

# **Future Directions for Eating Disorders Services in New Zealand**

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# Executive Summary

## **Gaps exist in the range and effectiveness of eating disorders services**

Analysis of the services and supports that are available in New Zealand for people who are affected by an eating disorder establishes a clear need for building and broadening the range and effectiveness of the available services. The greatest gaps exist in services for children and young people, and significant regional differences exist in access to eating disorders services.

*Future Directions for Eating Disorders Services in New Zealand* emphasises the need for integrated eating disorders services that:

- provide seamless service delivery across primary, secondary and tertiary settings, easy transitions between services, and continuity of care
- provide effective early intervention
- provide a wider range of services and a multi-disciplinary approach to care
- enable service users to actively participate in the planning of their own recovery
- support service users as close to their home as possible.

## **Actions to improve the range and effectiveness of eating disorders services**

This document proposes a tiered service model and principles to address the gaps in service provision and build an integrated eating disorders sector. Key areas for action include:

- increasing the number and widening the range of services
- establishing tertiary eating disorders services
- supporting seamless service delivery, easy transitions between services and continuity of care by providing:
  - each service user referred to a secondary service with a designated care co-ordinator
  - at least one designated eating disorders liaison person in each DHB (or appropriate group of DHBs)
- building a workforce in primary, secondary and tertiary services with:
  - the skills and experience to deliver effective services to people with an eating disorder
  - a culture that promotes service user participation and leadership
  - a culture that involves family/whānau in treatment and recovery.



# Introduction

*Te Tāhuhu: Improving Mental Health 2005–2015* (Ministry of Health 2005) and *Te Kōkiri: The Mental Health and Addiction Plan 2006–2015* (Ministry of Health 2006) commit the Ministry of Health and District Health Boards (DHBs) to building and broadening the range and effectiveness of services and supports that are funded for people who are severely affected by mental illness. *Te Kōkiri* also commits DHBs to strengthening linkages between specialist services and primary care services.

*Future Directions for Eating Disorders Services in New Zealand* will guide DHBs to build and broaden the range and effectiveness of services and supports they have available for people affected by an eating disorder. This guidance applies to all 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
- DHB provider arm mental health services
- community and residential mental health services.

Decisions about the level of funding available for eating disorders services and the provision of those services are the responsibility of individual DHBs. DHBs are responsible for prioritising health and disability services for their populations.

This document recommends a tiered service model for providing eating disorders services. DHBs will decide how to implement the service model as part of their district and regional planning and prioritisation processes, and will take into account the need for further workforce development.

The Ministry of Health anticipates that DHBs will use this document, collectively and individually, to guide their decisions about improvements to eating disorders services.

DHBs have agreed to demonstrate, as part of their regional planning processes, how they intend to implement the key directions of this document. DHBs have agreed to provide regional plans to the Ministry of Health by 30 June 2008 that include details of planned local and regional initiatives to improve eating disorder services.

Planned initiatives will be developed within current funding and be prioritised by DHBs as part of their overall planning of mental health and addiction services.

The regional plans will also include timeframes and milestones for implementation and, in particular, take account of the resources required for upskilling the current workforce.

Although much of the tiered service model is already in place, not all DHBs will start from the same base of services, so timeframes for implementing local plans will differ.

Although health professionals who are involved in the provision of eating disorders services are expected to consider this document, it does not override their 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.

## **Eating Disorders Service Specification**

This document complements the Eating Disorders Service Specification in the Nationwide Service Framework library, which DHBs and the Ministry of Health will revise in 2008.

# 1 Eating Disorders Services in New Zealand

It is important to acknowledge that in recent years progress has been made in providing people affected by eating disorders with access to an increased range of appropriate services. However, the analysis and consultation that underpins this document established a clear need for further service development.

## 1.1 Definition of 'eating disorder'

The term 'eating disorder' encompasses a range of conditions that have overlapping psychiatric and medical symptoms. These conditions are best thought of as psychological disorders with high levels of psychiatric and medical co-morbidity that may involve acute and chronic complications that can be life-threatening and/or lifelong (Gelder et al 2000; Buckett 2002).

The term 'eating disorder' is commonly used to refer to one or more of a range of disorders with wide degrees of severity and duration. Eating disorder diagnoses include anorexia nervosa (anorexia), bulimia nervosa (bulimia), and a composite category of 'eating disorders not otherwise specified', as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) (American Psychiatric Association 2000).<sup>1</sup>

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

Eating disorders will quite often involve one or more 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 for Adolescent Medicine 2003).

Most people with an eating disorder can be treated on an outpatient basis. A very small proportion of individuals with an eating disorder require hospitalisation and other intensive treatment interventions. Although females are much more likely to develop an eating disorder, males can also be affected by an eating disorder.

Mortality rates for eating disorders are high. Herzog et al (2000) reported that the suicide rate for women with an eating disorder was 58 times greater than it was for women without an eating disorder. In addition to a significantly elevated suicide risk, the medical complications of eating disorders, including the complications of starvation, contribute to eating disorders being associated with a relatively high risk of mortality.

Eating disorders are described in more detail in Appendix 1.

<sup>1</sup> 'DSM-IV-TR' means the text revision (TR) of the fourth edition (IV) of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association 2000).

## **1.2 Service users' expectations of care**

In 2006, Eating Disorder Services<sup>2</sup> surveyed 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 disorders service.

Service users valued (in descending order of importance):

- maintaining a sense of autonomy over their lives
- respect
- confidentiality
- anonymity
- 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.

Participants also valued the involvement of staff with personal and professional experience with eating disorders. In particular, the participation of former service users in treatment teams was held in high regard.

## **1.3 Development of eating disorders services**

This section outlines aspects of available services that stakeholders have identified as needing development.

### **1.3.1 Access to and range and number of services**

In 2007, the Mental Health Commission undertook a stocktake of mental health services, including eating disorders services. The Commission found that there continues to be considerable problems with access to eating disorders services, evidenced by a lack of beds and long waiting lists. The Commission also reported that the criteria services used for deciding who gained access to services might exclude people experiencing the early stages of an eating disorder from services.

<sup>2</sup> Eating Disorder Services was a Wellington NGO established in 1989 by people recovered from eating disorders. It was the provider of specialist eating disorder services for the Central Region from 1996 until 2006. Since 2007 the service has been provided by Hutt Valley DHB and renamed Central Region Eating Disorder Services.

Stakeholders also identified:

- 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))
- a lack of day programmes in some DHBs (or an insufficient number of programmes where they were available)
- a lack of specialist inpatient beds in some DHBs (or an insufficient number of beds where they are available)
- a nationwide shortage of residential inpatient beds
- a nationwide shortage of beds for comprehensive medical and 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)
- that some general practitioners were not confident in this area and not confident in managing a service user's immediate medical and psychiatric risks
- a shortage of family/whānau therapy and support for families/whānau.

### **1.3.2 Variability in services**

An analysis of current services and consultation with stakeholders found significant variations in the provision of eating disorders services across DHB regions. Appendix 2 (Table 6) shows regional variations in the provision of eating disorders services as at 31 October 2007.

