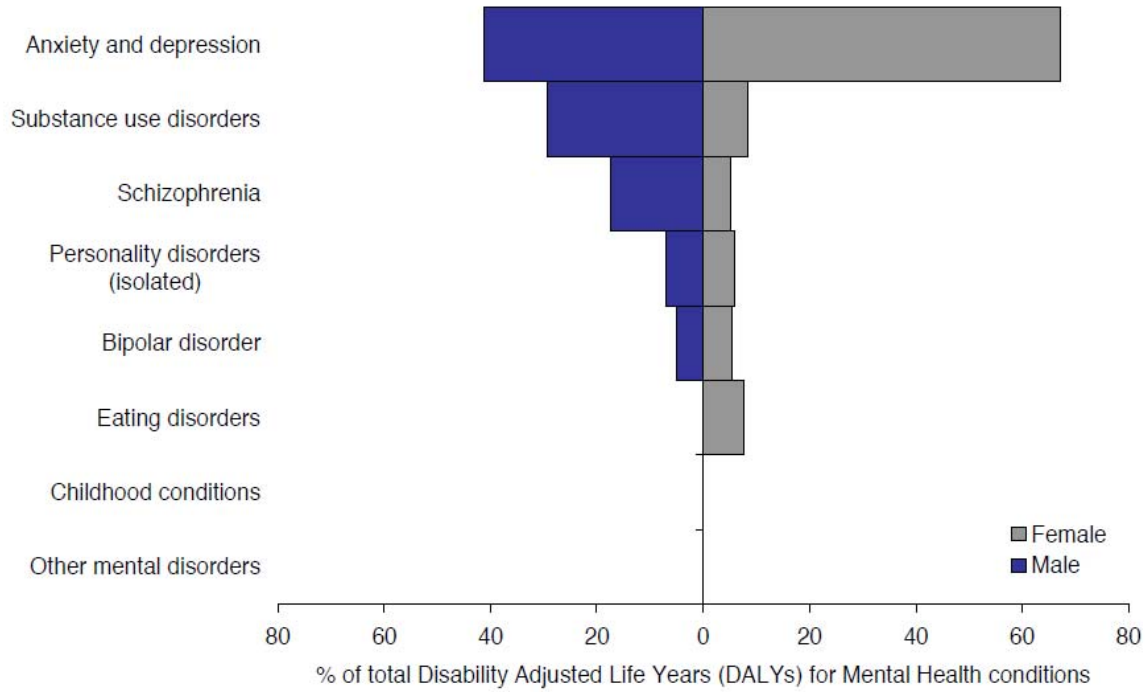
The number of recorded deaths of individuals who had been treated for an eating disorder in either an outpatient or inpatient setting from 2006-2011 was 28.

This suggests that there are individuals with eating disorders who are known to the public health system who die without an inpatient stay in a public hospital, reflecting an inadequacy in the system of care for individuals with eating disorders.

Disability Adjusted Life Years:

Eating disorders fall within the top ten leading causes of burden of disease in 15-24 year old Australian females (Australian Institute of Health and Welfare, 2007), and contribute significantly to the Disability Adjusted Life Years lost from mental health conditions in the age 15-24 (Figure 1).

Figure 1.
Disease Burden (DALYs) for specific Mental Health conditions, as a percentage of total Mental Health burden, by gender, 15-24 years, WA, 2006.



Source: Epidemiology Branch. Burden of disease in Western Australia. WA Burden of Disease Study. Department of Health, Perth, Western Australia, 2010.

4.1.2 Inpatient services available to youth with eating disorders

1. Princess Margaret Hospital

Princess Margaret Hospital provides in-patient care for patients under 16, and up to 18 years old for existing patients, on medical wards with in-reach from a specialist multi-disciplinary team.

2. Adult Inpatient Units

All Mental Health Units provide general psychiatric care with medical support for young people suffering eating disorders however these services are ill-equipped to persevere with treatment resistant anorexia nervosa and its medical complications. Many patients are discharged home without follow-up care. Patients with a body mass index (BMI) of less than 16 are able to be seen on medical wards, where psychiatric care relies on input from overstretched consultation liaison teams.

3. Hollywood Private Hospital

Hollywood Private Hospital provides specialist multidisciplinary inpatient care for patients with Eating Disorders aged 16 and above.

4. Other Private Hospitals

The Marion Centre and Perth Clinic provide some inpatient treatment for youth who are motivated for treatment with eating disorders and other psychiatric co morbidities

4.1.3 Current Public Health Service Utilisation

Number of patients:
Australian prevalence rates reported by Hay et. al. (2008) would suggest that in Western Australia's 2010 population of 335 000 individuals aged 16-25 years (males: 175000; females 160 000, ABS 2010), approximately 6000 females and 2500 males will meet criteria for an eating disorder. Of these patients, approximately 10% are expected to require hospitalisation in any one year. The breakdown of the estimated numbers of individuals with eating disorders in WA is presented in Table 1:

Table 1
Estimates of the number of individuals in 2010 in WA aged 16-25 years with eating disorders† based on point prevalence estimates.

	Point Prevalence	Female/Male Ratio	Number Females	Number Males
Anorexia Nervosa	0.3%	10:1	**430**	**50**
Bulimia Nervosa	0.9%	10:1	**1 300**	**150**
Binge Eating Disorder	2.3%	1:1	1 850	2 000
Eating Disorder NOS	1.9%	10:1	2 750	350
		Total	**6330**	**2550**

The majority of patients who receive inpatient treatment in WA public hospitals with a primary diagnosis of an eating disorder are aged 16-25 (Table 2). It is acknowledged that these are potentially underestimates as reports from clinicians suggest that patients with eating disorders on medical wards may be coded as a medical diagnosis without a secondary diagnosis of an eating disorder.

Table 2
The number of persons treated, and number of hospital separations of individuals with eating disorders† from inpatient health services by age on admission from 2006 to 2011.

	Total 2006-2011		Average/Year 2006-2011		Percentage of Total 2006-2011	
Age on admission	No Persons	Separations	No Persons	Separations	No Persons	Separations
0-15 yrs	168	409	28	68	22%	23%
16-25 yrs	429	1006	72	168	**55%**	**56%**
>25 yrs	183	370	31	62	23%	21%

† Eating disorders refers to a primary diagnosis of an eating disorder or a primary diagnosis of malnutrition with a secondary diagnosis of an eating disorder

Psychiatric vs Non-psychiatric care:

The proportion of patients within each age range who are treated for an eating disorder in Psychiatric units and non-psychiatric units are shown in Table 3. Patients below 15 years of age are seen by the PMH eating disorders unit, where the model of care is in line with best practise; emphasising medical stabilisation as the priority for inpatient care, with psychiatric inpatient care for co morbid conditions as required. This is in contrast with 16-25 year olds, the majority of whom are seen in the adult system in psychiatric wards.

Table 3

The average number of persons treated and separations from psychiatric and non-psychiatric inpatient units by age range and the percentage of ward type with eating disorders† from 2006-2011.

		Average/Year 2006-2011		Percentage of Psych/Non Psych Admission by Age 2006-2011	
Age on admission		No Persons	Separations	No Persons	Separations
0-15 yrs	**Psych Ward**	8	27	29%	40%
	Non-Psych	20	41	71%	60%
16-25 yrs	**Psych Ward**	57	134	79%	80%
	Non-Psych	15	33	21%	20%
>25 yrs	**Psych Ward**	23	51	74%	84%
	Non-Psych	8	10	26%	16%

Rural vs Metro:

The majority of patients treated in inpatient settings for eating disorders are seen in metropolitan hospitals (Table 4). In 2010, 74% of the West Australian population were living in metropolitan areas (Australian Bureau of Statistics, 2010). This indicates patients with eating disorders were either travelling to Perth to receive adequate care or are grossly under diagnosed in rural areas.

