

# Future Directions for Eating Disorders Services in New Zealand

Final Draft

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## Scope

This document, “Future Directions for Eating Disorders Services in New Zealand”, applies to all of the eating disorders service settings in the New Zealand health and disability sector, including:

- primary and preventative settings
- public and private hospitals
- inpatient and outpatient services
- District Health Board (DHB) provider arm mental health services
- community and residential mental health services.

Decisions about the level of funding available for and the provision of eating disorders services within respective districts and regions are the responsibility of individual DHBs. DHBs have responsibility for prioritising health and disability services for their populations.

The Ministry of Health anticipates that DHBs will use this document, both collectively and individually, to help guide improvements in their provision of eating disorders services. Although professionals who are involved in the provision of eating disorders services are expected to take the contents of this document into consideration, the document does not provide clinical guidelines or over-ride their individual responsibility to make decisions that are appropriate to the circumstances of the individual service user, in consultation with the service user and their family/whānau.

## Executive Summary

There is a need to build and broaden the range and effectiveness of services and supports that are funded for people who are affected by eating disorders in New Zealand. Currently, the greatest gaps exist in service provision for children and young people and Māori and Pacific peoples. There are also significant regional differences in access to eating disorders services.

This document emphasises a need for access to integrated eating disorders services:

- that provide seamless service delivery, easy transitions between services and continuity of care
- that allow a wider range of choices and approaches to care
- where service users can expect active participation in the planning of their own recovery and have the opportunity for leadership across services.

This document proposes actions for addressing gaps in service provision and building an integrated eating disorders sector. Key areas for action include:

- increasing the number and range of available services
- establishing two tertiary eating disorders centres for specialist care
- supporting seamless service delivery, easy transitions between services and continuity of care through:
  - providing a designated care co-ordinator for each service user
  - providing a designated eating disorder liaison person in each DHB, with a specific interest in eating disorders, who will:
    - be a key linkage between the two specialist tertiary eating disorders centres and their DHB
    - assist with supervision, training, advice, and referrals to medical and psychiatric settings
    - offer advice to practitioners dealing with service users at a local level
  - enabling clear communication between the two specialist tertiary eating disorders centres and eating disorders staff in local services
- building a workforce in primary, secondary and tertiary services with:
  - the skills and experience to deliver effective services to people with eating disorders
  - a culture that promotes service user participation and leadership
  - a culture that involves family/whānau in treatment and recovery.

This document should be seen as being complementary to the Eating Disorders Service Specification in the Nationwide Service Framework Library, which will be jointly developed by DHBs and the Ministry of Health.

## Background

As a result of evident concern about the provision of services for people with eating disorders in New Zealand, the Ministry of Health (the Ministry) visited each of the eating disorders services in New Zealand and the privately funded Ashburn Clinic at the end of 2004.

The Ministry then began a process of reviewing eating disorders services. In particular, the Ministry reviewed what eating disorders services provide, and identified where gaps in service provision exist. The Ministry consulted experts in the field and identified international evidence and best practice guidelines. It also ran a national focus group, including representatives from New Zealand's eating disorders specialist services as well as service user representatives.

In May 2006, the Ministry released "National Framework for Eating Disorder Services, a consultation document". The paper outlined how services might be delivered at local, regional and national levels. Detailed submissions were received on that document.

In March 2007, representatives from the eating disorders sector met, and general consensus was reached on the need for:

- two "centres of excellence" in New Zealand (incorporating national, regional, and local services)
- collaborative eating disorders services with clear linkages between all service levels.

In June 2007, the Ministry of Health provided the wider eating disorder sector with the draft "Future Directions for the Care, Management, Support and Treatment for Service Users with Eating Disorders in New Zealand" document for feedback. This final draft incorporates the feedback that was received. Feedback received on this final draft will inform the final document.

## **Section I: Current Eating Disorders Services in New Zealand**

### **1.1 Definition of an Eating Disorder**

The term 'eating disorder' encompasses a range of conditions that have overlapping medical and psychiatric symptoms. These conditions are best thought of as psychological disorders with high levels of complicating psychiatric and medical co-morbidity (Gelder et al 2000; Buckett 2002).

The term "eating disorder" is commonly used to encompass a range of disorders with wide degrees of severity and duration, some of which may not reach the criteria of an "eating disorder" as defined by the American Psychiatric Association's (2000) DSM-IV-TR.<sup>1</sup> Eating disorders include anorexia nervosa (anorexia), bulimia nervosa (bulimia) and Eating Disorders Not Otherwise Specified (EDNOS). Eating disorders have high risks of acute and chronic complications that can be life-threatening and/or life-long.

People experiencing an eating disorder may hold a disturbed perception of their body size and shape. Generally, people experiencing an eating disorder will attempt to control their weight and appearance through excessive dieting, exercising, and/or purging.

Mortality rates for eating disorders are high. Herzog (2000) reported that the suicide rate of women with an eating disorder was 58 times greater than it was for women without an eating disorder. Each year, one out of every 100 people with anorexia will die (Mental Health Foundation 2002), usually from the complications of starvation or due to suicide.

A more detailed description of eating disorders is contained in Appendix 1 of this document.

### **1.2 Service User Expectations of Care**

In 2006, Hutt Valley DHB undertook a survey of current and recently discharged eating disorders service users to understand their experiences of interacting with eating disorders services (Thompson 2006). These service users had been involved with general and/or specialist services, including day and/or residential programmes. The findings, while specific to Hutt Valley DHB, provided an insight into what service users valued from an eating disorder service; these were (in descending order of importance):

- maintaining a sense of autonomy over their lives
- respect
- confidentiality
- anonymity
- the need for a supportive and empathetic atmosphere
- being recognised and treated as an individual.

Participants who had previously experienced negative stereotypes and attitudes recalled feelings of anxiety, fear and apprehension when approaching an eating disorders service for the first time.

Those surveyed favoured staff with personal and professional experience with eating disorders over specific qualifications. In particular, the involvement of former service users in

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<sup>1</sup> The DSM-IV-TR is the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders; "IV" denotes Fourth Edition and "TR" denotes Text Revision.

treatment teams was held in high regard.

### 1.3 The current environment in New Zealand

#### 1.3.1 Access/range and number of services

The Mental Health Commission's *Blueprint* (1998) recommended a considerable expansion of programmes to treat people with eating disorders.<sup>2</sup>

**Table 1: A summary of the resource guidelines by age group**

Regional Specialist Services		1998 Resource Levels*	Resource guideline per 100,000 total population*	Resource guideline: total NZ population**	Resource guideline per 100,000 people by age group*			
					0-14	15-19	20-64	65+
Eating disorders – community teams	FTEs	15.4	2.40	96		0.40	2.00	
Eating disorders	Beds or 'care packages'	10.0	0.50	20		0.10	0.40	

\* Source: Mental Health Commission (1998, p. 102)

\*\* Based on a population of 4,000,000. The 2006 Census recorded New Zealand's population as being 4,143,282.

In 2007, the Mental Health Commission undertook a stocktake of mental health services, including eating disorders. The stocktake found that there are considerable access issues for service users with eating disorders. The Commission reported a lack of beds and long waiting lists. The Commission also reported that criteria used by current services could mean that people experiencing the early stages of an eating disorder were being excluded.

Some specific issues identified by stakeholders included:

- difficulties in providing inpatient treatment in paediatric wards for children under 14 years of age (and a shortage of specialist eating disorder capacity in child and adolescent mental health services (CAMHS))
- unavailability of day programmes in some DHBs (or insufficient in number where they are available)
- unavailability of specialist inpatient beds in some DHBs (or insufficient in number where they are available)
- a nationwide shortage of residential inpatient beds
- a nationwide shortage of beds for comprehensive medical/psychological care
- a shortage of appropriate support and/or accommodation for service users transitioning from one service setting to another (especially in relation to the shortage of inpatient and residential beds)
- GPs, some of whom are not confident in this area, having to manage a service user's immediate medical and psychiatric risks
- a shortage of family therapy and support.

<sup>2</sup> While the *Blueprint* (Mental Health Commission 1998) provides guidance and direction for the mental health service capacity that is needed to meet the needs of New Zealand's population, there is some recognition that the service provision environment has developed and altered since its 1998 publication. In addition, the *Blueprint's* age-group resource guidelines are widely considered to be at odds with the actual age of onset for many eating disorders.

The table below indicates some of the current gaps in service provision.