In addition to the issues noted in section 1.3.1, analysis and consultation indicated that other aspects of current service provision need to be considered, including:

- differences in the service options available across New Zealand
- differences in the way services are delivered
- differences in the length of stay for adolescents of similar severity (perhaps because of difficulty 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)
- an absence in many areas of clearly defined client pathways, which limits access to early and effective intervention.

### **1.3.3 Workforce issues**

Stakeholders identified workforce issues, including:

- 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 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 with young people
- the use of staff who rarely work with eating disorder service users, but who are called on when experienced professionals are not available.

The issues outlined above suggest that there may be challenges to overcome with respect to initial diagnostic capability and early intervention. There is overseas evidence that service users who go on to develop very serious eating disorders are likely to have visited their general practitioner or other generic health services on several occasions without their disorder being reported by the service user or detected by the practitioners (National Public Health Services for Wales 2006).

The use of casual or unqualified staff who lack knowledge and confidence in eating disorders may lead to counter-therapeutic practices and, therefore, poor outcomes.

### **1.3.4 Co-ordination of services**

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

### **1.3.5 Inequalities between population groups**

*Te Rau Hinengaro: The New Zealand Mental Health Survey* (Oakley Browne et al 2006) found that Māori and Pacific peoples were 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 higher prevalence rates for eating disorders in Māori and Pacific populations.

### **1.3.6 Responsiveness to families/whānau**

Stakeholders indicated that 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 ongoing input due to difficulties associated with the distance between their home and the facility. The importance of enabling and maintaining the involvement of families/whānau is discussed in section 3.3.

## **2 Future Directions for Eating Disorders Services in New Zealand**

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

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

- A wider range and choice of services is developed.
- Services are provided by a multi-disciplinary team in partnership with the service user and their family/whānau.
- Services are guided by the aim of supporting each service user toward long-term recovery.
- Services are provided as close to the service user's home as possible, taking into account the availability and location of specialist services (when specialist services are needed).
- Primary health practitioners have a crucial role with respect to providing effective early intervention and supporting each service user toward ongoing recovery.
- Services are built around those elements that have been shown to be valued by service users:
  - autonomy
  - respect
  - confidentiality
  - anonymity
  - a supportive and empathetic atmosphere  
being recognised and treated as an individual having former service users involved in treatment teams.
- Quality services are built on:
  - responsiveness
  - accessibility
  - a commitment to recovery
  - research and evaluation
  - evidence-based best practice
  - staff having access to a wide range of learning opportunities that inform innovation.
- Services are co-ordinated and integrated, with seamless service delivery, easy transitions between services, and continuity of care.
- A range of community and local services sit alongside (and are supported by) secondary and tertiary services.
- Services are appropriate for each service user's age, gender and culture.

- The developmental needs of children and adolescents are recognised, and services, wherever possible, are separate from services for adults.<sup>3</sup>
- Eating disorders services are 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.<sup>4</sup>

## 2.2 Organisation and management

This section describes the model for eating disorders services recommended for New Zealand. Figure 1 shows the three levels of eating disorders services that need to be available.

**Figure 1:** Three levels of eating disorders services

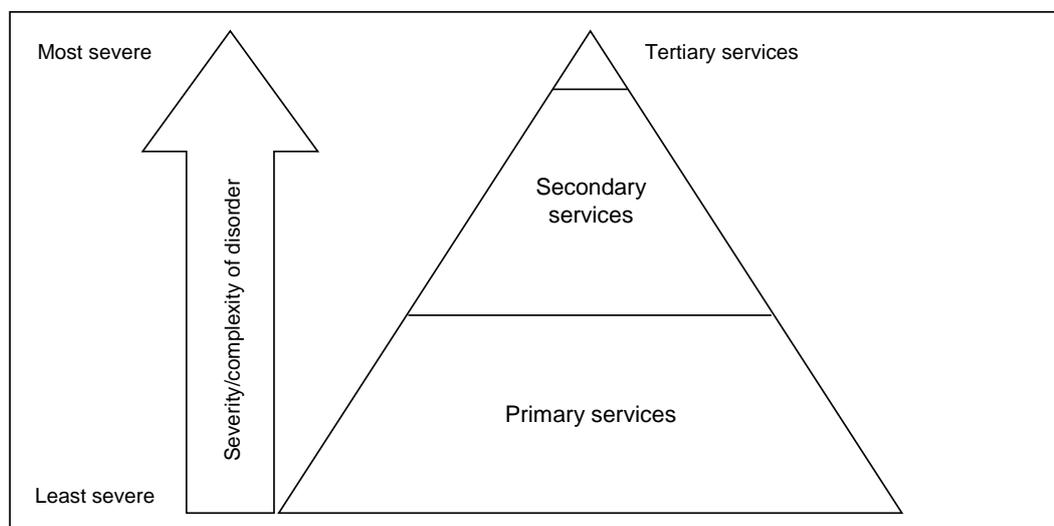


Figure 1 shows that the majority of service users will be managed within community-based (primary and secondary) services in their local DHB region. Some service users may require inpatient treatment in services provided by their local DHB. Only those service users most severely affected by an eating disorder are likely to require tertiary level services. Further detail on tertiary services is in section 2.3.4.

The model stresses that services must operate collaboratively and allow for service users' non-linear movement through service levels. A service user may access different services, in different ways, at different times or concurrently, across or between the various levels, depending on the severity of their illness. Likewise, service providers may operate across several levels and in different professional roles. Providing for non-linear transitions is necessary because of the potential for a service user's initial presenting symptoms to be severe or deteriorate rapidly at any time.

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

<sup>4</sup> This is supported by key government strategies to advance Māori 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).

Eating disorders services may vary in their individual management structures, but all services need to take a collaborative and consultative approach that involves funders and providers working across primary, secondary and tertiary service levels. This will ensure that services are provided in a manner that is effective, service user-centred, and culturally appropriate. Services need to be seamless, so service users can move through the services easily.

A commitment to a collaborative approach across all services and service levels will improve the provision of high-quality and clinically effective services, regardless of their geographical location.

### **2.2.1 Service setting most appropriate for the service user**

A comprehensive or 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 an eating disorder becoming chronic, the 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.

Sections 2.3.2 to 2.3.4 discuss the circumstances to be considered when deciding which service setting is the most appropriate for each service user.

### **2.2.2 Workforce decisions**

While responsibility for decisions on the structure and size of the workforce engaged in delivering eating disorders services resides with DHBs and individual providers, planners and providers (collectively and individually) may choose to consider the resource guidelines suggested by the Mental Health Commission in *Blueprint for Mental Health Services in New Zealand* (1998).<sup>5</sup>

<sup>5</sup> The Blueprint suggested that a need existed for 2.4 full-time equivalent staff per 100,000 people for community-based eating disorders services (Mental Health Commission, 1998, p 102). While the Blueprint provides guidance and direction for the mental health service capacity needed to meet the needs of New Zealand's population, we recognise that the service provision environment has developed and altered since 1998. In addition, the Blueprint's guidelines for the allocation of full-time equivalent staff to child and adolescent and adult services is widely considered to be at odds with the age of onset for eating disorders.