Table 4

Number of inpatient separations per year in rural and metropolitan hospitals of patients with eating disorders†.

Inpatient service location	**Year of separation**					
	2006	**2007**	**2008**	**2009**	**2010**	**2011**
Metro	265	307	209	328	279	209
Rural	14	10	13	12	9	16

† Eating disorders refers to a primary diagnosis of an eating disorder or a primary diagnosis of malnutrition with a secondary diagnosis of an eating disorder

Length of Stay:

The distributions for the length of stay of inpatients' with an eating disorder in medical and psychiatric settings are represented in Table 5 and 6 respectively. Of particular concern are the lengths of stays for youth and adults in medical settings. Low medians suggest a large number of people are being admitted with an eating disorder or malnutrition and are discharged very quickly. These patients will not be receiving adequate care. Also of note are the large maximum lengths of stays for patients with eating disorders, representing the complexity of treating these patients.

Table 5
Distribution of length of stay by age group for persons with eating disorders† in Medical Inpatient Units in 2006-2011.

	Age Group (years)								
	0-15 years			16-25 years			>25 years		
Yr of Separation	Median	Mean	Max	Median	Mean	Max	Median	Mean	Max
2006	29	31.5	67	7	13.1	56	3	3	5
2007	30	33.6	59	2	20.2	73	3	4.5	12
2008	29	31.1	66	14	21.4	68	4	5.6	12
2009	19	22.6	71	8	17.0	54	1	7.9	46
2010	28	25.4	44	28	20.8	52	4	5.1	18
2011	26	23.3	51	4	11.2	38	4	6.2	21
Total	**24**	**25.1**	**71**	**11**	**17.3**	**73**	**3**	**21.3**	**46**

* Length of stay is in days from admission to discharge, excluding days on leave.

† Eating disorders refers to a primary diagnosis of an eating disorder or a primary diagnosis of malnutrition with a secondary diagnosis of an eating disorder

The average length of stay is relatively stable across age groups for Psychiatric Inpatient Units.

Table 6
Distribution of length of stay by age group for persons with eating disorders† in Psychiatric Inpatient Units in 2006-2011.

	Age Group (years)								
	0-15 years			16-25 years			>25 years		
Yr of Separation	Median	Mean	Max	Median	Mean	Max	Median	Mean	Max
2006	4	15.8	63	14	23.4	74	12	18.7	101
2007	22	21.8	54	13	19.0	72	34	39.3	120
2008	26	32.1	72	21	24.8	69	24	36.8	180
2009	7	11.2	36	21	26.5	100	11	25.1	117
2010	9	10.1	27	23	27.4	105	16	20.4	68
2011	18	22	56	21	30.2	189	17	26.7	131
Total	**14**	**19**	**72**	**19**	**25**	**189**	**19**	**27**	**180**

* Length of stay is in days from admission to discharge, excluding days on leave.

The average length of stay for an eating disorders admission at the Weight Disorders Inpatient Unit (SA) is 20.7 days.

The majority of patient with Eating Disorders at PMH are admitted for malnutrition. The average length of stay for malnourishment at PMH is 29 days.

WA Activity Based Funding (ABF) suggests the average length of stay (ANOS) for an admission for an eating disorder or malnutrition should be 21 days.*

*ANOS = Average Nights of Stay: Calculated as 1/3 the high boundary point of a central episode for an eating disorder inpatient stay Inpatient Weighted Activity Unit Schedule (U66Z) (ABF Inpatient Weighted Activity Schedule 2011-2012). This is subject to change in the future as the Activity Based Funding Scheme is implemented and refined.

† Eating disorders refers to a primary diagnosis of an eating disorder or a primary diagnosis of malnutrition with a secondary diagnosis of an eating disorder

4.2 Future Health Service Profile

Recommendation 1: The service should expect of have approximately 4 beds utilised by youth with eating disorders at any one time.

Based on the WA Health Activity Based Funding Inpatient Weighted Activity Unit Schedule, the average nights of stay for a patient with an eating disorder should be 21 days. Utilising the number of patients currently presenting to public inpatient units (Table 2), the estimated number of inpatient beds required for patients aged 16-25 with eating disorders is four (See Table 7)

Table 7
Modelled number of beds required to meet inpatient demand of patients aged 16-25 with eating disorders.

Average Patients/ Year	ANOS	Total Bed Days/Year	Number of Beds
67	21	1407	4

Total Patient/Year = Average number of current inpatient admissions in WA 2006-2011

ANOS = Average Nights of Stay: Calculated as 1/3 the high boundary point of a central episode for an eating disorder inpatient stay Inpatient Weighted Activity Unit Schedule (U66Z) (ABF Inpatient Weighted Activity Schedule 2011-2012). This is subject to change in the future as the Activity Based Funding Scheme is implemented and refined.

4.3 Identified Need

There are **no public dedicated beds** for young people who first present over the age of 16 with an eating disorder. There is no public specialist inpatient service or day programs for young people over the age of 18 with eating disorders in WA. The adequacy of this system is assessed in the following sections.

There is now consensus that the treatment outcomes for Anorexia Nervosa is better amongst adolescents and youth than adults (The National Eating Disorders Collaboration, 2010a) . This makes it very important for investment in services, training and resources for early diagnosis and intervention for those with Eating Disorders, as the window of opportunity for successful outcome starts to fade after 3-4 years of illness. This is one disorder when early intervention is absolutely crucial and therefore access to evidence based best practice is essential.

4.3.1 Consultation

Extensive consultation has attempted to represent all relevant stakeholders in the formulation of the current proposal. The identified stakeholders who have been included in this consultation are:

- Consumers
- Carers
- Princess Margaret Hospital Eating Disorders Team
- Adult Inpatient Services:
    - Sir Charles Gairdner Hospital
    - Swan District Hospital
    - Fremantle Hospital
    - Graylands Hospital
- Hollywood Hospital
- The Centre for Clinical Interventions
- Bentley Adolescent Unit
- Rural Eating Disorders and Mental Health Services
- Department of Education/Hospital School Services
- Bridges Association Incorporated
- Women's Health Works
- Other Australian States' public health systems

Depending on their area of interest and expertise, stakeholders were interviewed regarding:

- Their perception of the need for a specialist youth eating disorders service
- What their needs would be from a specialist youth eating disorders service
- The structure and organisation that the specialist youth eating disorders service should take to be effective