District Health Board (DHB)	Main provider	Service location	Specialist inpatient unit	Residential unit	Day programme	Outpatient service	Regional services
<b>Northern Region</b> Waitemata Auckland Counties Manukau Northland*	Auckland DHB	Greenlane Hospital, Auckland	No	No	Yes	Yes	Yes
<b>Midland Region**</b> Waikato Bay of Plenty Lakes Tairāwhiti Taranaki	None	No	No	No	No	No	No
<b>Central Region</b> Capital & Coast Hutt Valley Wairarapa MidCentral Whanganui Hawke's Bay	Hutt Valley and Capital & Coast DHBs	Wellington Hospital Hutt Hospital	No	Yes	Yes	Yes	Yes
<b>Southern Region</b> Canterbury Nelson Marlborough West Coast South Canterbury Otago*** Southland	Canterbury DHB	Princess Margaret Hospital, Christchurch	Yes	No	No	Yes	Yes

\* Northland DHB only receives supervision and consultation from Auckland Eating Disorder Services.

\*\* Midland region DHBs receive supervision and consultation from Auckland Eating Disorder Services.

\*\*\* There is an agreement between the Otago DHB and the Canterbury DHB regional service provider.

A more comprehensive description of the eating disorders services currently available in New Zealand, including community services, is contained in Appendix 2 of this document.

#### 1.3.4. Workforce

The following workforce issues have been identified by key stakeholders:

- a shortage of eating disorders knowledge and expertise in:
  - primary care services
  - child and adolescent mental health services
  - adult mental health services
  - paediatric wards

- difficulties in establishing adequate and appropriately mixed multi-disciplinary teams (and a lack of specialist eating disorder supervision of such teams)
- a shortage of training and professional development opportunities
- low staff confidence in dealing with people with eating disorders of all ages, but particularly young people
- the number of staff who rarely work with eating disorder service users, but are called on when no other experienced professionals are available
- challenges to diagnostic capability and accuracy – there is overseas evidence that service users who go on to develop very serious eating disorders are likely to have visited their GP or other generic health services on a number of occasions without their disorder being reported by the service user or detected by the practitioners (National Public Health Services for Wales 2006).

The high numbers of casual staff and the lack of knowledge and confidence in eating disorders may lead to counter-therapeutic practice and, therefore, poor outcomes.

#### 1.3.5 Variability in services

New Zealand's service variability echoes a similar situation in the United Kingdom. The National Public Health Services for Wales (2006) reported that service variability reflects both service users' ambivalence to treatment and the uneven provision of generic and specialist eating disorders services.

Some areas to be addressed include:

- differences in service options across New Zealand
- differences in the way that services are delivered
- differences in length of stay for adolescents of similar severity (perhaps because of difficulty in accessing inpatient beds when needed)
- differences between treatment in paediatric wards (which tend to have brief admissions lasting from hours to weeks) and psychiatric wards (which tend to have long admissions lasting from days to weeks)

#### 1.3.4. Co-ordination

The Mental Health Commission (2007) found a lack of co-ordination between different mental health services for people with eating disorders. This finding is echoed strongly by people consulted in the development of this document.

#### 1.3.5 Inequalities

*Te Rau Hinengaro: The New Zealand Mental Health Survey* found that Māori and Pacific peoples are less likely to make contact with health services for mental health reasons, indicating barriers to access that are not explained by youthfulness or socioeconomic disadvantage. *Te Rau Hinengaro* also identified inequalities amongst rates of prevalence for eating disorders in the overall population and rates of prevalence in Māori and Pacific populations (Oakley Browne et al 2006).

#### 1.3.6 Lack of clear clinical pathways and guidelines

There is an absence in many areas of clearly defined client pathways, which limits access to early and effective intervention.

### 1.3.7 Complexity of issues

Eating disorders can be very time-consuming and complex for service providers, due to medical complications and the need for extensive family/whānau involvement at all stages of treatment.

### 1.3.8 Responsiveness to families/whānau

The provision of family-based interventions is inconsistent. When people with eating disorders are being treated at a regional facility, families/whānau are often unable to have on-going input due to difficulties associated with the distance between their home and the regional facility.

## **Section II: Future of Eating Disorders Services in New Zealand**

### **2.1 Principles for improving eating disorders services in New Zealand**

The following principles should apply to improving eating disorders services in New Zealand.

- The range and choice of services will be built and broadened, and gaps in services addressed.
- Services will be provided by a multi-disciplinary team in partnership with the service user and their family/whānau.
- Services will be built around those elements that have been shown to be valued by service users: autonomy; respect; confidentiality; anonymity; the need for a supportive and empathetic atmosphere; being recognised and treated as an individual; and the involvement of former service users in treatment teams.
- Quality services are built on:
  - responsiveness
  - accessibility
  - a commitment to recovery
  - research and evaluation
  - evidence-based best practice
  - access to a wide range of learning opportunities that will inform innovation.
- Services will be well co-ordinated and integrated – with seamless service delivery, easy transitions between services and continuity of care.
- A range of community and local services will sit alongside (and be supported by) secondary and tertiary services.
- Early intervention is important.
- Services will be provided in a safe environment.
- Service provision needs to take account of age and gender and be culturally appropriate.
- The developmental needs of children and adolescents will be recognised, and services will, wherever possible, be separate from the provision of care for adult service users.<sup>3</sup>
- Eating disorders services will be responsive to Māori, and ensure the participation of Māori in the planning of services for Māori, including designing services appropriate to the needs of Māori. This is supported by key Government strategies to advance Māori

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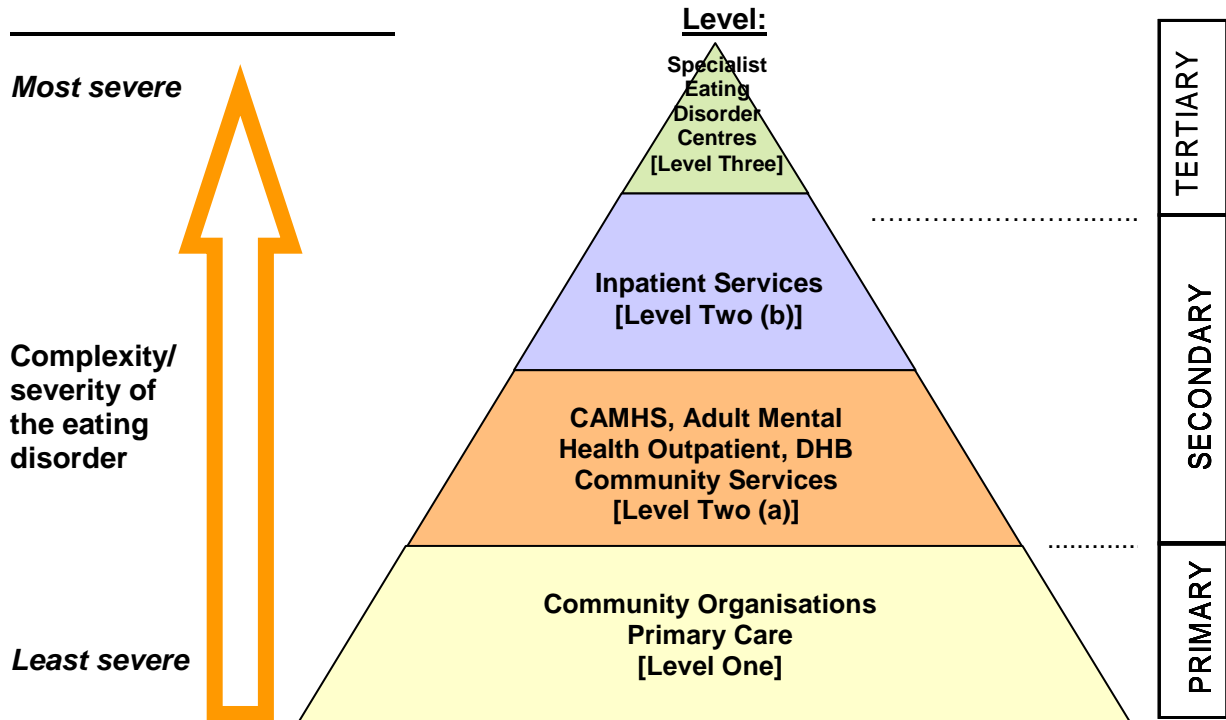
<sup>3</sup> In line with Article 37(c) of the United Nations Convention on the Rights of the Child (UNCROC) that requires "every child [aged 17 and below] deprived of liberty be separated from adults unless it is considered to be in the child's best interest not to do so".

health and affirm Māori approaches to health, such as *He Korowai Oranga: The Māori Health Strategy* (Minister of Health and Associate Minister of Health 2002).

## 2.2 Organisation and Management

This section describes the proposed model for eating disorders services in New Zealand.<sup>4</sup> Figure One outlines what eating disorders services need to be available and how services need to connect with each other.