## 2.3 Description of service levels in the proposed model

### 2.3.1 Three levels of eating disorders services

As shown in Figure 1, the proposed model for eating disorders services in New Zealand comprises three service levels: primary, secondary and tertiary.

To facilitate the collaboration and communication required to deliver seamless service delivery, easy transitions between services and continuity of care, the proposed model also involves:

- establishing at least one eating disorders liaison role in each DHB (or appropriate grouping of DHBs)
- providing each service user referred to a secondary service with a care co-ordinator.

#### Role of eating disorders liaison people

In the proposed model, each DHB (or appropriate grouping of DHBs) will have at least one suitably qualified eating disorders liaison person.<sup>6</sup> DHBs may decide that one liaison person is needed for child and adolescent service users and another for adult service users.<sup>7</sup>

The liaison role is likely to be based in the secondary (level two) services of a DHB, and will include responsibility for eating disorders services within that DHB.

A key function of the liaison person will be to support staff dealing with eating disorders in their DHB area, including staff in primary services.

The liaison person will:

- facilitate clear communication between their DHB and tertiary eating disorders services, and between their DHB and other DHBs
- be the key linkage between primary and secondary services in their DHB, particularly in providing general practitioners and other primary care practitioners with advice, support and assistance with referrals
- assist with the supervision and professional development of staff involved in providing eating disorders services in their DHB
- be involved in referrals and transitions of service users to and from medical and psychiatric settings
- receive support and education from tertiary eating disorders services.

<sup>6</sup> Smaller DHBs may decide that the role of liaison person could be shared with a larger neighbouring DHB. Such a decision would need to be agreed by the relevant DHBs, and the DHBs would need to be sure that the needs of their populations were appropriately met if a liaison role were shared. Decisions on the full-time equivalent allocations to the liaison role or roles would be the DHBs' responsibility.

<sup>7</sup> Decisions on the full-time equivalent allocations to the liaison role will be the responsibility of DHBs.

## Role of care co-ordinators

In the proposed model, each service user who is referred to a secondary eating disorders service will be provided with a designated care co-ordinator who is accessible to the service user, the multi-disciplinary treatment team and general medical staff.

The care co-ordinator will ensure that treatment planning is implemented, monitored and updated, and that relevant information is communicated across service levels. The care co-ordinator will also ensure that each service user's general practitioner is part of the multi-disciplinary team or has input into the service user's treatment plan, and is fully informed of the service user's progress toward recovery when receiving secondary or tertiary services and/or when transitioning out of secondary or tertiary services.

### **2.3.2 Primary and community (level one) services**

Level one services are community-based primary health services that are staffed by a mix of specialist and non-specialist health professionals and may include volunteers. (See the summary in Table 1.)

Some primary services will provide health promotion activities such as school programmes.

All staff in primary 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). Staff should be able to provide support, information, early intervention, and referral services. In particular, general practitioners and other health professionals in primary services need to have the skills to recognise, and monitor those with an eating disorder. They may begin to try to alleviate some of the symptoms but should also know when to facilitate a person's access to secondary services and/or tertiary services. For example, a young person with anorexia nervosa should be managed in primary care for two weeks and if no change in behaviour is noted should be referred on to a secondary/tertiary service.

Primary care should manage eating problems/difficulties that do not meet diagnostic criteria for an eating disorder. Primary care should be able to monitor and support those who have "stepped down" from or who continue to be involved with secondary services and are living in the community (with support from secondary services as required). However, because further workforce development (which is not a short-term process) is needed, DHBs' eating disorder liaison people should be available to advise and guide staff in primary services.

**Table 1:** Summary of primary and community services

| Service users most likely to need level one services  | Probable interventions and activities   | Providers  | Referral and access arrangements  |
|---|---|--|---|
| <p>Service users with or without a diagnosed eating disorder who present with patterns of concern or risk</p> <p>Service users with chronic eating disorders who need to be monitored</p> <p>Family/whānau members requiring information and support</p> <p>Service users transitioning from secondary or tertiary services</p> | <p>Initial identification and assessment</p> <p>Early intervention</p> <p>Support of service users and their family/whānau, including provision of advice, education, monitoring, counselling, brief interventions, self-help promotion, and medical treatment and management</p> <p>Focus on quality of life, and maintenance of health and social interaction</p> <p>Peer support</p> <p>Referrals to secondary services for (specialist) assessment and/or treatment</p> <p>Referral to primary mental health services (where available)</p> <p>Arrangement of access to Care Plus and other available primary care schemes</p> <p>Support of service users waiting to access a secondary or tertiary service (in collaboration with specialist services)</p> <p>Long-term monitoring independently or as part of shared care with specialist services</p> <p>Health promotion including raising awareness</p> | <p>General practitioners</p> <p>Primary health organisations</p> <p>Community mental health services</p> <p>Community alcohol and other drug services</p> <p>School and university health or welfare staff, including school guidance counsellors</p> <p>Community and voluntary sector services</p> <p>Counsellors and psychotherapists</p> <p>Youth one-stop shops</p> <p>Youthline</p> <p>Public health nurses</p> <p>Community non-government organisation (NGO) providers</p> <p>Māori health organisations</p> <p>Other community-based organisations involved in identifying people who have (or are at risk of developing) an eating disorder and supporting service users (such as sports teams or activity clubs, women's centres and women's refuges)</p> | <p>Normally direct access by service users and/or concerned family/whānau</p> <p>Recommendations from other NGOs</p> <p>Referrals from GPs, specialist services, schools, other community health professionals</p> <p>Referrals from secondary or tertiary services (where a service user no longer needs secondary or tertiary services)</p> |

### **2.3.3 Secondary outpatient and inpatient (level two) services**

Level two services are secondary outpatient and inpatient services. Each person referred to a secondary service will have a designated care co-ordinator.

#### **Secondary outpatient services**

Secondary outpatient services will be community-based outpatient services that provide a multi-disciplinary approach using staff with the appropriate experience and skills to support service users with an eating disorder. (See the summary in Table 2.)

Service users will be supported toward recovery while living in their own home, a supported accommodation residence or a residential service.

Staff should be available to provide rapid response services to each service user in the event that their symptoms become more serious.