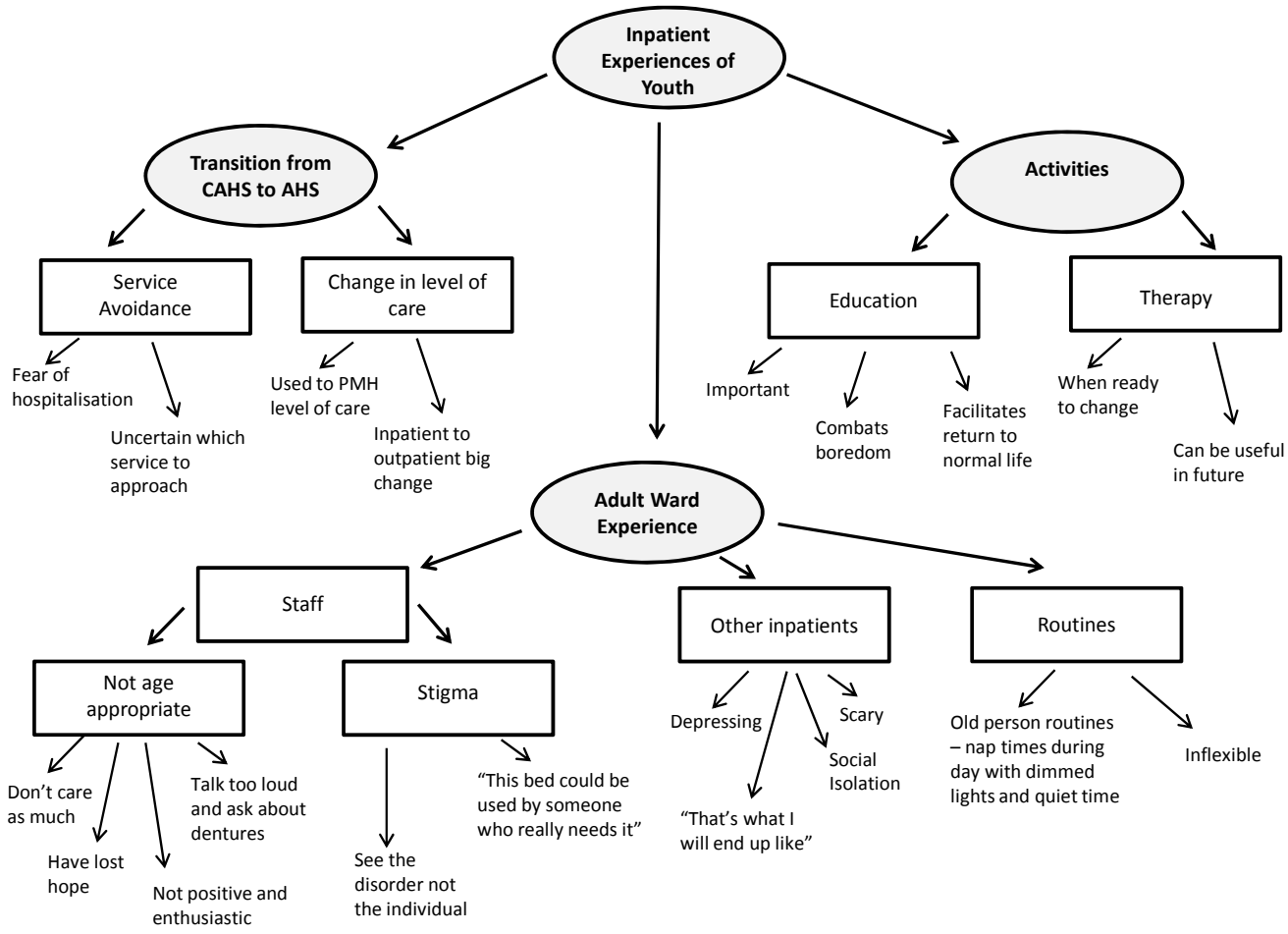
Consumer Consultation

Recommendation 2: The service requires staff who are competent in the treatment of youth and are able to provide developmentally appropriate treatment and activities.

Recommendation 3: Improved protocols for the transition from Child and Adolescent Services to Adult Services should be developed.

The thematic analysis of consumer consultations is represented in Figure 2. Consumers from the PMH Consumer Advisor Group were consulted as they are youth who have suffered acute eating disorders and experienced transition to adult services. Additional consumer input was achieved through written submissions (see Appendix 1). Key themes included experiences of developmentally inappropriate care, finding the transition from Child and Adolescent services to Adult services difficult, and the negative impact of being treated with adult patients.

Figure 2.
Thematic analysis of consumer consultations regarding a youth eating disorders inpatient service.



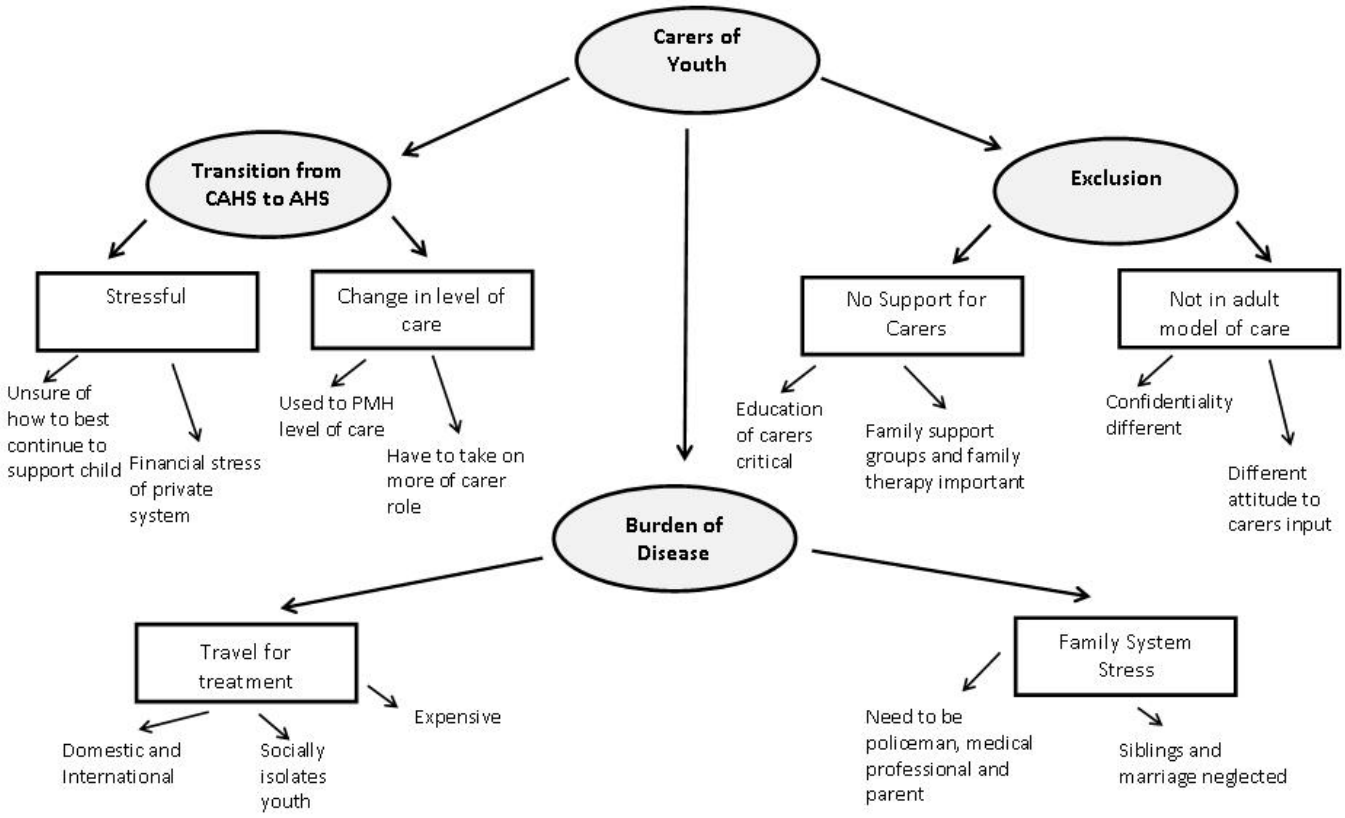
Carer Consultation

Recommendation 4: Carers should be facilitated to play an important role in the planning and implementation of treatment of youth with eating disorders.