**Figure One: Levels of eating disorders services**



While each level is described in isolation, movement through the levels can be non-linear. A service user may access different services, in different ways, at different times, or concurrently, across or between the various levels, according to the aetiology of their illness. Likewise, service providers may operate across several levels and in different professional roles.

Whilst eating disorders services may vary in their individual management structures, all eating disorders services need to have a collaborative and consultative approach that involves funders and providers working across primary/community, secondary and tertiary services to ensure that services are provided in a manner that is effective, service user-centred, and culturally appropriate. Services need to enable service users to move through eating disorders services in a seamless fashion.

A commitment to a collaborative approach, facilitated by the proposed specialist tertiary eating disorders centres, will improve the provision of high-quality and clinically effective services, regardless of geographical location.

<sup>4</sup> The model has adapted from the National Health Service Health Advisory Service report "Together We Stand" (1995).

### *Which service setting?*

A comprehensive/holistic assessment of each service user is important for deciding the most appropriate setting for the service user to receive advice, care, support, management and treatment. To avoid the disorder becoming chronic, an eating disorder needs to be recognised early, and intervention implemented as soon as possible following the onset of symptoms. While the service user's weight, rate of weight loss, cardiac function, and metabolic status are the most important physical considerations for determining the appropriate treatment approach (American Psychiatric Association Steering Committee on Practice Guidelines 2006), each individual's overall mental wellbeing should also be considered.

## **2.3 DESCRIPTION OF SERVICES IN THE PROPOSED MODEL**

Two important components of the proposed eating disorders model that are designed to support seamless service delivery, easy transitions between services and continuity of care are:

- an "eating disorder liaison person" in each DHB
- care co-ordinators for all service users with eating disorders.

### *Eating disorders liaison person*

Each DHB should have a suitably qualified eating disorders liaison person. This person is likely to be based in the secondary (Level Two) service of a DHB and will be responsible for the eating disorders service within that DHB. The liaison person would be available to provide advice to other staff dealing with eating disorders within their DHB area, including Level One services within the community. The liaison person would:

- be responsible for multi-disciplinary leadership, clinical auditing, and service accreditation
- assist with supervision, training, advice and referrals to medical and psychiatric settings
- be a key linkage between the DHB and the two specialist tertiary eating disorders centres.

### *Care Co-ordinators*

Each service user should have a designated 'care co-ordinator' who is accessible to the service user, the multi-disciplinary team and general medical staff. The 'care co-ordinator' will ensure treatment planning is implemented, monitored and updated.

### **2.3.1 LEVEL ONE: PRIMARY AND COMMUNITY SERVICES**

**Description:** Level One services are community-based primary health eating disorders services staffed by a mix of specialist and non-specialist health professionals, and volunteers and workers who routinely come into contact with people with eating disorders. All staff in these services should have the skills and experience to recognise people who may have an eating disorder (or who show early warning signs and/or risk factors) and provide support, information and counselling services. Some Level One services will provide health promotion activities such as school programmes.

<b>Service users most likely to need Level One services</b>	<b>Probable interventions and activities</b>	<b>Providers</b>	<b>Referral and access arrangements</b>
<ul style="list-style-type: none"> <li>• Service users with or without a diagnosed eating disorder who present with patterns of concern/risk</li> <li>• Service users with low intensity and chronic eating disorders that need to be monitored</li> <li>• Family/whānau members requiring information and support</li> </ul>	<ul style="list-style-type: none"> <li>• Initial identification and assessment</li> <li>• Support of service users and their family/whānau including advice, education, monitoring, counselling, brief interventions, self-help promotion, and medical treatment and management</li> <li>• Focus on quality of life, maintenance of health, social skills, etc</li> <li>• Peer support</li> <li>• Referral for further (specialist) advice or assessment and/or treatment</li> <li>• Referrals to primary mental health services (where available)</li> <li>• Arrangement of access to Care Plus and other available primary care schemes</li> <li>• Support of service users waiting to access a secondary or tertiary service (in collaboration with specialist services)</li> <li>• Long-term monitoring independently or as part of shared care with specialist services</li> <li>• Health promotion in the community including raising awareness</li> </ul>	<ul style="list-style-type: none"> <li>• General Practitioners</li> <li>• PHOs</li> <li>• School/University health or welfare staff including school guidance counsellors</li> <li>• Community and Voluntary Sector Services</li> <li>• Counsellors, psychotherapists</li> <li>• Youth one-stop shops</li> <li>• Rape Crisis</li> <li>• Youthline and Community Alcohol and Other Drug services.</li> <li>• Eating Difficulties Education Network (EDEN)</li> <li>• Eating Disorders Association (NZ) Inc.</li> <li>• Women's Centres</li> <li>• Other NGOs</li> </ul>	<ul style="list-style-type: none"> <li>• Normally direct access by service user or family/whānau (in the case of children and adolescents)</li> <li>• Websites, the white pages, word of mouth, and through recommendations from other NGOs</li> <li>• Referrals from GPs, specialist services, schools, other community health professionals</li> </ul>

### **2.3.2 LEVEL 2: SECONDARY OUTPATIENT AND INPATIENT SERVICES**

#### **Level Two (a): SECONDARY OUTPATIENT UNITS**

**Description:** Level Two (a) services are outpatient services that need to be delivered by experienced and skilled mental health workers with relevant eating disorders competencies to enable service users to be supported by a multi-disciplinary team at home or in outpatient clinics or other community settings.

Staff should be available to provide rapid response services to service users at high risk of medical or psychiatric complications in the community.

<b>Service users most likely to need Secondary Outpatient Services</b>	<b>Probable interventions and activities</b>	<b>Providers</b>	<b>Referral and access arrangements</b>
<ul style="list-style-type: none"> <li>• Service users whose behaviour/condition indicates the possibility of an eating disorder of</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist care and day programmes to address and prevent further deterioration in the service user's presenting</li> </ul>	<p>Outpatient services for people with eating disorders in the following provider arm</p>	<ul style="list-style-type: none"> <li>• Referral from Level One services to outpatient</li> </ul>

<p>sufficient severity to require assessment and/or ongoing intervention</p> <ul style="list-style-type: none"> <li>• Service users for whom the eating disorder illness is not life-threatening</li> <li>• Some service users returning from inpatient treatment</li> </ul>	<p>physical and mental health symptoms</p> <ul style="list-style-type: none"> <li>• Structured interventions and therapy</li> <li>• Intensive clinic and/or home-based day-care or family/whānau interventions</li> <li>• Advice and back-up to mental health crisis services on a 24-hour basis</li> <li>• Structured relapse prevention planning</li> <li>• Intensive community-based outreach</li> <li>• Monitoring and reviewing of service users receiving residential care</li> <li>• Partnership with the service user and family/whānau, and key people in the service user's local community, including schools, and peer group</li> <li>• Risk assessment, including managing an escalation in symptoms, or a medical or psychiatric crisis</li> <li>• Consulting with inpatient services and Level Three centres for advice on management of service users</li> <li>• Referrals to Level Three centres</li> <li>• Primary Care Liaison to enable the delivery of advice, training and support to colleagues in Level One services and to ensure effective co-ordination of service provision</li> <li>• Advice to, and collaboration with, primary care about other support services and treatments/interventions for service users whose eating difficulty does not meet service entry criteria to generalist services</li> </ul>	<p>services:</p> <ul style="list-style-type: none"> <li>• Child and Adolescent Mental Health Services (CAMHS)</li> <li>• Adult Mental Health Outpatient Services</li> <li>• Multi-disciplinary Community Mental Health Teams</li> <li>• Paediatric Outpatient Services</li> <li>• Pacific Mental Health Services</li> <li>• Māori Mental Health Services</li> </ul> <p>DHBs may also fund outpatient services from community eating disorder counselling services as part of level 2 services</p>	<p>mental health teams</p> <ul style="list-style-type: none"> <li>• Referral from paediatric services or physicians</li> <li>• Direct access</li> </ul>
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### **Level Two (b): SECONDARY INPATIENT SERVICES**

**Description:** Level Two (b) services are secondary generic specialist services in psychiatric units, paediatric wards or general medical wards. Eating disorders inpatient services should be delivered in psychiatric units unless this is not appropriate due to the acute medical condition of the service user.

Staff in inpatient services need to have specific assessment and intervention skills and clinical experience in managing people with eating disorders.

In general, Level Two (b) inpatient services should be the “gatekeepers” for referrals to the

specialist tertiary eating disorders centres. However, there may cases where an acutely unwell person is assessed by their GP as being in immediate need of admission to a specialist tertiary centre (although it may still be necessary for Level Two (b) staff to assist in providing immediate treatment and support for the transition to one of the specialist tertiary eating disorders centres).