**Table 2:** Summary of secondary outpatient services

| Service users most likely to need secondary outpatient services  | Probable interventions and activities   | Providers  | Referral and access arrangements  |
|--|---|--|---|
| <p>Service users whose behaviour and symptoms indicate the possibility of an eating disorder of sufficient severity to require assessment and/or ongoing intervention</p> <p>Service users for whom the eating disorder illness is not life-threatening</p> <p>Service users transitioning from inpatient to community-based treatment</p> | <p>Comprehensive or holistic assessments of service users</p> <p>Specialist care and day programmes to support recovery and prevent deterioration in the service user's presenting physical and mental health symptoms</p> <p>Structured evidence-based interventions and therapy</p> <p>Intensive clinic-based and/or home-based day-care and/or family/whānau interventions</p> <p>Advice to mental health crisis services</p> <p>Structured relapse prevention planning</p> <p>Intensive community-based outreach</p> <p>Monitoring and reviewing of service users receiving residential care</p> <p>Partnership with the service user and their family/whānau, including enabling their ongoing participation in the service user's care</p> <p>Collaborating with inpatient services and tertiary services for advice on managing service users</p> <p>Referrals to inpatient and tertiary services</p> <p>Liaison to enable the delivery of advice, training and support to colleagues in primary services and to ensure effective co-ordination of service provision</p> <p>Provision of collaborative advice to primary services about appropriate support services and interventions to support service users whose eating disorder does not meet service entry criteria to secondary services</p> | <p>Outpatient services for people with eating disorders in community-based District Health Board provider arm services such as:</p> <ul style="list-style-type: none"> <li>• existing community-based eating disorders services</li> <li>• child and adolescent mental health services</li> <li>• adult mental health services</li> <li>• paediatric outpatient services</li> <li>• Pacific mental health services</li> <li>• Māori mental health services</li> <li>• public health nurses</li> <li>• private providers</li> <li>• community-based non-government organisations</li> </ul> | <p>Referral from primary services to outpatient mental health teams</p> <p>Referral from paediatric services or physicians</p> <p>Direct access</p> |

### Secondary inpatient services

Secondary inpatient services will be delivered in psychiatric wards, paediatric wards or general medical wards. (See the summary in Table 3.)

A comprehensive or holistic assessment of each service user is important for determining the most appropriate setting for a service user to receive advice, care, support, management and treatment. In general, inpatient services will be for service users who have not responded to outpatient services or who are in immediate need of medical stabilisation and/or intensive support.

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

**Table 3:** Summary of secondary inpatient services

| <b>Service users most likely to need secondary inpatient services</b>  | <b>Probable interventions and activities</b>  | <b>Providers</b>   | <b>Referral and access arrangements</b>  |
|--|---|--|--|
| <p>Service users in need of more intensive care than can be safely provided by a community-based outpatient service</p> <p>Service users who have not responded to community-based outpatient services</p> <p>Service users who present with symptoms that warrant inpatient stabilisation</p> <p>Service users who need refeeding</p> | <p>Comprehensive or holistic assessments of service users</p> <p>Treatment, relapse prevention and discharge planning by a multi-disciplinary team</p> <p>Evidence-based multi-disciplinary interventions and therapy</p> <p>Respite care</p> <p>Medical intervention when required</p> <p>Appropriate psychiatric services when required</p> <p>Managing transitions between teams and levels</p> <p>Partnership with the service user and their family/whānau, including enabling their ongoing participation in the service user's care</p> <p>Specialist liaison and consultation with other services (including paediatric services, child and adolescent and adult mental health services)</p> <p>Collaboration with tertiary services</p> <p>Referrals to tertiary services</p> <p>Provision of collaborative advice to primary services about appropriate support services and interventions to support service users whose eating disorders do not meet service entry criteria to secondary services</p> <p>Liaison to enable the delivery of advice, training and support to colleagues in primary services and ensure effective co-ordination of service provision</p> | <p>Inpatient services for people with eating disorders in District Health Board provider arm services such as:</p> <ul style="list-style-type: none"> <li>• child and adolescent mental health inpatient units</li> <li>• adult mental health inpatient units</li> <li>• Māori mental health inpatient units</li> <li>• medical inpatient units</li> <li>• paediatric inpatient units</li> <li>• private providers.</li> </ul> | <p>Referrals from outpatient services</p> <p>Referrals from primary services or general medical (including paediatric) wards in an emergency</p> |

### 2.3.4 Tertiary (level three) services

Tertiary eating disorders services will have designated eating disorders beds and provide highly specialised eating disorders inpatient services for the most severely ill service users. (See the summary in Table 4.)

Tertiary eating disorders services will enable the close medical and psychiatric treatment and monitoring of a service user in a contained and structured setting by appropriately trained and experienced multi-disciplinary staff. Tertiary eating disorders services could also provide secondary services (for their local DHB or wider region).

The location and number of designated tertiary eating disorders services will need to be decided collectively by DHBs.<sup>8</sup>

Separating children and adolescent service users from adult service users is strongly recommended, although older adolescents may be treated in an adult setting if this is deemed developmentally and clinically appropriate.<sup>9</sup> Arrangements for the nearby accommodation of family/whānau, to facilitate their ongoing involvement in treatment, are also highly desirable.

#### Criteria for access to tertiary eating disorders services

Criteria for access to tertiary eating disorders services will need to be developed collectively by DHBs. However, service users most likely to be referred to a tertiary service will include those:

- with a severe and life-threatening eating disorder
- who have not responded to secondary outpatient or inpatient interventions or require the expertise or interventions of a tertiary eating disorders service.

Specific factors to consider before referring (and relocating) a service user to a tertiary service include the:

- complexity of the service user's needs due to co-morbid physical health conditions
- complexity of the service user's needs due to co-morbid mental illness
- service user's suicide risk
- ability to maintain the involvement of the service user's family/whānau in treatment (and the involvement of the service user in their family/whānau), particularly when the service user is a child or an adolescent or a parent or caregiver.

<sup>8</sup> During the development of this document, many stakeholders agreed on the need for two specialist eating disorders centres. The Ministry of Health acknowledges that demographic considerations suggest that DHBs and their populations would benefit from having two tertiary centres (in Auckland and Christchurch), but recognises that other considerations, such as geography, may indicate a need for three centres (in Auckland, Wellington and Christchurch).

<sup>9</sup> Consideration needs to be given to the requirements of article 37(c) of the United Nations Convention on the Rights of the Child.

Service providers, in consultation with service users, their family/whānau and specialists at the tertiary eating disorders service, may agree not to transfer a service user who meets criteria for referral to a tertiary service if it is agreed to be in the service user's best interests to remain in their local DHB service. In these situations, the secondary service would be able to access support and input from the tertiary eating disorders service.

Access to tertiary service beds should be flexible enough so that if a service user in one region needs a bed in a tertiary eating disorders service, but there is no bed available in the region, any bed that is available in another region is an option.

In general, secondary inpatient services will be the 'gatekeepers' for referrals to tertiary eating disorders services. However, there may be times when an acutely unwell person is assessed by their general practitioner or other community-based professional as being in immediate need of admission to a tertiary service. (It may still be necessary for secondary inpatient staff to support referral and assist in providing immediate treatment and support for the transition to a tertiary service.)

### Co-ordination and collaboration

A designated clinical leader with an appropriate clinical background in treating eating disorders should be responsible for each tertiary eating disorders service, including having responsibility for research, audits, service accreditation and leadership in the wider eating disorder sector.

The clinical leader of each tertiary eating disorders service will maintain close collaborative links with other tertiary services in addition to close collaborative links with the primary and secondary services of affiliated DHBs. Effective, strong linkages between the tertiary services and DHBs should be maintained predominantly through DHBs' designated liaison people (as described in section 2.3.3).