The thematic analysis of carer consultations is represented in Figure 3. Carer consultations were achieved through the PMH parents meeting and fathers meeting as well as a call for written submissions distributed through email networks of PMH, Bridges, and Women's Health Works. The most striking aspect of the carer's consultation were the experiences of families travelling both interstate and overseas to receive adequate treatment for their children.

Figure 3

Thematic analysis of carer consultations regarding a youth eating disorders inpatient service.



Service Provider Consultation

Recommendation 5: A key priority for the service should be ensuring continuity of care through the continued development of effective linkages between services to facilitate effective transition, mutual support between services, and consistent treatment protocols.

Public health service providers report the treatment of patients with eating disorders can be stressful and intimidating and that they require more resources and training to provide adequate care.

Case Examples of Inadequate Care:

- GP reports feeling youth patient needed inpatient care but unable to refer to appropriate service. Resulted in malnourished patient being inappropriately treated in community.

- Hollywood Eating Disorders Treatment Program reports patients who are treatment resistant and behaviourally disturbed being managed under the Mental Health Act and referred to Graylands despite needing specialist medical care.

- Centre for Clinical Interventions Eating Disorders Program reports having to discharge patients who are malnourished (BMI<14) to GP despite the patients needing specialist care.

- Adult Psychiatric Units report discharging patients without 'adequate community support' and expecting the patients to return for another inpatient stay within several weeks.

- Adult inpatient wards report relying on the good will of nursing staff and medical teams to attend case conferences and patient meetings to allow best practice treatment.

- Adult psychiatric and medical staff report that the treatment of eating disorders requires specialist skills and knowledge across medical and psychiatric fields, a strong continuity to care, and time to develop a therapeutic relationship. Lacking the resources to provide these factors leads to unwillingness to treat patients with eating disorders.

- All service providers contacted to date agree a youth inpatient eating disorders service would be beneficial.

The working group informing this report identified that an inpatient service is one part of the continuum of care provided by the public health system. It is important for consumers to experience consistent treatment messages and to have a clear understanding of what services are able to provide. Transition between services (e.g. from inpatient to outpatient) was identified as a significant period of risk. The development of protocols and relationships between services was identified as a key priority in delivering excellence in continuity of care.

Training:

Recommendation 6: Training should be an integral activity of the new service. The public specialist eating disorders services should collaborate to deliver comprehensive training options to inpatient, outpatient and community services.

The Centre for Clinical Interventions (CCI) and the PMH Eating Disorders Training and Evaluation Centre (EDTEC) offer training courses and workshops to service providers. In 2011, tertiary mental health centres requested and were supplied with 10 training and consultation sessions in response to the needs of their staff, in addition to the regular training schedules of CCI and PMH EDTEC. These requests by adult and youth services reflect the need for more resources, training and support for service providers of patients with eating disorders.
It is noteworthy that the majority of training for eating disorders is supplied to mental health services. Medical inpatient service providers and general practitioners express a need for training in core eating disorders treatment concepts, such as refeeding syndrome and treatment resistance.

4.3.2 Gaps Analysis

Others Australian States were contacted in order to construct a gaps analysis of the current WA public eating disorders service (Table 8) Of particular relevance to the current proposal is the gaps in service in Western Australia for youth aged 16-25, for whom there are no public specialised inpatient eating disorders services available.

Table 8
Comparison of the Australian States' public eating disorders inpatient services.

	Type of Public Service	WA	SA	VIC	NSW	QLD
Children 8-16	Specialist Inpatient ED's Service	✓	✓	✓	✓	
	Consultation Liaison Services	✓	✓	✓	✓	✓
	Number of Available Beds	(8)	(3)	(14)	13	(6)
	Day Program or Residential Program	✓				
Youth 16-25	Specialist Inpatient ED's Service		✓*	✓*	✓	
	Consultation Liaison Services		✓*	✓*	✓	✓
	Number of Available Beds	0	✓*	✓*	8	0
	Day Program or Residential Program					
Adult 18+	Specialist Inpatient ED's Service		✓	✓	✓	
	Consultation Liaison Services		✓	✓	✓	✓
	Number of Available Beds	0	6	15	5	5
	Day Program or Residential Program					

Parentheses indicate beds that are available to patients with eating disorders but not dedicated to eating disorders.

* Indicates service delivery covers full youth age range but not with a dedicated youth service. E.g. adult service may take referrals from 16.

NB: NSW Youth service is the Westmead Adolescent Unit accepting patients aged 14-18.

Victorian services vary slightly by health area service, but all areas have some level of child, adolescent and adult cover.

4.3.3 Summary of Identified Need:

There is a significant gap in the adequacy of care provided to youth with eating disorders who require inpatient care. Youth constitute the majority of individuals being admitted to WA public hospitals for treatment of eating disorders and contribute significantly to the total burden of disease of individuals aged 16-24. The data presented above suggest individuals aged 16-25 who are presenting for inpatient admissions are being discharged very quickly, being treated in psychiatric units which are ill-equipped to deal with medical complications, and that rural patients with eating disorders are not being treated in rural hospitals. 28 patients who had been treated for an eating disorders by the WA public health service died between 2006-2011.

Modelling of the number of patients with eating disorders aged 16-25 who require hospitalisation each year suggests an average of 4 beds will be utilised at any one time by patients with eating disorders.

Consultation with consumers, carers and service providers suggest experiences of inadequate inpatient care for patients with eating disorders is common and consistent.

Western Australia provides a specialist eating disorders inpatient service for children. However, for patients diagnosed with an eating disorder above the age of 16 or those leaving the PMH service at 18, there is no public specialist inpatient service available. South Australia, New South Wales, and Victoria provide specialist eating disorders inpatient services to16-25 year olds.

This proposal has also identified a gap in the provision of service to patients with eating disorders who are aged 25 years and older. This is an issue which may impact on a youth eating disorders service as the need from older groups is likely to utilise resources from a youth service. Clear understanding will need to be established of the relationship of a youth inpatient service with the care of adults over the age of 25.

4.4 Risk Assessment

4.4.1 ANZAED Position Statement

The Australia New Zealand Academy for Eating Disorders (ANZAED) Position Statement: "Inpatient Services for Eating Disorders recognises that patients (and their families) may suffer psychological trauma when treated in inappropriate settings. There are well-recognised problems and risks with;

- Managing patients in high security psychiatric units where the medical difficulties of eating disorder patients can be overlooked and where their needs may be placed at a lower priority than patients who have greater behavioural disturbance

- Mixing adolescents with adults suffering acute psychoses, the latter who may have severe behavioural disturbance

- Management by professionals unfamiliar with current management and/or the potential for adverse effects of excessively punitive and coercive approaches"

The risks associated continuing the current service status quo or with developing a youth specific eating disorders inpatient service are presented in the following two sections.

4.4.2 Risk Matrix

A risk assessment of two options is presented in Table 9 and 10 – to continue the current service status quo or to develop a youth specific eating disorders inpatient service. The identified risks associated with doing nothing are significantly higher than those associated with developing the service.

Option1. Do Nothing

Table 9.
Risks associated with continuing current service.