Service users most likely to need Level Two (b) services	Probable interventions and activities	Providers	Referral and access arrangements
<ul style="list-style-type: none"> <li>• Service users where adequate care cannot be safely provided in community settings</li> <li>• Service users who need re-feeding</li> </ul>	<ul style="list-style-type: none"> <li>• General mental health assessment</li> <li>• Agreed treatment plan</li> <li>• Interventions and therapy</li> <li>• Relapse prevention and monitoring</li> <li>• Provision of respite care</li> <li>• Provision of medical intervention when required</li> <li>• Provision of appropriate psychiatric services for service users in medical wards using a multi-disciplinary approach</li> <li>• Managing transition between teams and levels</li> <li>• Specialist liaison and consultation with other services (including paediatric services, CAMHS and adult mental health services)</li> <li>• Collaboration with Level Three centres including training, support and consultation</li> <li>• Referrals to Level Three Centres</li> <li>• Primary Care Liaison to allow the delivery of advice, training and support to colleagues in Level One services and to ensure effective co-ordination of service provision</li> <li>• Partnership with the service user and family/whānau, and key people in the service user's local community, including schools, and peer group</li> </ul>	<p>Inpatient services for people with eating disorders in the following provider arm services:</p> <ul style="list-style-type: none"> <li>• Child and Adolescent Mental Health inpatient unit</li> <li>• Adult Mental Health inpatient unit</li> <li>• Māori Mental Health inpatient unit</li> <li>• Medical Inpatient Units</li> <li>• Paediatric Inpatient units</li> </ul> <p>Private providers</p>	<ul style="list-style-type: none"> <li>• Referrals from outpatient mental health teams</li> <li>• Referrals from Level One provider or paediatric services/physicians in an emergency</li> </ul>

### 2.3.3 LEVEL THREE: TERTIARY SERVICES – Specialist Eating Disorder Centres

**Description:** These are services with designated eating disorders beds providing highly specialised eating disorders inpatient services for the most severely ill service users. Level Three specialist tertiary eating disorders centres will enable close medical and psychiatric treatment and monitoring in a contained and structured setting by appropriately trained and experienced multi-disciplinary staff.

The location and number of specialist tertiary eating disorders centres will need to be decided collectively by DHBs. However, considering population size and geography, it seems that sufficient resources and expertise exist to support two Level Three centres in

New Zealand. Based upon existing tertiary services, workforce, and facilities, these centres may be best based in Auckland and Christchurch.

The two specialist tertiary eating disorders centres could effectively serve half the New Zealand population each. If one was based in Christchurch, it could cater for the Capital and Coast and Hutt Valley DHB populations as well as the entire South Island population; the proposed Auckland Centre would cater for the rest of the North Island population. The specialist tertiary eating disorders centres may also provide secondary care (for their local DHB or for their wider region). DHBs may wish to consider the numbers of beds recommended in the *Blueprint* (Mental Health Commission 1998) when considering the size of the centres as well as taking into account current service provision needs.

Separating children and adolescents from adults is recommended, although older adolescents may be treated in an adult setting if this is deemed developmentally and clinically appropriate.<sup>5</sup> Arrangements for the nearby accommodation of family/whānau, to facilitate their ongoing involvement in treatment, are also desirable.

Criteria for access to a specialist tertiary eating disorders centre will need to be developed collectively by DHBs. However, criteria to be considered may include:

- service users who have a severe and life-threatening eating disorder condition
- service users who have not responded to Level 2 outpatient or inpatient interventions or who are seen as requiring the expertise or interventions of a specialist tertiary eating disorders centre
- service users with particularly complex needs and/or co-morbid physical health conditions
- service users who have a co-morbid/additional mental illness and/or are considered to be a suicide risk
- service users whose physical condition makes specialised inpatient care essential
- service users with pre-existing medical conditions that are complicated by the eating disorder, which may prolong recovery or effect mortality.

*Co-ordination/collaboration:*

A designated clinical leader with the appropriate clinical background in eating disorders should have responsibility for each Level Three centre, including responsibility for research, auditing, service accreditation, and leadership in the wider eating disorder sector. The clinical leaders of each specialist tertiary eating disorders centre should maintain close collaborative links with the other Level Three centre in addition to close collaborative links with their affiliated DHBs and service providers. Effective, strong linkages between individual DHBs should be maintained predominantly through DHBs' designated liaison persons (as described in the previous section).

<b>Service users most likely to need Level Three services</b>	<b>Probable interventions and activities</b>	<b>Providers</b>	<b>Referral and access arrangements</b>
<ul style="list-style-type: none"> <li>• Service users who have not responded to Level 2 outpatient or inpatient interventions or who are seen as requiring the expertise or interventions of a</li> </ul>	<ul style="list-style-type: none"> <li>• Provision of 24-hour seven-day a week service by designated nursing and other health professionals skilled in the treatment of eating disorders, providing comprehensive and co-ordinated multi-disciplinary</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist Eating Disorder Centres: inpatient services and day care programme services.</li> </ul>	<ul style="list-style-type: none"> <li>• Via Level 2 or in accordance with the Specialist Eating Disorder Centres criteria and/or the Eating Disorder</li> </ul>

<sup>5</sup> With consideration to the requirements of Article 37(c) of the United Nations Convention for the Rights of the Child.

<p>Level Three Centre</p> <ul style="list-style-type: none"> <li>• Service users with particularly complex needs and/or co-morbidity</li> <li>• Service users who have severe and life threatening eating disorder condition(s)</li> <li>• Service users whose physical condition makes specialised inpatient care essential</li> </ul>	<p>care</p> <ul style="list-style-type: none"> <li>• Provision of medical and psychiatric treatment, monitoring, management, support and rehabilitation in a number of settings</li> <li>• Access to dietician services and family therapy</li> <li>• Care, co-ordination, and case management of all admitted service users by eating disorder nurse specialists</li> <li>• Intensive day care services and programs, including meals and meal support</li> <li>• Intensive outpatient consultation</li> <li>• Designated beds for those cases where outpatient care or day-patient care is not sufficient</li> <li>• Nasogastric feeding by appropriately trained staff</li> <li>• Strong links with the DHB of domicile including videoconferencing and other technology to allow local treatment teams to participate in assisting the service user's transitions in their pathway of care</li> <li>• Supporting local clinicians to maintain service users in their own communities – including consultation, case discussions, team meetings, telephone contact and teleconferences, in-house training</li> <li>• Referring service users back to local DHB services for ongoing support supported by comprehensive multi-disciplinary planning prior to discharge, including agreed follow-up and rehabilitation plans</li> </ul>		<p>Service Specification</p>
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Service providers, in consultation with service users, their family/whānau and specialists at the tertiary eating disorder centre, may agree not to transfer some service users who meet the criteria for access to a Level Three centre if it is agreed that it is in their best interests to remain within the local DHB service. In these situations, the secondary service would be able to access specialist support and input from the specialist tertiary eating disorders centre.

Access to Level Three beds should be flexible enough so that if a service user in the northern region needs a bed in a specialist tertiary eating disorder centre, and there is no availability in the proposed Auckland centre, any available beds in the proposed Christchurch centre should be an option, and vice versa.

*Current Ministry of Health Travel and Accommodation Policy*

When a service user is referred for treatment by their publicly funded health or disability

specialist (not a GP) to another publicly funded specialist, the service user may be eligible to claim travel and accommodation assistance under the National Travel Assistance Scheme. The service user's specialist will need to approve accommodation and specialised transport needs, including taxi, mobility taxi, or air travel. When a child is eligible for travel and accommodation assistance, they will always be eligible for assistance towards a support person's costs (Ministry of Health 2007a).

### **Section III: Guidelines for the provision of Eating Disorders Services**

The following section provides guidelines for the provision of eating disorders services in New Zealand. These guidelines are not intended to cover all aspects of eating disorders services. They do, however, reflect some of the priorities identified by key stakeholders in the New Zealand eating disorders sector.

The guidelines below do not cover clinical practice. The National Institute for Clinical Excellence's *Eating Disorders* guidelines (2004) and the Royal Australian and New Zealand College of Psychiatrists (2004) guidelines are useful resources for clinical guidance on how to best treat eating disorders.