**Table 4:** Summary of tertiary services

| Service users most likely to need tertiary services   | Probable interventions and activities   | Providers                                | Referral and access arrangements  |
|---|---|--|---|
| <p>Service users who have not responded to secondary outpatient or inpatient interventions or who are determined to be in need of the expertise and interventions provided by a tertiary service</p> <p>Service users with particularly complex needs</p> <p>Service users who have severe and life-threatening eating disorder conditions</p> <p>Service users whose physical condition makes specialised inpatient care essential</p> | <p>Twenty-four-hour seven-day a week service by designated nursing and other health professionals skilled in the treatment of eating disorders and comprehensive and co-ordinated multi-disciplinary care</p> <p>Medical and psychiatric treatment, monitoring, management, support and rehabilitation in several settings</p> <p>Access to dietician services and family therapy</p> <p>Care, co-ordination, and case management of all admitted service users by eating disorder specialists</p> <p>Intensive day-care services and programmes, including meals and meal support</p> <p>Intensive outpatient consultation</p> <p>Nasogastric feeding (when needed) by appropriately trained staff</p> <p>Partnership with the service user and their family/whānau, including ongoing participation in the service user's care</p> <p>Strong links with the District Health Board of domicile, including video-conferencing and other technology to allow local treatment teams to participate in assisting the service user's transitions in their pathway of care</p> <p>Supporting local clinicians to maintain service users in their own communities, including consultation, case discussions, team meetings, telephone contact and teleconferences, in-house training</p> <p>Referring service users back to local District Health Board services for ongoing support supported by comprehensive multi-disciplinary planning before discharge, including agreed follow-up and rehabilitation plans</p> <p>Collaborative advice and support to primary and secondary services about appropriate support services and interventions to support service users whose eating disorder does not meet service entry criteria to tertiary services</p> | <p>Tertiary eating disorder services</p> | <p>From secondary services or in accordance with tertiary eating disorders service criteria and/or the Eating Disorders Service Specification</p> |

### Ministry of Health travel and accommodation policy

When a service user is referred for treatment by their publicly funded health or disability specialist (that is, not a general practitioner) to another publicly funded specialist, the service user may be eligible to claim travel and accommodation assistance under the Ministry of Health's National Travel Assistance Scheme. The service user's specialist needs to approve the service user's accommodation and specialised transport needs, including a taxi, a mobility taxi or air travel.

When a child is eligible for travel and accommodation assistance, they will always be eligible for assistance towards their support person's costs (Ministry of Health 2007).

## **3 Guidelines for Providing Eating Disorders Services**

This section contains guidelines for providing eating disorders services in New Zealand. The guidelines do not supplant internationally recognised clinical guidelines or cover all aspects of eating disorders services. However, they do reflect some of the priorities identified by stakeholders in the New Zealand eating disorders sector.

The guidelines published by the National Institute for Clinical Excellence (2004), Royal Australian and New Zealand College of Psychiatrists (2004) and American Psychiatric Association Steering Committee on Practice Guidelines (2006) are key resources for clinical guidance on how to best treat eating disorders.

### **3.1 Guidelines for assessment, treatment and management**

#### **3.1.1 Assessment occurs as soon as possible**

When a general practitioner refers a person to a mental health service or an eating disorders service for assessment, the person receives a comprehensive psychiatric assessment as soon as is practicable.

#### **3.1.2 Assessment is undertaken by specialist with clinical experience**

Each comprehensive assessment is undertaken by an eating disorders specialist (who is a psychiatrist or other suitably qualified and experienced mental health practitioner with clinical experience in the area of eating disorders).

If an eating disorders specialist is not readily accessible, support and assistance is sought through the DHB's eating disorders liaison person.

#### **3.1.3 Assessment is comprehensive**

Each assessment of a service user considers their physical, psychological and social needs, as well as their risk of self-harm.

Each assessment considers the service user's roles in their everyday life (particularly when the service user is a parent or caregiver).

#### **3.1.4 Treatment planning occurs as soon as practicable**

Treatment planning is undertaken as soon as practicable after a service user's diagnosis. The immediate risk to the service user, including the risk of physical harm, self-harm or suicide, informs the commencement of treatment and the service setting.

#### **3.1.5 Planning is undertaken in partnership**

Treatment, discharge and relapse prevention planning is undertaken by a multi-disciplinary team, which includes the service user's general practitioner, in partnership with the service user and their family/whānau.

### **3.1.6 Care is co-ordinated by a care co-ordinator**

The care of each service user is co-ordinated by a care co-ordinator.

The care co-ordinator (or their 'cover') is easily contactable.

The role of care co-ordinator includes responsibility for ensuring effective communication across service levels and among the multi-disciplinary treatment team and the service user, family/whānau and the service user's general practitioner (if the general practitioner is not part of the treatment team).

### **3.1.7 Treatment planning is regularly reviewed and involves the service user and family/whānau**

Each service user's treatment, discharge and relapse prevention planning evolves through regular multi-disciplinary reviews and regular input from all members of the multi-disciplinary team.

Reviews are undertaken in active partnership with the service user and their family/whānau. However, while consideration is given to the wishes of the service user and their family/whānau, the medical and mental health needs of the service user are paramount.

### **3.1.8 Treatment evolves and is personalised to each service user**

Treatment evolves and is personalised to each service user in accordance with the stage and acuity of their disorder and any co-morbidities, as well as their age, gender and cultural needs. If a service user's wellbeing deteriorates significantly, their treatment planning is comprehensively reviewed.

### **3.1.9 Service users and their family/whānau have access to support groups**

Service users and their family/whānau are made aware of, and have access to, appropriate support groups where they can interact with others who are having or have had similar experiences.

### **3.1.10 Treatment planning ensures a service user has social support systems**

Each service user's treatment, discharge and relapse prevention planning ensures appropriate social support systems and networks are in place for service users to rebuild their self-esteem and self-belief, and considers the service user's accommodation, income, employment and education.

### **3.1.11 Each multi-disciplinary team has input from a range of practitioners**

Each multi-disciplinary team includes, or has provision for input from, a range of health practitioners, including psychiatrists, psychologists, psychotherapists, dieticians, mental health nurses, occupational therapists, social workers, and the service user's general practitioner. 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 Assistance is sought from secondary or tertiary services as required**

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 secondary or tertiary services is sought to assist with service users' treatment and/or referral to more appropriate treatment settings. Assistance from secondary services in other DHBs, or from the tertiary eating disorders services, should be sought through the relevant DHB eating disorders liaison person.

### **3.1.13 DHBs have comprehensive written policies and procedures**

DHBs have comprehensive written policies and procedures for service users' discharge, transitions to, and referrals (including the transfer of clinical and/or care co-ordinator responsibility) from:

- each level of eating disorders services
- medical and psychiatric services
- other DHBs' services
- family/whānau
- social services
- private settings
- non-governmental organisations (NGOs)
- schools
- carers
- support groups.

### **3.1.14 Services provide work or school re-entry and social rehabilitation programmes**

Services try to provide service users with access to comprehensive work or school re-entry and social rehabilitation programmes that operate in conjunction with day programmes and/or community support networks.

### 3.2 Guidelines for services 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: A strategic framework for specialist mental health services for children and young people in New Zealand* (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 requires the sustained collaboration of a wide range of organisations in the wider health and social services sectors.