Risk	Controls	Likelihood	Consequence	Rating
Continuation of inadequate treatment for malnutrition and medical complications leading to death.	Inadequate	Possible	Catastrophic (HP)	High
Patient with inadequate mental health treatment suicides.	Inadequate	Possible	Catastrophic (HP)	High
Patient treated in inappropriate setting leading to poor treatment prognosis.	Inadequate	Very Likely	Major (HP)	Extreme
Individual with ED avoids service due to negative experiences leading to poor outcomes.	Inadequate	Possible	Major (HP)	High
Patient with ED 18-25 yrs causes stress in health system due to lack of treatment expertise.	Inadequate	Likely	Moderate (HS)	High
Burden of disease transferred to family due to inadequate public care.	Inadequate	Likely	Major (HP)	High

Option 2. Develop Youth Specific Eating Disorders Inpatient Service

Table 10.
Risks associated with developing a youth specific eating disorders inpatient service.

Risk	Controls	Likelihood	Consequence	Rating
Insufficient resources invested resulting in unsustainable service.	Unknown	Possible	Major (OO)	High
Inadequate expertise re ED treatment available resulting in unsustainable service	Unknown	Possible	Catastrophic (OO)	High
Inadequate integration across inpatient services (i.e. medical, psychiatric, child, youth, adult) leading to continuation of inadequate care.	Unknown	Possible	Major (HP)	High
Service need from patients over 25 resulting in service operating outside of scope and becoming overburdened.	Unknown	Possible	Moderate	Medium
Increased service utilisation leading to overburdening of community resources.	Unknown	Possible	Moderate	Medium
Community services not engaged adequately leading to lack of referrals.	Unknown	Possible	Moderate (FL)	Medium
Inadequate demand from population to fully utilise service.	Unknown	Rare	Moderate (FL)	Low

5.0 Staged Approach to Development of Service

5.1 Working Party Group Members

1. Sylvia Meier
   Executive Director
   Child and Adolescent Mental Health Service

2. Dr Caroline Goossens
   Clinical Director
   Child and Adolescent Mental Health Service

3. Anthony Collier
   Acting Youth Mental Health Clinical Lead
   Child and Adolescent Mental Health Service

4. Paula Nathan
   Director
   Centre for Clinical Interventions

5. Dr Lisa Miller
   Consultant Psychiatrist
   Consultation Liaison Team
   Sir Charles Gairdner Hospital

6. Prof David Forbes
   Professor , School of Paediatrics & Child Health
   University of Western Australia
   Paediatrican
   Gastroenterology Department & Eating Disorders Program
   Princess Margaret Hospital for Children

7. Dr Eileen Tay
   Director
   Eating Disorders Program
   Hollywood Hospital

8. Julie Potts
   Eating Disorders Program Manager
   Princess Margaret Hospital

9. Nathan Gibson
   Director
   Adult Mental Health
   North Metro Health Service

10. Dr Anthea Fursland
    Principal Clinical Psychologist
    Eating Disorders Program
    Centre for Clinical Interventions

11. Dr Greg Ong
    Consultant Physician
    Sir Charles Gairdner Hospital

12. Chris Harris
    Transition Coordinator
    Eating Disorder Program
    Princess Margaret Hospital

5.2 Stages of Development

Recommendation 7: A hub and spoke model specialist inpatient eating disorders service should be developed for youth with eating disorders.

A staged approach to the development of a youth eating disorders inpatient service is outlined below. The goal of the current proposal is a hub and spoke inpatient service, a model of care based on the National Eating Disorders Collaboration National Framework (NEDC 2010). The NEDC recognise that hub and spoke models of care promote:

"Integrated, coordinated options for treatment across Australia. Major population centres need specialist Eating Disorder units providing excellence in care and resourced to provide support for the development of peripheries of competence in rural and remote settings. City centres in area health regions have the capacity to link with clinicians in the public and private sectors and with university based professional units to provide seamless care across the age spectrum and duration of illness for Australians with Eating Disorders. They are able to innovate and evaluate clinical outcomes as well as provide satellite support to urban and remote areas." (NEDC 2010, pg 42)

Recommendation 8: The service should be developed in several stages to allow the utilisation of currently available resources, followed by an expansion of the service to meet need.

This approach proposes four phases to the development of the service:

1. Utilise current available resources to develop standardised protocols, resources and training materials for the treatment of eating disorders at SCGH.
2. Establish basic multidisciplinary assessment, consultation and liaison team.
3. Expand team to increase treatment options for patients.
4. Expand team to increase research and training components.

The proposed development outlined below is intended as a guide to future service and model of care development.

5.2.1 Current Resources

Recommendation 9: Current work by Psychiatric and Medical consultants at SCGH with patients with eating disorders should be immediately supported by Stage 1 funding.

Through the working group formed for this project, resources currently available within the Child and Adolescent Health Service and the Adult Health Service have been identified that are capable of providing some improvement in the adequacy of inpatient care received by inpatients' with eating disorders in the adult health system.

The Princess Margaret Hospital Eating Disorders Evaluation and Training Centre (EDTEC) is able to provide:

- Training and consultation to support the development of treatment protocols and training materials at SCGH.
- A service level agreement with SCGH to continue to provide ongoing support expertise, supervision and to assist in the collaborative process of transition between the services.

Sir Charles Gairdner Hospital Consultation Liaison team is able to provide:

- Semi-regular meetings of relevant staff and attendance at case conferences to facilitate the improvement of care for patients with eating disorders.
- An initial Grand Round at Sir Charles Gairdner Hospital.
- Collaboration with PMH to:
    - Adapt PMH Eating Disorders guidelines and protocols.
    - Develop an online training module.
    - Develop an eating disorders resources file for medical staff at Sir Charles Gairdner Hospital.

The Centre for Clinical Interventions is able to provide:

- Increased education to medical staff at SCGH in regards the services that CCI offers and the procedures for accessing those services.
- Continuous liaison and support for transitioning patients to community care

5.2.2 Hub and Spoke Model

The development of a Hub and Spoke model inpatient service is detailed below as a guide to outcomes, costing and staffing. This model is based on the current PMH model of care which provides multidisciplinary inpatient care to patients who require medical stabilisation due to malnourishment and associated medical complications, along with training and consultation support for community health services.

	Aim	**Outcomes**
Stage One	Provide medical and psychiatric funding to support consultation liaison and training already conducted by clinicians at SCGH. Develop treatment protocols and training resources for treatment of eating disorders.	• Acknowledge medical cost of current treatment of patients with eating disorders and provide some specialised medical management. • Establish relationship with PMH Eating Disorders Training and Evaluation Team with aim of developing resources and training materials for staff at SCGH.
Stage Two	Develop multidisciplinary team capable of providing assessments, liaison services and Community Services support.	• Provide comprehensive inpatient assessment • Liaise with inpatient staff • Establish relationships with community services • Establish training and support for community services
Stage Three	Expand team to provide treatment options for inpatients.	• Structured eating programs • Therapy • Dietician consults • Occupational therapy, social worker, and physiotherapy support
Stage Four	Expand team to increase training and research components.	• Include psychology and medical registrars on team • Integrate research into service • Establish collaborative research approaches between PMH, Youth, Adult and Community Services. E.g. CCI.

Medical and psychiatric consultants will provide leadership and management to the youth service. Their roles will include:

- Weekly case conferences with and without patient
- Managing individualised care plans
- Consultation and liaison with community service providers
- Meeting competency and up skilling requirements
- Managing and containing team
- Providing consistency in care.

Government of Western Australia
Department of Health

Proposed Staffing Budget

NB: All figures include on-costs.

