

A Nationally Consistent Approach to Eating Disorders

Opportunities to Implement the National Eating Disorders Framework

National Eating Disorders Collaboration

February 2013

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Acknowledgements

Collaboration, defined as the act of ‘voluntarily and cooperatively working together to achieve a common goal’, is the core operating principle of the National Eating Disorders Collaboration (NEDC). This collaborative approach has brought together representatives from the three key interest groups in the eating disorder sector – people with lived experience, clinicians and researchers – together with stakeholders from a wide variety of related sectors to review knowledge and develop consensus on strategies for a nationally consistent approach to eating disorders.

The contribution from NEDC members and stakeholders and other interest groups in creating this report has been invaluable in shaping our understanding of the opportunities and challenges of implementing eating disorder prevention and treatment initiatives and has enabled the NEDC to develop a more complete and accurate picture of what is happening for eating disorders in Australia. The NEDC gratefully acknowledges the time, effort and passion that people have brought to this process.

The NEDC also acknowledges the considerable work that has already been done by some state governments, academic institutions and consumer advocacy groups on identification of gaps and opportunities for improved service for people with eating disorders. The NEDC gap analysis process has been, to some extent, a confirmatory, consolidation process, ensuring that the views expressed in earlier reports are still current, are of national relevance and that they have a level of consensus support for national implementation.

Particular thanks must also go to the Steering Committee of the NEDC who have provided expert leadership for the gap analysis process and the development of this report.

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i. The National Eating Disorders Collaboration

The National Eating Disorders Collaboration (NEDC) is the second phase of a project initiated and funded by the Commonwealth Government Department of Health and Ageing (DoHA) in 2009.

The primary purpose of the NEDC is to bring together eating disorder stakeholders and experts in mental health, public health, health promotion, education, research and the media to develop a nationally consistent approach to the prevention and management of eating disorders.

The project's objectives include:

- Provide or facilitate access to helpful, evidence-based information for young people and their families on the prevention and management of eating disorders and healthy eating
- Promote a consistent evidence-based national approach to eating disorders
- Develop and assist in implementing a comprehensive national strategy to communicate appropriate evidence-based messages to schools, the media and health service providers

In working towards these objectives, the NEDC is actively pursuing the vision and goals outlined in the first phase of the project:

1. Eating disorders are a priority mainstream health issue in Australia
2. A healthy, diverse and inclusive Australian society acts to prevent eating disorders
3. Every Australian at risk has access to an effective continuum of eating disorder prevention, care and ongoing recovery support

In developing all reports and resources, the NEDC has drawn upon research evidence and consultation with clinicians, researchers, community-based organisations, people with experience of eating disorders and their carers and other interested stakeholders.

ii. Executive Summary

Eating disorders are a group of serious and complex mental illnesses. A person with an eating disorder requires treatment that is specific to their disorder and delivered by health professionals who have been trained in the delivery of evidence-based approaches.

Without appropriate intervention as early as possible in the course of illness, eating disorders are likely to persist long term, lead to physical health complications, and reduce quality of life and life expectancy.

This report profiles what is known about approaches to eating disorder prevention and treatment in Australia, from the perspectives of service providers, clinicians and people with experience of eating disorders, and compares this with evidence-based standards.

The calibre of eating disorder research in Australia is world class and Australian researchers are amongst the world leaders in this field, despite very restricted access to funding by comparison with other health sectors.

While small in number, there are specialist eating disorder services in Australia that put this research into practice. These services have developed on an opportunistic basis, largely in isolation from each other and other health sectors, and have been driven by individual expertise, perceived local need and funding opportunity.

Good practice in eating disorder prevention and treatment can be identified in individual clinicians and individual services. The health system in Australia has not yet systematically adopted these good practices.

Identifying Priority Gaps

There are significant gaps in the continuum of care available to patients with eating disorders in Australia. Most people have, at best, access to only one part of the continuum. There are too few services for the number of people experiencing eating disorders, with no evidence of geographic planning for a full continuum of care. No single Local Health District has been identified to date that delivers a full continuum of care for people with eating disorders.