The priority for child and youth specialist mental health services in *Te Tāhuhu: Improving Mental Health 2005–2015* (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 services are working with children and adolescents, their families/whānau are all-important. Furthermore, 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 differences in physiology, development and cognition. 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 rate, 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 et al (2000) reported that readmissions of service users increased steadily as the service user's length of stay in an eating disorder unit became briefer and their weight at discharge was lower.

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

- early detection and community management
- management by services as close to home as possible
- intensive medical stabilisation, where necessary, and nutritional rehabilitation
- family/whānau-based therapeutic programmes

- support for the service user's educational needs
- educational and vocational rehabilitation
- smooth transitions between and among services based on the service user's needs and severity of illness, not service limitations
- access to appropriate psychotherapeutic support at all stages of treatment
- planned transitions to adult care, when required.

Therefore, in addition to the above guidelines for eating disorders services, the following guidelines apply to eating disorders services for children and adolescents.

### **3.2.1 Clinicians are suitably qualified to work with children and adolescents with eating disorders**

Clinicians involved in the provision of services to children and adolescents with eating disorders are suitably qualified to work with children and adolescents with eating disorders.

### **3.2.2 Multi-disciplinary team is supervised by clinician with expertise in treating children and adolescents with eating disorders**

When a child or an adolescent eating disorders service user is managed and supported in a paediatric or medical setting, supervision of the multi-disciplinary treatment for the eating disorder is provided, whenever possible, by a clinician with expertise in treating children and adolescents with eating disorders (who is likely to be located in child and adolescent mental health services).

When such expertise is not locally available, specialist support and advice is sought through an eating disorders liaison person.

### **3.2.3 Children and adolescents with eating disorders receive inpatient treatment separately from adults with eating disorders**

As a general principle, and in line with the United Nations Declaration on the Rights of the Child and New Zealand government policy, children and adolescents with eating disorders who require inpatient treatment are accommodated, whenever possible, in a setting that is separate to services for adults.

### **3.2.4 Inpatient treatment of children and adolescents with eating disorders is developmentally appropriate**

Facilities for the residential or inpatient treatment of children and adolescents with eating disorders have developmentally appropriate services that are focused on family therapy and behavioural support and management to restore weight, have access to adequate medical and psychological support, and provide prompt and seamless transitions to other treatment settings (when needed).

### **3.2.5 Children and adolescents with eating disorders are treated as close to their usual place of residence as possible**

Whenever possible, outpatient, residential and inpatient treatment services for children and adolescents with eating disorders are in a location that is as close to their usual place of residence as possible, primarily to minimise dislocation from their family/whānau during treatment, but also to aid reintegration into their family/whānau and social environment during later stages of 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 facilitate ongoing contact between the service user and their family/whānau, including appropriate accommodation arrangements.

### **3.2.6 Adolescents who excessively restrict or purge food intake or binge are referred for specialist assessment**

Adolescents who excessively restrict food intake, or vomit, purge or binge with or without severe weight loss are referred for specialist assessment.

### **3.2.7 Children and adolescents with eating disorders have access to education and recreation programmes**

Children and adolescents who are receiving treatment for an eating disorder have access to appropriate education, leisure and recreation programmes.

### **3.2.8 Children and adolescents discharged from inpatient treatment receive intensive outpatient support**

Children and adolescents discharged from inpatient treatment receive intensive outpatient support that is facilitated by a multi-disciplinary team providing continuity of care in a comprehensive, co-ordinated and developmentally appropriate manner.

### **3.2.9 Education of, and liaison with, school nursing and counselling staff is important**

The education of, and liaison with, school nursing and counselling staff is recognised as important, and is undertaken in order to provide a safe and accessible space for young people with eating disorders to disclose their behaviour and/or problems.

### **3.3 Considerations for families/whānau**

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

Family/whānau members, including siblings, should usually be included in the treatment of children and adolescents with eating disorders as they play a crucial role in treatment and recovery. Therapy involving family/whānau should include educating the family/whānau about the disorder and strengthening the parental subsystem and the roles of family/whānau members. Interventions may include sharing information and advice on behavioural management and facilitating communication (National Institute for Clinical Excellence 2004).

When a young person is so unwell that they need inpatient treatment, it is crucial to facilitate the ongoing involvement of their family/whānau. A key part of inpatient treatment for children and adolescents with eating disorders is the process of reintegrating the child or adolescent into their family/whānau. It is often quite straightforward to assist the service user to restore weight in a hospital, but a greater challenge is 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 guidelines apply to the involvement of service users' family/whānau in their treatment and recovery.

#### **3.3.1 Care co-ordinator ensures family/whānau members are included during the service user's treatment and recovery**

Each service user's care co-ordinator ensures members of the service user's family/whānau are included and no one is unreasonably excluded during the service user's ongoing treatment and recovery process.

#### **3.3.2 Eating disorders professionals work in partnership with and support family/whānau**

Eating disorders professionals work in partnership with and support the family/whānau of each service user.

Each service user's care co-ordinator facilitates the involvement of family/whānau and ensures regular communication between the multi-disciplinary team and family/whānau, as well as communication within the team about the involvement of family/whānau.

#### **3.3.3 Communication is clear and open**

Communication is clear and open so the family/whānau is well informed and in a strong position to support the service user's recovery. However, care must be taken to consider the service user's right to privacy.

### **3.3.4 Families/whānau, particularly parents, are educated to support the service user**

Families/whānau, particularly parents, are educated to support the service user's smooth transition home, and better long-term care and family functioning.

### **3.3.5 Families/whānau of service users have access to psychological support**

The families/whānau of service users have access to psychological support and are informed about support groups.

## **3.4 Considerations for parents and caregivers with eating disorders**

When a parent or caregiver 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 impact on children either directly in relation to nutrition and the role of food in the family/whānau or indirectly in terms of the parent's or caregiver's ability to acknowledge or attend to their developmental needs.

The following guidelines apply when a parent or caregiver has an eating disorder.

### **3.4.1 Children's safety and welfare are paramount**

Children's safety and welfare are paramount.

### **3.4.2 Needs of children of a parent or caregiver with an eating disorder must be considered**

Consultation and engagement with the family/whānau of a parent or caregiver experiencing an eating disorder includes consideration of the needs of their children.

### **3.4.3 Parent or caregiver's treatment team involves professionals to address children's needs**

When possible, the multi-disciplinary treatment team responsible for a parent or caregiver with an eating disorder include the active involvement of a relevant health professional or support worker to ensure the needs of any children are taken into account. The service user's care co-ordinator has a crucial role in securing this involvement.

### **3.4.4 Parents and caregivers with eating disorders are treated as close to their usual place of residence as possible**

When a service user is a parent or caregiver, service providers try to provide appropriate (primary and secondary) services as close as possible to the service user's usual place of residence. When a parent or caregiver requires tertiary inpatient treatment for an eating disorder, service providers facilitate ongoing contact between the service user and their children, including appropriate accommodation arrangements.

### **3.5 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.

When 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 (Compulsory Assessment and Treatment) Act 1992 is only applied to service users who are of such an abnormal state of mind that they are of serious danger to themselves or others, or are of seriously reduced capacity for self-care. On this basis, the Act can be invoked to provide treatment for an eating disorder.