Position	Stage 1	EFT	Stage 2	EFT	Stage 3	EFT	Stage 4	EFT
Consultant Psychiatrist	$ 115, 994	0.4	$ 115, 994	0.4	$ 173, 991	0.6	$ 289, 995	1
Medical Consultant	$ 115, 994	0.4	$ 115, 994	0.4	$ 173, 991	0.6	$ 289, 995	1
Dietician	$ 24, 231	0.2	$ 60, 578	0.5	$ 121, 156	1	$ 121, 156	1
SRN Consultation Liaison Nurse	$ 47, 510	0.4	$ 118, 776	1	$ 237, 552	2	$ 237, 552	2
Specialist Clinical Psychologist			$ 78, 555	0.5	$ 78, 555	0.5	$ 157, 109	1
Admin Assistant			$ 35, 609	0.5	$ 35, 609	0.5	$ 71, 218	1
Social Worker			$ 60, 578	0.5	$ 121, 156	1	$ 121, 156	1
Senior Research Scientist			$ 36, 124	0.2	$ 90, 309	0.5	$ 121, 156	1
Training Coordinator					$ 65, 584	0.5	$ 65, 584	0.5
Trainee Registrar					$ 121, 156	1	$ 121, 156	1
Senior OT					$ 60, 578	0.5	$ 121, 156	1
RN Eating Disorders					$ 98, 651	1	$ 98, 651	1
Clinical Psychology Registrar							$ 110, 894	1
CS Physiotherapist							$ 60, 578	0.5
Total Financial Year	**$ 303, 729**	**1.4**	**$ 622, 208**	**4.4**	**$ 1, 378, 288**	**9.7**	**$ 1, 987, 356**	**14**

6.0 Evaluation

The program will be evaluated against the National Standards for Mental Health Services (2010) using the Key Performance Indicators developed from the nine domains from the *Key Performance Indicators for Australian Public Mental Health Services* (2005):

Effectiveness: care, intervention or action achieves desired outcome in an appropriate timeframe.

Appropriateness: care, intervention or action provided is relevant to the client's needs and based on established standards.

Efficiency: achieving desired results with the most cost-effective use of resources.

Accessibility: ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.

Continuity: ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.

Responsiveness: the service provides respect for all persons and is client orientated. It includes respect for dignity, cultural diversity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.

Capability: an individual's or service's capacity to provide a health service based on skills and knowledge.

Safety: the avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.

Sustainability: system or organisation's capacity to provide infrastructure such as workforce, facilities, and equipment, and be innovative and respond to emerging needs.

7.0 Next Steps

- *Phase 3*: Utilise currently available resources to initiate service through the working group established for this project.
- *Phase 4*: Expand and roll out service over 3-4 years.
- *Phase 5*: Evaluate service.

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9.0 Appendices

9.1 Appendix 1 – Community Health Data

The pattern of the majority of patients being between the age of 16-25 holds for WA community mental health services (Table 11):

Table 11
The number of persons treated and occasions of service (OCS) delivered with a primary diagnosis of an eating disorder from Community Mental Health Services by age from 2006 to 2011.

	Total 2006-2011		**Average 2006-2011**		**Percentage 2006-2011**	
Age on admission	No Persons	OCS	No Persons	OCS	No Persons	OCS
0-15 yrs	252	17 727	42	2 955	15%	27%
16-25 yrs	974	42 502	162	7 083	**59%**	**63%**
>25 yrs	417	7 024	70	1 171	26%	10%

Table 12.
Comparison of the Australian States' public outpatient and community eating disorders services.

	Type of Public Service	WA	SA	VIC	NSW	QLD
Children 8-16	Outpatient Services	✓	✓	✓	✓	
	Day Program	✓			✓	
	Community Mental Health Services	✓	✓	✓	✓	✓
	Training and Support	✓				✓
Youth 16-25	Outpatient Services	✓*	✓*	✓	✓	
	Day Program			✓	✓	
	Community Mental Health Services	✓*	✓*	✓*	✓*	✓*
	Training and Support	✓*	✓*	✓*		✓*
Adult 18+	Outpatient Services	✓	✓	✓	✓	
	Day Program			✓	✓	
	Community Mental Health Services	✓	✓	✓	✓	
	Training and Support	✓*				✓

* Indicates service delivery covers full youth age range but not with a dedicated youth service. E.g. adult service may take referrals from 16.

9.2 Appendix 2 – Submissions

Consumer Submission 1:

Having been officially diagnosed with anorexia nervosa at the age of 15 and 7 months I was fortunate, in light of this proposal, to fall into the age gap that exists in the mental health system. Having turned 16 weeks after being discharged there were no real outpatient services I could utilise besides those at PMH, which I could not face using since going back there made me feel inadequate due to the weight I had gained since my 'release'. Due to the lack of support in the system I spent a good two years abusing alcohol and other drugs to try and deal with the many psychological problems I still had. After many failed suicide attempts and years of struggling I know my journey to 'recovery' isn't over although I feel I am well on my way and I hope that in some way my experience can help others.

- While I realise the health system is already thinly stretched and has changed over the last seven years I feel more public awareness regarding eating disorders and the services available will enable both sufferers and families to make better informed choices regarding treatment. Considering the incredible stress a child with an eating disorder places on a family making these resources more easily available is paramount. Due to my mum and her friends' lack of understanding regarding eating disorders my condition was allowed to progress to an incredibly serious stage before my mum stepped in and decided something needed to be done. As a member of the F.A.C.E.S. group operating at PMH I am personally more than happy to offer up free time to partake in public campaigns to spread awareness about eating disorders and the many treatment options currently available. Creating a more prominent public awareness campaign also helps alleviate the stigma surround eating disorders and gives hope to current (and past) sufferers.

- Having been through the inpatient system at PMH I can assure you that the staff recruited to work in this new department will be one of the most important aspects in terms of its success. Since each journey to 'recovery' is so different it's essential patients have staff that can give them individual the treatment they need. Not only should staff have the right mind-set to work with the patients but they also need the right training and mentoring. Another important aspect is how to maintain staff moral in such an intense environment. Ensuring they have adequate facilities to "de-stress' in, counselling/support when needed and an involved social committee are just a few ideas that may help keep staff motivated.

- Education is the only thing that got me through my struggle with my eating disorder. Ever since I was 14 I've wanted to be a biomedical scientist and it was the realisation that this dream couldn't occur while I gave into my demons that eventually forced me to take ownership of my life and get serious about getting well. Ensuring patients have the support from their educational institution, be it school, TAFE, university etc. is necessary to ensure a sense of normality following discharge. Again this will mean

building rapport between the department and these institutes, something F.A.C.E.S. already does (with patients schools) and I'm sure would be happy to help build continue to build.

- Looking at the ward itself I think being on a medical ward is more appropriate. The stigma attached to having an eating disorder is already considerable and is not helped by being on a psychiatric ward. Ideally it would be separate but that would obviously be up to the budget settled on. The colours should be bright and uplifting with emphasise, or at least encouragement placed on individualising a patients own personal space for the duration of their stay. (Craft is one of the few things that gets you through an admission and being able to display it around you and create a happy positive space that speaks to you and mirrors your own individual treatments needs is especially helpful).

- Therapy options are also crucial for the new system. It needs to be realised by all involved that each individual is incredibly different in terms of the treatment they need and how they will respond to a particular type of treatment. There should by no means be a 'one size fits all' approach when determining how a patient will be treated and in some capacity (even if they are refusing to co-operate) a patient should be involved in these decisions.