#### **3.1 Assessment, Treatment and Management**

- 3.1.1 Where a GP refers a person to an eating disorders service for assessment, the person will receive a comprehensive psychiatric assessment as soon as is practicable.
- 3.1.2 Where possible, each comprehensive assessment will be undertaken by an eating disorders specialist; in the event that an eating disorders diagnostic specialist is not readily accessible, support and assistance should be sought via the DHB's eating disorders liaison person.
- 3.1.3 Each assessment of a service user will include consideration of their physical, psychological and social needs, as well as a comprehensive assessment of risk for self-harm.
- 3.1.4 The care of each service user will be co-ordinated by a "care co-ordinator". The care co-ordinator (or their "cover") will be easily contactable.
- 3.1.5 Treatment planning will be undertaken as soon as is practicable after a service user's diagnosis. The immediate risk to the service user, including risk of suicide, will inform the commencement of treatment.
- 3.1.6 Treatment, discharge and relapse prevention planning will be undertaken by a multi-disciplinary team in partnership with each service user and their family/whānau.
- 3.1.7 Each service user's treatment planning will evolve through regular multi-disciplinary reviews, with involvement and regular input from all members of the multi-disciplinary team. Reviews will be undertaken in active partnership with the service user and their family/whānau. However, whilst consideration will be given to the wishes of the individual and their family/whānau, the medical and mental health needs of the service user will remain paramount.
- 3.1.8 Treatment will evolve and be personalised to each service user in accordance with the stage and acuity of their disorder and any co-morbidities, as well as taking into

account their age and cultural needs. Should a significant deterioration in the wellbeing of a service user occur, a comprehensive review of the service user's treatment planning will be undertaken.

- 3.1.9 Service users and their family/whānau will be made aware of, and have access to, appropriate support groups where they can interact with others who have had similar experiences.
- 3.1.10 Each service user's treatment, discharge and relapse prevention planning will ensure that there are appropriate social support systems/networks in place for service users to rebuild their self-esteem and self-belief, including consideration of accommodation, income, employment and education. Social support mechanisms, along with improving self-functioning, are vital for the long-term recovery from mental health problems such as eating disorders (Raeburn 2000).
- 3.1.11 Each multi-disciplinary team should include, or have provisions for input from, a range of practitioners that includes psychiatrists, psychologists and psychotherapists, dieticians, mental health nurses, occupational therapists and social workers. Other physical health specialists (such as dentists) may need to be consulted for the treatment and management of acute and ongoing physical (and dental) complications. The treatment and management of children and adolescents may require input from school teachers and school counsellors.
- 3.1.12 In treatment settings where staff do not have the training or experience to deal with service users with complex needs, assistance, supervision, and leadership from Level Two or Level Three services will be sought to assist with service users' treatment and/or referral to more appropriate treatment settings. Assistance from Level Two services in other DHBs, or from the two specialist tertiary eating disorders centres, should be sought via the relevant DHB eating disorders liaison person.
- 3.1.13 DHBs will have a comprehensive written policy and procedure for discharges to and/or referrals from:
- other DHBs' services
  - tertiary services
  - social services
  - private settings
  - NGOs
  - schools
  - community and primary services
  - carers
  - support groups.
- 3.1.14 Services will endeavour to provide service users with access to comprehensive work/school re-entry programmes that operate in conjunction with eating disorders day programmes out of the DHB or specialist tertiary eating disorders centre in conjunction with social rehabilitation assessors and/or community support networks.

## **3.2 Additional considerations for Children and Adolescents**

The development of services for children and adolescents is a government priority and is outlined in the Government's Families - Young and Old policy directives. The Minister of Health has prioritised health-wide improvements in child and youth health and wellbeing.

*New Futures* (Ministry of Health 1998) recognised that improving the mental health and wellbeing of children and youth, addressing the range of risk and protective factors, and building resiliency in children and adolescents would require the sustained collaboration of a wide range of organisations in both the wider health and social services sectors.

The priority for child and youth specialist mental health services in *Te Tāhuhu – Improving Mental Health* (Ministry of Health 2005) is to continue to build and broaden the range and choice of services and supports for children and adolescents who are severely affected by mental illness, with an immediate emphasis on increasing the number of services that are funded for children and adolescents.

*New Futures* noted that when working with children and adolescents, their families/whānau are all-important. In particular, the ongoing effect of any mental health problem needs to be minimised, and the developmental milestones (physical, social, intellectual, educational, cultural, and emotional) appropriate to that child or adolescent need to be achieved.

Eating disorders in children and adolescents differ from those in adults due to developmental and cognitive differences. The Society for Adolescent Medicine (2003) recommended that the threshold for intervention in adolescents be lower than in adults because of the potentially irreversible effects of an eating disorder on the physical and emotional development of adolescents, the high mortality, and the evidence suggesting improved outcomes with early treatment.

The American Psychiatric Association Steering Committee on Practice Guidelines (2006) reported that it is well established that younger service users who receive prompt, appropriate and intensive intervention have a much better full recovery rate. A full and early course of treatment is cost-effective for treating eating disorders. Halmi (2000) reported that readmissions of service users increased steadily as the length of stay in eating disorder units became briefer and the weight at discharge was lower.

The Paediatric Society of New Zealand (2006) asserted that the best service for a child or adolescents with an eating disorder is one that includes:

- early detection and community management
- management by services as close to home as possible with specialist input
- intensive medical stabilisation, where necessary, and nutritional rehabilitation
- family/whānau-based therapeutic programmes
- support of educational needs
- educational and vocational rehabilitation
- smooth transitions between and among services based upon the needs of service users and severity of illness, not service limitations
- access to appropriate psychotherapeutic support at all stages of treatment
- planned transitions to adult care, when required.

Adolescents who excessively restrict food intake, or vomit, purge or binge with or without severe weight loss require treatment even if they do not meet strict criteria for eating disorders (Canadian Paediatric Society 1988).

In addition to the above overall guidelines for eating disorders services, the following specific guidelines apply to eating disorders services for children and adolescents:

- 3.2.1 Where a child or adolescent eating disorders service user is managed and supported in a paediatric or medical setting, oversight of the multi-disciplinary treatment for the eating disorder will be provided by the specialist eating disorders capacity of mental health services.

- 3.2.2 As a general principle, and in line with the United Nations Declaration on the Rights of the Child (UNCROC) and New Zealand government policy, children and adolescents with an eating disorder who require inpatient treatment should be admitted to a child and adolescent mental health unit or paediatric ward.<sup>6</sup>
- 3.2.3 Facilities for the inpatient treatment of children and adolescents with eating disorders should have developmentally appropriate services that are focused on family therapy and behavioural support and management, have access to adequate medical and psychological support, and be able to provide prompt and seamless transitions to other treatment settings (when needed).
- 3.2.4 Whenever possible, treatment services for a child or adolescent with an eating disorder will be provided in a location that is close to their usual place of residence, primarily to minimise dislocation from their family/whānau during treatment, but also to aid re-integration into their family/whānau and social environment during later stages of their treatment. When a child or adolescent requires specialist inpatient treatment due to the acuity of their eating disorder, and appropriate inpatient facilities are not situated within a reasonable proximity of the service user's usual place of residence, service providers will facilitate nearby accommodation of family/whānau.
- 3.2.5 Children and adolescents who excessively restrict food intake, or vomit, purge or binge with or without severe weight loss will be referred for specialist assessment and treatment
- 3.2.6 Children and adolescents who are receiving treatment for an eating disorder will have access to appropriate education, leisure and recreation programmes. Children and adolescents discharged from inpatient treatment will receive intensive outpatient support, which will be facilitated by a multi-disciplinary team providing continuity of care in a comprehensive, co-ordinated and developmentally oriented manner.
- 3.2.7 Education of, and liaison with, school nursing and counselling staff will be recognised as being important and be undertaken in order to provide a safe, accessible space for young people with eating disorders to disclose their behaviour and/or problems.

### **3.3 Additional considerations for families/whānau**

Understanding and improving familial interactions plays an important part in the management of eating disorders.

Family/whānau members, including siblings, should normally be included in the treatment of children and adolescents with eating disorders. This is because family/whānau dynamics can often contribute to, maintain, or even exacerbate the condition. However, family/whānau can also play a crucial role in treatment and recovery. Therapy involving the family/whānau should include educating the family/whānau about the disorder and strengthening the parental subsystem and the roles family/whānau members. Interventions may include sharing information and advice on behavioural management, and facilitating communication (National Institute for Clinical Excellence 2004).

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<sup>6</sup> Admission to adult units can have a negative impact on young people as association with people with more chronic forms of the disorders can lead to new learned illness behaviours and demoralisation.

When a young person is so unwell that inpatient treatment is needed, it is crucial to enable the on-going involvement of family/whānau. A key part of inpatient eating disorder treatment for children and adolescents is the process of re-integration into the family/whānau. It is often quite straightforward to assist the service user in weight restoration in a hospital; a greater challenge may be to help the service user and their family/whānau learn (or re-learn) supportive practices – which could be as simple as eating together.