## **4 Workforce Development**

### **4.1 Importance of suitably qualified and experienced staff**

Eating disorders services require staff with expertise in physical and psychological health. Effective eating disorders services must have suitably qualified and experienced staff who are responsive, knowledgeable and supportive. Services need to demonstrate to service users that the people who are involved in their care have an understanding of the needs, thoughts, feelings and priorities of each service user (Thompson 2006).

### **4.2 Importance of opportunities for staff to develop expertise**

Opportunities are needed for health professionals to develop eating disorders expertise. These include ongoing education, support and supervision from tertiary eating disorders services. The provision of effective eating disorders services requires building the knowledge and skills of the entire physical and mental health workforce as well as the workforce specifically engaged to deliver eating disorders services. Developing the early intervention skills of primary health care practitioners is particularly important.

### **4.3 Specific workforce development issues**

The workforce issues that need to be considered in the development of eating disorders services include:

- providing opportunities for staff to access training and development that are appropriate for the level of care they provide and the characteristics of their service users
- providing opportunities for staff to ensure 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 with eating disorders
- providing staff with access to library and internet services so they can read literature on eating disorders
- supporting staff attendance, where feasible, at national and international meetings in order to support their 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 and performance review processes
- developing recruitment strategies for Māori, Pacific peoples, and people of other cultures to join the eating disorders workforce.

#### **4.4 Role of the Ministry of Health in workforce development**

The Ministry of Health plans to build and strengthen the eating disorders workforce through its ongoing mental health and addiction workforce development programme.

#### **4.5 Role of tertiary eating disorders services in workforce development**

The proposed tertiary eating disorders services 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 people
- providing opportunities for specialty training posts for registrars
- co-ordinating and contributing to the development and implementation of national guidelines
- providing guidance and direction to help health professionals to undertake professional development that maintains and develops their clinical and professional skills (such as updated practice guidelines and referral processes)
- taking a role in co-ordinating and developing a eating disorder forum (outlined in section 5).

## **5 Eating Disorders Forum**

Stakeholders have suggested an eating disorders forum (or eating disorders network) be formed.

### **5.1 Purpose of an eating disorders forum**

An eating disorders forum would encourage stakeholders (including NGOs) within the eating disorders sector to work together and share their knowledge and experiences, and foster collaboration across primary, secondary, and tertiary services.

The forum would encourage national discussion of aspects of prevention, early intervention, education and treatment of (and outcomes achieved for) service users. Enhanced communication would ensure closer connections between the people and organisations with expertise available across the different 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 participants are separated by considerable geographical distances.

### **5.2 Development of an eating disorders forum**

The following parameters have been suggested to guide the development of an eating disorders forum.

- The forum would be an open, multi-disciplinary group of health professionals, representatives from DHBs and other organisations (including NGOs) and other stakeholders.
- There would be an agreed structure to the forum, with a regular review process to ensure goals were being achieved and that the needs of all stakeholder groups were being recognised and met.

### **5.3 Role of the Ministry of Health**

The Ministry of Health will support the establishment and initial meetings of the forum. In time, this role may be transferred to the tertiary centres.

## **6 Research and Development**

During the process of developing this document, ideas and principles were suggested for research and development that would be useful to guide the Ministry of Health and the sector in developing initiatives to improve eating disorders services.

### **6.1 Who could undertake research**

A variety of entities could commission and undertake research that could inform the development of eating disorders services. Collaborative research could be undertaken among researchers in New Zealand or with researchers and organisations based in Australia and other countries.

### **6.2 Aim of research**

Research should be aimed at achieving measurable improvements in the care of service users, and the experiences of service users should be regarded as crucial to research that informs the development of services.

### **6.3 Research topics**

Suggestions for research included:

- developing outcome measures that establish service user and carer satisfaction as important components
- considering the applicability of suitable technology (such as the use of video-conferencing), particularly given New Zealand's relatively small and dispersed population
- investigating the needs of Māori and methodologies for the inclusion of Māori in developing culturally appropriate services and care pathways
- investigating the needs of Pacific peoples in order to provide culturally appropriate eating disorders services
- investigating the needs of migrants in order to provide culturally appropriate eating disorders services
- evaluating the effectiveness of initiatives and interventions (including peer support) at any level in the care continuum
- investigating methodologies that enable the effective collection and analysis of national-level data on access and outcomes
- further exploring the incidence and prevalence of eating disorders in New Zealand, particularly among children and adolescents and specific cultural groups
- further investigating the treatment options available, and the efficacy of those options, within New Zealand
- contributing to the development of clinical pathways and guidelines for early intervention and primary services in the New Zealand context

- investigating, developing and establishing effective, evidence-based eating disorder prevention and awareness initiatives in schools
- investigating the feasibility and effectiveness of establishing mobile eating disorders teams to work with local primary and secondary care services to deliver care as close as possible to the homes of children and adolescents
- investigating whether strategies are required to counter images and themes that are presented in, or conveyed by, various media, entertainment and advertising formats
- investigating the appropriate use of alternative and emerging therapies in the treatment of eating disorders
- contributing to the establishment of evidence-based guidelines that are specific to the New Zealand context to assist staff in providing effective early intervention and supporting service users with mild-to-moderate eating disorders in primary care settings, including criteria for referring service users to more-specialised eating disorders services
- developing a stronger understanding of the workforce development required to establish effective eating disorders services, with strong links to the wider body of workforce development research
- further investigating eating disorders with co-morbid mental illness, and how this might affect care planning and protocols for service co-ordination across different services.

## **6.4 Role of the Ministry of Health**

The Ministry of Health is planning to build and strengthen the eating disorders services that are available in New Zealand through its ongoing mental health and addiction research and development programme.

# Appendix 1: Further Information on Eating Disorders

In addition to the information in section 1.1, the following should be noted.

- 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.
- The American Psychiatric Association Steering Committee on Practice Guidelines (2006) reported that disordered eating behaviours appear to be globally distributed. Studies have shown increases in the prevalence of eating disorders in Japan and China, and increases in disturbed attitudes in non-Western countries such as Iran and Fiji.
- The American Psychiatric Association Steering Committee on Practice Guidelines (2006) reported that most eating disorders in service users start when 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 disorders.
- One study estimated that up to 5 percent of women presenting to (or registering with) a general practitioner had an undiagnosed eating disorder, with up to 50 percent of cases remaining unrecognised (Marks et al 2003).

## Types of eating disorders

### Anorexia nervosa

Anorexia nervosa is characterised by the severe restriction of food intake, and generally results in significant (and dangerous) weight loss. Anorexia, while rare, has the highest level of mortality of any psychiatric disorder, due to medical complications and suicide.

Anorexia nervosa is the eating disorder for which a person is most likely to require specialist inpatient treatment.

In diagnosing anorexia, the National Institute for Clinical Excellence (2004) reported that although weight and body mass index are important indicators, they should not be considered the sole indicators of physical risk because they are unreliable, especially in children.

Although a significant proportion 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).