- More support for parents is also paramount in ensuring the success of the program. My mum was always told that my admission was only the beginning of my recovery and that when I was discharged the real process would start. I don't think at the time she fully appreciated the depth of what my caseworker was telling her since she was just so happy I would live. The years that followed were (I'm assuming) the worst of her life due to the tremendous strain I put her under trying to cope with 'being well' and not killing myself. Providing more parent support during a patients admission and providing them with tools and knowledge of what life will be like after discharge is crucial. Continuing this support after a patient has gone home is also important. It should be noted that these sessions should occur with the staff and parents alone without the presence of the patient.

- I think it should be mentioned (although it is probably already known) that most patients go into the program with anorexia and come out with bulimia. (The culture again may have changed since I've been through the system). This issue needs to be addressed and coping strategies for patients and parents should be given before, during and after discharge.

- Emphasise needs to be placed on creating accessible and conveniently timed outpatient services. Currently the only options I have regarding treatment for some of my lingering problems involve either paying $5000 (which I don't have) and missing two weeks worth of university or missing an assessed lab for two months meaning I will likely get a poor grade for my university unit (weekdays during work hours are not optimal times to have services for people trying to get their lives back on track since, surprise surprise, they will probably be at work or school). Services need to be created that focus

on things like the reintegrating into society and building a network of friends since isolation is a big factor in this disease. This also feeds into the idea of tapering down the support given to patients, which helps them overcome their illness and at the same time feel confident in their ability to continue their success on their own.

The sense of abandonment you feel from the system is so detrimental to the recovery process and it is wonderful to see this being addressed. I urge you to fully consider the issues that are raised throughout the duration of this project and to look beyond budgets and see the bigger picture; these young people are our future and we owe them every chance of recovery we can afford.

Carer Submission 1:

My daughter is now 23 and in the recovery stages from anorexia. She was first diagnosed in 2004 just as she reached that special age of 16. We believe it first started for her at around 13.

Between 2004 & early 2010 she has had; 7 admissions to Hollywood clinic, the first in mid 2004 almost at feeding tube stage, the last in 2010, three separate programs at the Centre for Clinical Interventions, 2 years (late 2008 to early 2010) seeing a clinical psychologist as she ran out of session time at CCI.

In early 2010 things unravelled with a return to extremely restrictive eating and personal life disruption. It would appear the unravelling had started around 3/4 of the way through 2009. The first half of 2010 was a really difficult time for our daughter & our family. Her treating psychologist was not addressing/treating my daughter as a person with an eating disorder but a person with personal issues & relationship difficulties.

Fortunately in mid 2010 we found a person who is an eating disorders educator. This person had her own extreme experience working to save her daughter from the grip of extreme anorexia, you may know the story of Bronte Cullis & her parents Graham Cullis & Jan Clarke. At the end of July, my Wife, Daughter & I travelled to Melbourne for our first Eating Disorder education sessions with Jan Clarke. During our 10 day stay in Melbourne we (we = Daughter, Mother & Father) saw Jan for seven separate sessions with each session lasting around 5 hours. These were not treatment sessions they were Education Sessions. We as parents were given an education about an Eating Disorder its; How What Why When Where for parents, while at the same time our daughter recieved the same education from a perspective of living an ed experience. These education sessions proved to be so benefitial and worthwile. For the ***first time*** in six years we as **""Parents""** were allowed to & **required** (Jan agreed to meet our daughter on the proviso the we also met with Jan) to participate as ""Parents"" to learn about our daughter's experience with the eating disorder & most of all we learnt the; Parents do's, dont's & do nothings of an eating disorder & recovery from it and our daughter learnt the same from a living experience view point.

After our first education sessions with Jan in Melbourne we returned home to Perth with a new perspective of eating dissorders & an educated hope for our daughter's recovery and good idea of what our role was to assist & support that recovery. Between August 2010 & March 2011 we flew Jan from Melbourne to see us at our home 6 times. On these trips to Perth Jan would spend two or three days in Perth seeing us for up to 5 or 6 hours each day. Jan has also been available via e-mail, phone & text. Luckily Jan's sessions are not expensive and she took special deal flights.

The education that we as Parents & our Daughter have recieved from Jan has enable a significant change to occur for our Daughter & our family. In the 21 months since our visit to Melbourne and the start of our eating disorder education our Daughter has travelled a long way on the path & journey of recovery. Her life is now significantly less driven by anxiety, self doubt & strict control of food & body. Our Daughter found a dietition that specialises in eating disorders who has now through contact with our daughter developed a rapour with Jan Clarke.

Fortunately for us we found Jan Clarke and her way of helping those experiencing an eating disorder & their families I only wish that we had been able to be given this education at the time our daughter was first diagnosed then so much of the lived experince over the past 9 years would not have occurred and my daughter's recovery acheived so much earlier in her teenage years.

Having experinced the treatment process & method applied to our Daughter at Hollywood Clinic, Centre for Clinical Intervention & her treating Psychologist I am firmly of the belief & conviction that ""Medical Specialist/Professional"" ***only*** treatment has one important area & stake holder left out. It leaves out "EATING DISORDER EDUCATION" and leaves out Parent and Family participation. This is even more so when the living experince person turns 18, here the Australian Privacy rules step in and isolate & lock out a most import support group ""PARENTS"" as the system prevents & inhibits the treatment professionals engaging in & with the ""Parents"'. Especially if the parent is/has been significantly traumatised by the eating disorder and is in a anxiety/disstressed type frame of mind and state. In these situations the anxious/distressed parent can be percieved by the treatment professionals as a problem/difficult/agressive/bad parent that must be blocked out/prevented from participation/involvement instead of being seen as a ***traumatised victim of the eating dissorder***. These traumatised victims (Parents, family, Carers) ***""""need help & education""""""!!!!!*** from treatment professionals not isolation, abandonment & worst of all in some cases punishment.

A well developed & holistic program that educates & supports parents, family & carers is one that I believe will help tremendously. Unfortunately I feel there are situations where the patient/treatment professional only/exclusive method/approach has not succeded and in some cases that I know of personally a life has been lost that could have had a different result.

Carer Submission 2:

When my daughter was an inpatient for an eating disorder on a general adolescent ward I found that there was a lack of understanding of the nursing staff of the treatment of eating disorders. I felt that the eating disorder team and the nursing staff on the ward were very disconnected from each other by the hospital protocols. Although some respect was shown to me as primary carer on the ward in general I was, intentionally or unintentionally, patronised by the staff and felt a lack of connection between them and myself. The staff were sometimes kind and sometimes openly hostile and dismissive of both myself and my daughter. I accept that I was in shock and some of my perceptions could have been a little skewed by that, however the dismissive attitude was real.

I found the staff on the psychiatric ward to be more accepting of the condition and empathetic to myself and my daughter. Sadly the strict restrictions of the psychiatric ward re socialisation made me feel she was becoming more of an outsider by the day.

I found the eating disorders team very supportive and helpful during my daughter's transition. I felt that there was the potential for my daughter to be abandoned and this was very frightening. The fact that there was little out there to turn to was extremely frustrating and I feel lucky that the eating disorders team guided my daughter to an excellent gastroenterologist and psychiatrist. During that time and now we are blessed with a wonderful psychologist.

Obviously on a 16-25 years eating disorders unit would be treating the cause of the eating disorder. From a carer's perspective I would like to see a carer mentor/advocate as a component of any group treating a particular patient. I feel the parent/carer has a knowledge of the patient that is just as important as the knowledge the various practitioners have in how to treat and promote recovery from eating disorders. I realise that every patient and every carer are different but I fell sure it would be possible to find a system that allows the parent/carer more input. I also felt I needed more direction on how to help my daughter from someone I trusted. Stress is a big factor for a carer and often those directions need to be repeated or even put in writing for the carer to refer back to.