The following specific guidelines apply to involving service users' family/whānau in their treatment and recovery:

- 3.3.1 Each service user's care co-ordinator will ensure that members of the family/whānau feel heard, and that no-one feels left out, during the service user's ongoing treatment and recovery process.
- 3.3.2 The family/whānau of each service user will be in partnership with, and supported by, eating disorders professionals. Team members will communicate with families/whānau, and with each other about the involvement of family/whānau, on a regular basis.
- 3.3.3 There will be clear and open communication so that families/whānau are well-informed and in a strong position to be supportive of service users in their recovery. However, care must be taken to consider the rights of service users to privacy.
- 3.3.4 Family/whānau, particularly parents, will be educated to support a smoother transition home, and better long-term care and family functioning.
- 3.3.5 Families/whānau of people with eating disorders will have access to psychological support (as well as being informed of support groups).

#### **3.4 Additional considerations for parents and caregivers who experience eating disorders**

When a parent has an eating disorder, their illness can endanger the safety of their children. Having a parent or caregiver with an eating disorder can have a significant developmental impact on children either directly in relation to nutrition and the role of food in the family/whānau, or indirectly in terms of the ability of the parent to acknowledge or attend to the developmental needs of the child.

The following specific guidelines apply when a parent or caregiver is receiving treatment for an eating disorder:

- 3.4.1 A child's safety and welfare are paramount.
- 3.4.2 All service users will receive a comprehensive assessment that includes consideration of the roles they undertake in their everyday lives.
- 3.4.3 Consultation and engagement with the family/whānau of a parent or caregiver experiencing an eating disorder will include consideration of meeting the needs of the child(ren).
- 3.4.4 Where possible, the multi-disciplinary treatment team responsible for a parent or caregiver with an eating disorder will seek and include the active involvement of a relevant health professional or support worker to ensure the needs of the child(ren) are taken into account. The service user's care co-ordinator will have a crucial role

in securing this involvement.

- 3.4.5 When a service user is parent or caregiver, service providers will endeavour to provide appropriate (outpatient and primary) services as close as possible to the service user's usual place of residence. When a parent or caregiver requires specialist inpatient treatment for an eating disorder, service providers will facilitate on-going contact between the service user and their child(ren), including appropriate accommodation arrangements.

### **3.5 Additional considerations in relation to involuntary treatment**

Service users with the most severe eating disorders are often the least likely to seek help and will often refuse treatment, even if their condition is life-threatening.

Where it is deemed clinically appropriate by specialists with the necessary authority, service users, including children and adolescents, may be treated under the Mental Health (Compulsory Assessment and Treatment) Act 1992.

The Mental Health Act is only applied to service users who are of an abnormal state of mind that is to such a degree that they are of serious danger to themselves or others, or are of seriously reduced capacity for self-care. On this basis, the Mental Health Act could be invoked to provide treatment for an eating disorder.

## **Section IV: Workforce Development**

Eating disorders services require expertise in both physical health and psychological health. Effective eating disorders services must have experienced, responsive, aware and supportive staff who demonstrate to the service user that those involved in their care have an understanding of the needs, thoughts, feelings and priorities of the service user (Thompson 2006).

Opportunities are needed for health professionals to develop eating disorders expertise. This will include ongoing education, support and supervision from specialist tertiary eating disorders centres.

The Ministry of Health's "Let's get real: Real skills for people working in mental health & addictions" project will describe the essential knowledge, skills, and attitudes required to deliver effective mental health and/or addiction treatment services.<sup>7</sup> The document will underpin all future workforce development in the sector.

Workforce issues to consider in the further development of eating disorders services include:

- providing opportunities for staff to access training and development that is appropriate for the level of care they provide and the characteristics of their service users
- providing opportunities for staff to ensure that they have a full understanding of, and comply with, local, national, and international guidelines, and integrated care pathways, to ensure competency and a uniformly high standard of care
- encouraging staff to participate in training or study that gives them enhanced skills for working with people experiencing eating disorders
- providing access to library and internet services, including relevant literature on eating disorders

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<sup>7</sup> The Ministry of Health is consulting on a draft of "Let's get real" during September and early October 2007. More information is available on this document at [www.moh.govt.nz/letsgetreal](http://www.moh.govt.nz/letsgetreal).

- supporting attendance, where feasible, at national and international meetings in order to support continuing professional development
- supporting collegial support, training and networking opportunities through affiliations with the Australia and New Zealand Academy of Eating Disorders
- linking professional development to annual appraisal/performance review processes
- developing recruitment strategies for Māori, Pacific Island people and those of other cultures to join the eating disorders workforce.

#### *Workforce Development Role of the Specialist Tertiary Eating Disorders Centres*

The two proposed Level Three specialist tertiary eating disorders centres will provide specialist support and supervision to the wider eating disorders workforce. This could include:

- providing professional development and training initiatives for DHBs' eating disorders care co-ordinators and eating disorders liaison roles
- providing opportunities for specialty training posts for registrars
- assisting with case management and referrals when required
- co-ordinating and contributing to the development and implementation of national guidelines
- providing guidance and direction to assist health professionals to undertake professional development that maintains and develops their clinical and professional skills (such as up-dated practice guidelines and referral processes)
- taking a role in co-ordinating and developing a Eating Disorder Forum (outlined in Section V of this document).

Services should consider how to provide strong peer support to assist in preventing staff burn-out when involved with service users. This may involve staff rotating within the sector to work with a variety of service users with different eating disorder acuties in different settings.

## **Section IV: The Eating Disorders Forum**

Stakeholders have suggested the establishment of an Eating Disorders Forum (or Eating Disorders Network).

A proposed form and scope of a forum is included in this document to provide some further momentum to the idea. There may be various ways of funding and organising such a forum, including via support from DHBs, service providers or external funding sources.

### **Purpose of the forum**

The forum would be a way of facilitating and encouraging stakeholders within the eating disorders sector to work together and share knowledge and experiences.

The forum would encourage discussion of aspects of prevention, early detection, education, and the treatment of (and outcomes achieved for) service users. Enhanced communication would ensure closer connections between the expertise available across the differing levels of eating disorders services.

The forum would promote the development and use of consistent evidence-based guidelines and best practice principles within eating disorders services.

Effective communication across all levels of care, and across all specialities and professional

groups, could be facilitated by the use of information technology (including video-conferencing), especially when the participants are separated by considerable geographical distances.

To support collaboration across primary, secondary, and tertiary services, the Forum could also:

- encourage greater collaboration amongst DHBs, NGOs, and consumer support groups
- support the recognition and training of NGOs and support groups to provide additional services to complement established DHB services
- encourage greater sharing of the experiences of service users amongst the eating disorders services to facilitate overall service improvement.

### **Development of the Forum**

The following parameters have been suggested to guide the forum's development.

- The forum would be an open multi-disciplinary group of health professionals, individuals and organisations, possibly led by the specialist tertiary eating disorders centres, with membership also including DHB Planners and Funders, PHOs and primary and community care and support providers, service users and family/whānau.
- There would be an agreed structure to the forum, with a regular review process to ensure that goals are being achieved and that the needs of all stakeholder groups are being recognised and met.

## **Section VI: Research and Development**

During the process of developing this document, a number of ideas were suggested about research and development that would be useful to guide the Ministry of Health and the sector in the future development of initiatives to improve the provision of eating disorders services. These included:

- Research should be linked to achieving measurable improvements in the care of service users.
- Service user and carer satisfaction are important outcome measures and may influence treatment approaches. Satisfaction measures should be considered an integral aspect of research.
- Given New Zealand's relatively small and dispersed population and the availability of suitable technology, the eating disorders sector could undertake collaborative research within New Zealand, or links could be established with Australian specialist eating disorders centres.
- There is a need for Māori involvement in developing care pathways that address service users' cultural needs and identify practitioners' cultural competencies. There is a similar need with respect to the involvement of Pacific Island and immigrant peoples to provide culturally appropriate and safe eating disorders services.
- Formal research policies and protocols should be established to evaluate the effectiveness of initiatives of any level in the care continuum. Such research would require the input of service users, as well as clinical and academic expertise.
- Services need to analyse, evaluate, and report on the efficacy of treatment approaches.
- Current and past service users assist in research that informs the future planning of eating disorders services.

- Services provide and maintain data so that national-level data can be collated, accessed and analysed.

Some specific proposals for research were also suggested:

- There is a need to assess the epidemiology, course, treatment options, and efficacy of treatment within New Zealand, which would allow evidence-based practices and appropriate prevention and primary care models to develop. Such research should link with international work in this field.
- There is a need to assess the feasibility and effectiveness of establishing mobile eating disorder expert teams to work with local primary and secondary care services to deliver care as close as possible to the homes of children and adolescents.
- There is a need to investigate whether strategies are required to counter images and perspectives that are carried in various media, entertainment and advertising formats.
- There is a need to investigate the appropriate use of alternative therapies in the treatment of eating disorders.
- There is a need for research to establish evidence-based guidelines to assist staff in supporting mild to moderate uncomplicated eating disorder cases, including criteria for who and when to refer to more specialised eating disorders services.
- There is a need to establish links between the needs of eating disorders services and the greater body of workforce development research.