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 percent of people with anorexia not recovering.

### **Bulimia nervosa**

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

Bulimia is found mainly in older females and has a lower mortality (Wells et al 1989). Its highest rate of onset is around ages 18 to 20. There is good evidence for the use of Cognitive Behaviour Therapy in the treatment of bulimia nervosa (National Institute for Clinical Excellence 2004).

### **Eating disorders not otherwise specified**

The composite category of 'eating disorders not otherwise specified' (EDNOS) from the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)* (American Psychiatric Association 2000) is the most common eating disorder category.

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 among 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 and Adolescent Medicine Committee 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 estimates of the prevalence of eating disorders vary.

*Te Rau Hinengaro: The New Zealand Mental Health Survey* 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 17 years (Oakley Browne et al 2006).

The data in Table 5 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 5:** Twelve-month and lifetime prevalence of eating disorders in New Zealand

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

Notes: The figures in brackets indicate that there is a 95 percent chance that the true value lies within that range.

\* The Australian figure for 12-month prevalence is 1-1.5 percent and for lifetime prevalence is 5 percent for women, which is consistent with the figures found for other Western populations.

Source: Oakley Browne et al (2006, Tables 3.1, 4.1, 9.4 and 10.1).

## Eating disorders and mortality

Eating disorders can be fatal. Herzog et al (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 percent for people with anorexia. Nielsen (2001) estimated mortality rates ranging from 0.3 percent to as high as 20 percent.

Generally, death occurs as a result of the physical (usually cardiac) complications of malnutrition as well as from suicide. Most of the deaths associated with 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: The New Zealand Mental Health Survey* highlighted the elevated risk for suicide associated with eating disorders (Oakley Browne et al 2006). Data showed the risk of suicide is higher for people with eating disorders than the risk of suicide in those with a mood disorder. Of people with an eating disorder, 22.9 percent reported suicidal ideation, 10.1 percent reported making suicide plans, and 9 percent reported making a suicide attempt. Of people with a mood disorder, 20.2 percent reported suicidal ideation, 7.6 percent reported making suicide plans, and 3.4 percent reported making a suicide attempt.

## **Clinical resources**

The clinical guidelines that should be considered when eating disorders services are provided include:

- *Australian and New Zealand clinical practice guidelines for the treatment of anorexia nervosa* (Royal Australian and New Zealand College of Psychiatrists 2004)
- *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders* (National Institute for Clinical Excellence 2004)
- *Practice Guideline for the Treatment of Patients with Eating Disorders* (American Psychiatric Association Steering Committee on Practice Guidelines 2006)
- Policy statement: identifying and treating eating disorders (American Academy of Paediatrics 2003)
- Eating disorders in adolescents: position paper of the Society for Adolescent Medicine (Society for Adolescent Medicine 2003).

## Appendix 2: Eating Disorders Services in New Zealand

Service users with eating disorders are supported by a range of service providers that include community or non-government organisations, primary care services, secondary mental health services, general medical, psychiatric, and paediatric services, and tertiary care services. Some District Health Boards collaborate to offer regional services.

### District Health Board provider arm services

District Health Board provider arm services are summarised in Table 6.

**Table 6:** Summary of District Health Board provider arm services, as at 31 October 2007

| District Health Board   | Regional services | Main provider   | Location of regional service             | Specialist inpatient or residential unit | Day programme | Outpatient service |
|---|-------------------|-----------------|--|--|---------------|--------------------|
| <b>Northern Region</b><br>Waitemata<br>Auckland<br>Counties Manukau<br>Northland*                                     | Yes               | Auckland DHB    | Greenlane Clinical Centre, Auckland      | No                                       | No            | Yes                |
| <b>Midland Region**</b><br>Waikato<br>Bay of Plenty<br>Lakes<br>Tairāwhiti<br>Taranaki                                | No                | None            | No                                       | No                                       | No            | No                 |
| <b>Central Region</b><br>Capital & Coast<br>Hutt Valley<br>Wairarapa<br>MidCentral<br>Whanganui<br>Hawke's Bay        | Yes               | Hutt Valley DHB | Johnsonville                             | Yes                                      | Yes           | Yes                |
| <b>Southern Region***</b><br>Canterbury<br>Nelson Marlborough<br>West Coast<br>South Canterbury<br>Otago<br>Southland | Yes               | Canterbury DHB  | Princess Margaret Hospital, Christchurch | Yes                                      | No            | Yes                |

Notes: Regional variations or the absence of regional services does not necessarily mean there are DHBs that are not meeting the needs of individuals within their local area.

\* Northland District Health Board (DHB) receives only supervision and consultation from Auckland eating disorders services.

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

\*\*\* All South Island DHBs have agreements with Canterbury DHB for access to its regional service.

## **Private services**

### **Ashburn Clinic and other private services**

DHBs, service users and their family/whānau have the option of funding service users to attend the Ashburn Clinic, and otherwise privately funded eating disorder services. The Ministry of Health contributes to funding for beds at the Ashburn Clinic on a limited basis.

### **New Zealand Eating Disorder Specialists**

New Zealand Eating Disorder Specialists (<http://nzeatingdisorderspecialists.co.nz>) is a private clinic in Auckland that helps people and their families to overcome eating disorders.

## **Non-government organisations**

Several non-government organisations (NGOs) or community and voluntary organisations provide support, education, information, counselling and referral services to service users and their family/whānau, as well as information for the 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 to service users with other types of eating disorders, such as subclinical conditions.

NGOs often help service users 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.

NGOs can have 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.

NGOs operating in the eating disorders sector include the following.

- The Eating Difficulties Education Network (EDEN) is an Auckland-based NGO that provides support and information. It promotes body trust and satisfaction, size acceptance, and diversity on individual and societal levels.  
Website: <http://www.eden.org.nz>  
Telephone: (09) 378 9039
- The Eating Awareness Team (EAT) is a Christchurch-based NGO that offers support, information, and referral for food and body image issues.  
Telephone: 0800 690 233

- The North Shore Women’s Centre offers information, support, courses and counselling to women with eating-related problems.  
Website: <http://www.womyn-ctr.co.nz>  
Telephone: (09) 444 4618
- The Eating Disorders Association of New Zealand is an Auckland-based NGO that offers support and information to people affected by an eating disorder.  
Telephone (09) 522 2679.

## **Other information sources**

In addition to its clinical guidelines, the Royal Australian and New Zealand College of Psychiatrists (2005) has produced a guide for carers and consumers.

The Mental Health Foundation has produced “Mental Health Information New Zealand” booklets that cover anorexia and bulimia and provide general information to service users, their families/whānau and people involved in supporting and treating people with eating disorders (Mental Health Foundation 2002). The booklets also provide the contact details for support groups and organisations that offer help to service users with eating disorders, as well as listing useful websites and books.

The Central Region Eating Disorder Service (CREDS) has a website that provides information about its services and detailed information about eating disorders (<http://www.eatingdisorders.org.nz>).

A large amount of information about eating disorders is available from the internet. However, some sites contain misinformation. Health practitioners are encouraged to advise and caution service users and their family/whānau and friends about the accuracy of such information.

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