Another aspect of an eating disorder is the loss of social skills and I think therapies to replace them are very important. Education can be tricky but I feel it is important to keep someone with an eating disorder learning, to keep that person wanting to learn, this would be an example of a good area for the parent carer mentor to support the parent.

For the carer to understand food and to understand how the mechanics of food and an eating order patient work is important. Our family uses meals as a basis for celebration and communication, when my daughter rejected food we lost one of our most important ways of relating to her, we felt as if we no longer spoke the same language. We all needed a translation of how to circumvent this and still feel connected. 8 years on and we still have not solved this quandary.

Community Submission 1: Bridges

Many thanks for the opportunity to comment regarding your development of a youth inpatient service. We at Bridges are very pleased to hear of this proposal as we are extremely concerned for young people and adults over the age of 16, with respect to access to inpatient care. We are aware of numerous situations where people are turned away from public medical and psychiatric hospitals, and for some people in private sector we are aware of their frustration about the lack of choice/options for inpatient care. We are also aware for those people who are admitted, they often find themselves frightened and vulnerable in inpatient settings, which cater to a wide array of psychiatric patients, often experiencing psychosis and behavioural disorders, frequently men. These environments don't meet the needs of often young, thin, medically compromised individuals, typically female. Many people also report experiencing these admissions as punitive due to anxiety and a lack of specialist skill in the staff. We would also like to see the needs of boys and men attended to, as well as the needs of fathers. We would like you to consider gender in the design of the inpatient unit to make it accessible to male sufferers, and consider when providing family support, the specific needs of fathers.

Bridges would support the development of a dedicated public inpatient unit for young people, separate from children and adolescents, and separate from adults with chronic eating disorders. We would suggest this unit cater to a person's medical and psychiatric needs, as well as emotional, social and educational needs. The attitude and skill of staff is crucial, with the capacity to provide kind and firm boundaries, and to really attend to the person as an individual. Adoption of ideas from youth friendly clinical practice are recommended, with attention to non-clinical type environments and staff attitudes. The family's needs are also important and may include needs for support, information, skills or family therapy. We would recommend that the unit provides a range of therapies and have close links to outpatient services. To prevent patients being lost to treatment after discharge an assertive case management model is recommended. A unit that caters to step-down approaches, with view to development of day hospital would be most successful, with a community outreach arm to facilitate discharge and engagement with outpatient care. Inpatient units can have difficult peer dynamics and we would recommend that in addition to staff support, a peer support model is included, that is the provision of hope and support by people who have recovered from the illness, with adequate training and support. This could be achieved by inclusion of Bridges or Body Esteem in the planning stages, and allocating financial resource towards consumer participation. Peer support in this area is highly specialized and programs such as the Body Esteem Program have a high degree of skill and knowledge in this area that could be utilized.

Whilst we are delighted to hear of the development of an inpatient unit, we are also aware that in some ways this is providing the ambulance at the bottom of the cliff. This is of course important, as it saves lives and provides intensive treatment for the individuals with eating disorders and associated severe medical and psychiatric compromise. However, we would also strongly recommend that your long term plan address the dire need in the community for people with mild to moderate eating disorders, for example by funding and developing community services such as ourselves at Bridges, to provide information, referral and support, as well as boosting capacity of outpatient services such as CCI and the development of a wider

array of treatment options in the outpatient and community sector, preferably with strong links to the inpatient/day-patient team. We are aware of very long wait lists at CCI as well as frustration by consumers about the lack of choice over treatment model. This service needs expansion, in addition to other options becoming available in other community health settings. A case management model is important for reluctant sufferers with complex needs.

Something that we are concerned about at Bridges is the inclusion of parents, carer's and partners in the treatment process. Even with youth and adults, families and significant others provide a majority of care and they can play a strong role in recovery or in perpetuating the illness. We would suggest that parent education and skills training is embedded at every level of care, including the inpatient setting, Individuals will be vulnerable to relapse and readmission, if their support systems are not well trained and supported on discharge.

Thank you very much for consulting with us on this project. We would be very willing to help and support any progress towards the goal of improving services for eating disorders in WA.

Regards

Julie McCormack

President

Bridges

Community Submission 2: Body Esteem

Re: Submission for Project Initiation Proposal

Given our resources and the scope of our program, I did not address the criteria that focuses on the type of inpatient care required. I have however provided some anecdotal evidence that may be useful in supporting the need for additional in-patient care for adolescents aged 16-25, focusing primarily on the 16-18yr gap.

From the perspective of the Body Esteem Program, we are aware of a significant gap in service for women aged 16-18yrs, who are suffering from an eating disorder. Specifically if the family does not have Private Health Cover, there are currently very few treatment options available to them. I assume that you know about our service, the Body Esteem Program only accepts women who are 18yrs and over, and it is not really a treatment option in itself but rather a support process for additional treatments and therapies. However, we are currently applying for funds to create a Clinical Position on our team in order to better address the needs of women under 18yrs, who we believe are falling through the gap. PMH does a commendable job caring for the Adolescents that fit their current criteria. It would be a huge relief to see them resourced to treat girls over 16 in the near future.

Anecdotally, I have recently taken several phone calls from very distressed parents who are seeking help for their daughters. I advise them to write to local MPs etc but the general response is that they are so exhausted from trying to find adequate help for their child that they have no time or energy left to lobby their cause. Some of the experiences include:

-A woman who had a 16yr old daughter who was so unwell she was having seizures due to her purging activities. The mother had taken her daughter to the Emergency Ward of a local hospital and had her health stabilized but she was released after 24 hours. With no private health cover, and no specialized public beds in Perth for an adolescent of this age, the woman was preparing to repeat this scenario an indefinite number of times.

-Another woman who was in tears on the phone as I told her that there was nothing our Program could offer, as she said she had phoned every public hospital seeking help and had been completely unsuccessful in finding anything for her 16yr old daughter.

-A 16 year old girl with Bulimia who contacted me and disclosed that she was regularly self-harming and had twice attempted suicide through overdose. Given that her complications and age put her outside of the scope of this program, I could only urge her to seek help from Headspace and CCI.

-A father who called me because one of his daughter's had gained a lot of support from the Body Esteem Program a year or two ago, and now his younger daughter has an eating disorder as well. She had been admitted to Hollywood Clinic but for some reason, found it very distressing, so he was wondering what other options for Inpatient Treatment were available to her. I had to tell him there were none in Perth.

-Mums and Dads who attend our Parent Program to better understand how they can support their child through their eating disorder but who have to accept that their child cannot access support from our program for another year or two. Generally during this time their child will go in and out of Hollywood Clinic to have weight restored, if the family can afford it, or will be on the waitlist for CCI for some time or may fly interstate for treatment, or access whatever kind of alternative support the individual family might find for them (sometimes the psychiatric unit of the local public hospital)

These are some examples of the recent challenges faced by our program when trying to provide adequate referral for people in desperate situations. As an NGO, our resources are limited to the self-help groups we facilitate and we often find that we have very little to offer someone who does not fit our criteria or who is too young or unwell to access our program. Having more public, in-patient, specialised care to direct those enquiries towards, would reduce the challenges faced by our team and greatly assist service provision. We are happy to discuss this further as the proposal progresses.

Kind Regards

Kathy Logie
Program Coordinator