## **APPENDIX 1: Understanding an Eating Disorder**

The term 'eating disorder' encompasses a range of conditions that have overlapping medical and psychiatric symptoms. These conditions are best thought of as psychological disorders with high levels of complicating psychiatric and medical co-morbidity (Gelder et al 2000; Buckett 2002).

The term 'eating disorder' is commonly used to encompass a range of disorders with wide degrees of severity and duration, some of which may not reach the criteria of an "eating disorder" as defined by the American Psychiatric Association's (2000) DSM-IV-TR.<sup>8</sup> Eating disorders defined by the DSM-IV include anorexia nervosa (anorexia), bulimia nervosa (bulimia) and Eating Disorders Not Otherwise Specified (EDNOS). Eating disorders have high risks of acute and chronic complications that can be life-threatening and/or life-long. Early identification of symptoms and behaviours may prevent an escalation toward fulfilling the criteria for a full diagnosis and prevent long-term damage or the disorder continuing into adulthood.

People experiencing an eating disorder are likely to hold a disturbed perception of their body size and shape. Generally, people experiencing an eating disorder will attempt to control their weight and appearance through excessive dieting, exercising, and/or purging.

Someone with an eating disorder will generally have intense treatment needs, and will quite often have one or more additional co-morbid psychiatric disorders. Frequent co-morbidities include affective disorders (such as depression), anxiety disorders (especially social phobia and Obsessive Compulsive Disorder), substance abuse disorders (such as alcohol problems), and personality disorders (Society of Adolescent Medicine 2003).

Eating disorders affect a small proportion of the population, and only a very small proportion of individuals with an eating disorder will require hospitalisation and other intensive treatment interventions. Although females are much more likely to develop an eating disorder, males can also be afflicted by an eating disorder. Epidemiological data for New Zealand is provided below.

The exact causes of eating disorders remain unknown. Environmental factors like society and culture can contribute to the development of an eating disorder, but have not been identified as a cause. Having a parent or sibling who has experienced an eating disorder can be an indicator of an individual being at risk of also developing an eating disorder.

Eating disorders occur across cultural groups. The American Psychiatric Association Steering Committee on Practice Guidelines (2006) has reported that disordered eating behaviours now appear to be globally distributed. Studies have shown increases in eating disorders in Japan and China, and increases in disturbed attitudes in non-Western countries such as Iran and Fiji.

### **Types of eating disorders**

#### *Anorexia*

Anorexia, while rare, has the highest level of mortality of any psychiatric disorder, due to medical complications and suicide. Anorexia tends to be the eating disorder that is most likely to require specialist inpatient treatment, although distinctions can be made between severe and mild anorexia.

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<sup>8</sup> The DSM-IV-TR is the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders; "IV" denotes Fourth Edition and "TR" denotes Text Revision.

In diagnosing anorexia, the National Institute for Clinical Excellence (2004) reported that although weight and Body Mass Index (BMI) are important indicators they should not be considered the sole indicators of physical risk (as they are unreliable in adults and especially in children).

Although a significant percentage of service users recover from anorexia, younger service users who receive prompt and appropriate intervention have a much better full recovery rate (American Psychiatric Association Steering Committee on Practice Guidelines 2006; Mental Health Commission 2007).

### *Bulimia*

Bulimia is characterised by episodes of food binging and purging. People experiencing bulimia tend to eat large quantities of food in relatively short periods of time, then take laxatives or self-induce vomiting to get rid of most or all of the food (National Institute for Clinical Excellence 2004).

### *EDNOS*

EDNOS is the most common DSM-IV eating disorder, and includes disorders characterised by “binge eating”. As with anorexia and bulimia, many EDNOS service users will have disordered perceptions of their body size and shape, and will attempt to control their size and shape by excessive dieting, exercising, or purging. A service user with an EDNOS diagnosis may be amongst the most acutely unwell service users; research suggests that EDNOS service users experience as many difficulties as those diagnosed with anorexia or bulimia (Canadian Paediatric Society 1988; American Academy of Paediatrics 2003).

## **Epidemiology Statistics**

The secretive nature of eating disorders, the delay in service users seeking treatment, and differences in assessment methods, means that estimates of the prevalence of eating disorders vary.

### *Prevalence*

The data in the below table, sourced from *Te Rau Hinengaro* (Oakley Browne et al 2006), outlines the estimated 12 month and lifetime prevalence rates for eating disorders in New Zealand. Readers should note that not all service users will be in need of specialist eating disorders services.

**Table One: The prevalence of eating disorders over 12-months, over a lifetime, and the projected risk of a lifetime eating disorder**

	<b>% of all surveyed</b>	<b>% of all Māori surveyed</b>	<b>% of all Pacific peoples surveyed</b>
<b>12-month prevalence</b>	0.5* (0.3, 0.6)	1.0 (0.5, 1.6)	1.5 (0.7, 2.6)
Anorexia	<0.1 (0.0, 0.1)	0.0 (0.0, 0.2)	
Bulimia	0.4 (0.3, 0.6)	1.0 (0.5, 1.6)	1.5 (0.7, 2.6)
<b>Lifetime prevalence</b>	1.7* (1.5, 2.1)	3.1 (2.3, 4.1)	4.4 (3.1, 6.2)
Anorexia	0.6 (0.4, 0.8)	0.7 (0.2, 1.6)	
Bulimia	1.3 (1.1, 1.5)	2.4 (1.8, 3.2)	3.9 (2.7, 5.5)

Note: the figures in brackets indicate that there is a 95% chance that the true value lies within this range.

\* Australian figure for 12-month prevalence is 1-1.1.5% and 5% for lifetime for women, which is in line with other Western populations.

*Te Rau Hinengaro* found that half of all cases of anorexia start before the age of 19, and almost all before the age of 45, with the median age of onset for an eating disorder being 17 years of age (Oakley Browne et al 2006). The lifetime prevalence for eating disorders in the 16-24 year old age group was found to be 2.0%. The survey found that the highest lifetime prevalence rate for eating disorders was in the 25-44 age group (where 2.9% of the overall population, 3.6% of Māori, and 6.6% of Pacific peoples aged between 25 and 44 could be expected to have experienced an eating disorder by the age of 75).

The American Psychiatric Association Steering Committee on Practice Guidelines (2006) reported that most eating disorders start while service users are in their teens and 20s, but earlier and later onsets have been recorded. Adults who have an eating disorder often present with long-standing co-morbid psychiatric and personality disorder issues.

One study has estimated that up to 5% of women presenting to (or registering with) a GP have an undiagnosed eating disorder, with up to 50% of cases remaining unrecognised (Marks et al 2003). There have also been reported increases in women of Asian descent presenting for eating disorder treatment (Buckett 2002).

It has been estimated that about one-third of cases of anorexia follow a chronic course (Palmer and Treasure 1999). Morris and Twaddle (2007) reported that anorexia takes an average of five to six years from diagnosis to recovery, with up to 30% not recovering.

Bulimia is found mainly in older females and has a lower mortality (Wells et al 1989), and its highest rate of onset is around ages 18 to 20. Bulimia tends to run a relapsing and remitting course with about 66% of bulimic service users recovering within five years (Morris and Twaddle 2007).

#### *Risks from eating disorders*

Eating disorders can be fatal. Herzog (2000) reported that the suicide rate of women with an eating disorder was 58 times greater than it was for women without an eating disorder. Crow and Nyman (2004) reported a long-term mortality rate of 10% in anorexia. Nielsen (2001) estimated mortality rates ranging from 0.3% to as high as 20%. Generally, death occurs as a result of the physical (usually cardiac) complications of malnutrition as well as due to suicide. Most of the deaths from eating disorders occur either in the first two years or after 15 years of suffering, further indicating the importance of early intervention.

*Te Rau Hinengaro* highlighted the elevated risk for suicide associated with eating disorders. Data showed the risk is higher compared with those who have a mood disorder. 22.9% of those with an eating disorder reported suicidal ideation, 10.1% reported making plans, and 9% reported making an attempt. Of those people with a mood disorder, 20.2% reported suicidal ideation, 7.6% reported making plans, and 3.4% reported making an attempt.

## APPENDIX 2: Current eating disorders services in New Zealand

Service users with eating disorders are currently supported by community/non-government organisations (NGO), primary care services, secondary mental health services, general medical, psychiatric, and paediatric services, and tertiary specialist care settings.

Some DHBs collaborate to offer regional services. Most mental health services are provided through community based multi-disciplinary teams.<sup>9</sup> Some DHBs also provide outreach services to rural communities.

Current availability of DHB Provider Arm Services are summarized in the table below:

District Health Board (DHB)	Main provider	Service location	Specialist inpatient unit	Residential unit	Day programme	Outpatient service	Regional services
<b>Northern Region</b> Waitemata Auckland Counties Manukau Northland*	Auckland DHB	Greenlane Hospital, Auckland	No	No	Yes	Yes	Yes
<b>Midland Region**</b> Waikato Bay of Plenty Lakes Tairāwhiti Taranaki	None	No	No	No	No	No	No
<b>Central Region</b> Capital & Coast Hutt Valley Wairarapa MidCentral Whanganui Hawke's Bay	Hutt Valley and Capital & Coast DHBs	Wellington Hospital Hutt Hospital Johnsonville	No	Yes	Yes	Yes	Yes
<b>Southern Region</b> Canterbury Nelson Marlborough West Coast South Canterbury Otago*** Southland	Canterbury DHB	Princess Margaret Hospital, Christchurch	Yes	No	No	Yes	Yes

\* Northland DHB only receives supervision and consultation from Auckland eating disorders services.

\*\* Midland region DHBs receive supervision and consultation from Auckland eating disorders services.

\*\*\* There is an agreement between the Otago DHB and the Canterbury DHB regional service provider.

<sup>9</sup> For a more in depth stocktake of child and adolescent services, see Ramage et al 2005.

## Existing options for service user placement within DHB hospital services

	Options for the care of service users in New Zealand				
	Paediatric & Specialist Paediatric	General Medical	General Psychiatric	Specialist Adolescent Psychiatric	Specialist eating disorders services
<b>Age band</b>					
Child	✓			✓	✓
Adolescent	✓	✓	✓	✓	✓
Adult		✓	✓		✓

Note: All 21 District Health Boards have specialist Child and Adolescent Mental Health Services (CAMHS) for 0–19 year-olds. The age range for adult mental health services (AMHS) starts at 18 years. The overlap in age range between CAMHS and ADMHS gives flexibility for service provision based on the service user's developmental needs.

### Not-for-profit Organisations

Several NGO and community/voluntary organisations provide support, education, information, counselling and referral services to service users and their family/whānau, as well as information for the general public. These services raise awareness of the problems and issues around body image, the role of the dieting industry and the media, and the emergence of eating disorders, as well as providing education and support for those service users with other types of eating disorders, such as sub-clinical conditions.

These organisations often help service users who present with disordered eating patterns before they need treatment from a more specialised eating disorder service. These organisations also provide support for those coming out of secondary and tertiary services. NGO services may also offer access to counselling, support groups, self-help, and other educational activities.

### NGO and private eating disorders services available in New Zealand January 2007 by Region

	NGO Service	Private Services
Northern*	EDEN	
Midland**	No	
Central	WEDS**	
Southern***	EAT***	Yes*

\* DHBs, service users and their family/whānau have the option of funding service users to attend the only private eating disorder service, the Ashburn Clinic. The Ministry of Health contributes to funding for beds on a limited basis.

\*\* WEDS is currently reorganising itself to most likely operate as an education and prevention service on eating disorders.

\*\*\* Canterbury District only service.

### Advocacy

Advocacy groups play a significant role in providing feedback to primary, secondary and tertiary eating disorders services to improve service provision, as well as working alongside support groups to ensure appropriate and helpful advice is provided to service users.

## APPENDIX 3: Additional Resources

### *Publications*

**Blueprint for Mental Health Services in New Zealand (Mental Health Commission, 1998)** defines the levels of specialist mental health services as well as the changes required to implement the government's *National Mental Health Strategy*.

**New Futures: A Strategic framework for specialist mental health services for children and young people in New Zealand (1998)** describes the functions of specialist services, explains how these services should develop, and identifies areas for further development. It also describes benchmarks for access to specialist services for children and adolescents with severe mental illness, and benchmarks for the role of consultation–liaison for those with less severe disorders.

**Te Tāhuhu – Improving Mental Health 2005–2015: The second New Zealand mental health and addiction plan (2005)**, and **Te Kōkiri: The Mental Health and Addiction Plan 2006–2015 (2006)** provide the strategic policy context for mental health and wellbeing in New Zealand and describe the government's outcomes for mental health and addiction. These documents confirm the basic premises of *New Futures* and establish the fundamental policy setting and future direction for child and adolescent mental health, and alcohol and other drug services. *Te Kōkiri* remains the primary vehicle for the implementation of *Te Tāhuhu – Improving Mental Health*. *Te Tāhuhu* identifies that people with specific mental health needs (including eating disorders) require services with focused expertise.

**Whakamārama te Huarahi – To Light the Pathways: A Strategic Framework for Child and Adolescent Mental Health Workforce Development (2006)** builds on priorities set by the Ministry of Health in *Tauawhitia te Wero: The national mental health and addiction workforce development plan, 2006–2009*, and *Te Tāhuhu*, where there is a strong emphasis on increasing services for children and young people and building a workforce to deliver those services, and the development of child and youth core competencies. *Kia Puawai te Ararau: National Māori Mental Health Workforce Development Strategic Plan 2006–2010* has a particular focus on child and adolescent workforce development.

**Youth Health: A Guide to Action (2002)** is a plan of action to improve the health of New Zealand's 12 to 24 year olds. This action plan proposes that young people are valued participants in community efforts to create a healthier environment. It recognises that the wellbeing of young people is dependent on healthy connections among whānau, schools, peers, work and training, culture and environment.

The **National Mental Health Sector Standard (2001)** aims to achieve better mental health services and ensure consistency in the delivery of mental health treatment and support for New Zealanders who use mental health services.

### *Standards by Relevant Organisations*

Operational standards as recommended by the following organisations are best taken into consideration in service delivery:

- Royal Australian and New Zealand College of Psychiatrists (2004) *Australian and New Zealand Clinical Practice Guidelines for the Management of Anorexia Nervosa*
- National Institute for Clinical Excellence (2004) *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders*
- American Academy of Paediatrics

- Society for Adolescent Medicine
- American Psychiatric Association Working Group on Eating Disorders *Practice Guideline for the Treatment of Patients with Eating Disorders* (2000 and updated in 2005).

### *Other Resources*

The Mental Health Foundation has a series of Mental Health Information New Zealand booklets that cover anorexia and bulimia (Mental Health Foundation 2002). These provide general information to service users, their families/whānau and people involved in supporting and treating people with eating disorders. These booklets give the contact details for support groups and organisations that offer help to service users with eating disorders. They also list useful websites and books.

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has published a booklet for carers and service users about anorexia that contains similar information and contact details (2005).

The National Institute for Clinical Excellence Eating Disorder Guidelines (2004) and RANZCP guidelines provide guidance on how to best treat eating disorders according to the condition they most resemble. These guidelines also emphasise against applying too strict a definition to any eating disorder.

### *Support groups and information<sup>10</sup>*

- North Shore Women's Centre ([www.womyn-ctr.co.nz](http://www.womyn-ctr.co.nz)): information, support, courses and counselling. Tel: (09)44 44 618.
- Youthline: confidential help, support and advice on 0800 37 66 33.
- The Mental Health Foundation: information on anorexia and bulimia, including symptoms and risk factors, living with an eating disorder, possible treatment and resources available.
- Eating Difficulties Education Network (EDEN) ([www.eden.org.nz](http://www.eden.org.nz)): an Auckland-based non-profit community agency, aiming to promote body trust and satisfaction, size acceptance and diversity on an individual and societal level.
- Eating Disorder Services (EDS) ([www.eatingdisorders.org.nz](http://www.eatingdisorders.org.nz)): Wellington-based, not for profit community organisation that provides education and support services for service users and families/whānau affected by eating disorders.
- Eating Awareness Team (EAT) (<http://www.mherc.org.nz/eatingawareness.htm>): Christchurch-based support, information, and referral for food and body image issues. Telephone: 0800 690 233.
- [www.dietitians.org.nz](http://www.dietitians.org.nz): New Zealand Dietitians Association is the national association of the dietetic profession.
- Overeaters Anonymous: is a fellowship of individuals who, through shared experience, strength and hope, are recovering from compulsive overeating  
[http://www.oa.org/all\\_about\\_meetings.htm?country=NEW%20ZEALAND#intl](http://www.oa.org/all_about_meetings.htm?country=NEW%20ZEALAND#intl)

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<sup>10</sup> There is a large amount of information on the Internet in relation to eating disorders. Service users, family/whānau and friends need to be aware that the lack of professional supervision of these sources may sometimes lead to misinformation.

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