The key gap identified in the NEDC Gap Analysis is the lack of a systematic approach that embeds eating disorder treatment into mainstream health systems and ensures that the majority of people with eating disorders have access to evidence-based care. Evidence for the lack of a systematic approach can be found in the inconsistencies between states and territories and between differing regions in the implementation of prevention programs, specialist treatment programs and community-based recovery support programs. The absence of systematic implementation of eating disorder initiatives can be identified at all levels in the continuum of care, from prevention to recovery support, and at all levels of administration, from policies to data collection.

Reference to eating disorders is largely absent from health policies and funding arrangements. Reliance on an understanding of other mental illnesses as the basis for policy development has led to initiatives that do not address the complexity and duration of eating disorders. The absence of eating disorders, particularly binge eating disorder and EDNOS, from policy, plans, data collection and access criteria for services compounds the invisibility of these serious illnesses. The outcome is a high cost in health complications, quality of life, life expectancy and measurable financial costs. Systems are required to support integration of services provided at different levels of care, in different settings, from community services to tertiary services, and potentially in different health regions or even different states. This level of formal integration is essential to address gaps in workforce capacity and specialist service provision.

The challenges in developing a systematic response to eating disorders in the Australian context are shared with many other health sectors. These challenges include the stigma associated with mental illness, providing expert community-based care to relatively small populations, and the integration of physical and mental health, and health and non-health services, as part of a whole treatment pathway.

In addition to these shared issues, inquiry for this report identified the following key gaps in current approaches to eating disorders:

Access to treatment and support

- The results of surveys used in the development of this report indicate that 85% of people seeking treatment experience difficulty accessing appropriate treatment and 60% of clinicians experience difficulty referring clients for eating disorder treatment
- There are no specialist eating disorder inpatient services for adults in TAS, NT and WA
- There are no specialist eating disorder services in regional areas
- No local health district provides a full continuum of care
- Most treatment services, including specialist eating disorder services, do not include the full range of professionals for the multidisciplinary team
- Current funding initiatives for mental health support a treatment dosage that is substantially less than the evidence-based treatment dosage
- Most treatment for eating disorders is provided through private practice and through private hospitals. Lack of recognition of eating disorders in private health insurance, Medicare benefits and other funding initiatives leads to difficulties in accessing treatment, particularly for people who are reliant on public health services

Workforce knowledge and skill

- Half of health professionals receive no training in eating disorders and an additional 47% receive training they believe is inadequate to equip them to treat eating disorders
- There is very limited awareness of the presentation of eating disorders, other than extreme weight loss in anorexia nervosa, in both health professionals and the general community

Standards

- The results of surveys used in the development of this report indicate that 57% of clinicians providing community-based treatment do not use guidelines for working with clients with eating disorders. When guidelines are used they are not consistent and do not necessarily reflect existing evidence-based guidelines
- Lack of strategies to provide integrated treatment in general health services results in a ‘revolving door’ experience for people with an eating disorder, exiting a service once medically stable and receiving no follow-up support until they are next medically compromised

Family support

- Lack of access to recovery and family support services in the local community increases costs and disruption to normal life and increases the risk of relapse
- Lack of integration of support services with treatment for people who access treatment from general health services, reduces effectiveness of treatment and increases family stress

Consistent implementation of prevention

- There is no consistent implementation of eating disorder prevention initiatives
- Eating disorders are not included in the development or evaluation of mental health, obesity prevention and general health promotion initiatives

Data to inform health system development

- No data has been collected on eating disorders by the Australian Bureau of Statistics
- To date no data has been available on eating disorders to guide the development of mental health initiatives, such as Better Access to Mental Health Services

The Cost of Eating Disorders

A recently released report from Deloitte Access Economics (2012) estimates the total annual socio-economic impact of eating disorders at \$69.7 billion (Access Economics, 2012). This figure includes financial costs of \$99.9 million per annum for health system costs and \$15.1 billion per annum for productivity costs.

The “burden of disease” from eating disorders is estimated as \$52.6 billion, which is comparable to the estimated value of the burden of disease for anxiety and depression of \$41.2 billion, and for obesity at \$52.9 billion (Access Economics, 2012). Combining the burden of disease and financial costs, the total socio-economic impact of eating disorders is \$69.7 billion (Access Economics, 2012).

These are conservative estimates of the cost of eating disorders. The estimates of prevalence used in these calculations are lower than those from Australian studies of prevalence and the costs of treatment are based on limited Australian data collection.

Studies suggest that only 22% of people with eating disorders access specialist treatment for their illness (Swanson, Crow et al., 2011) and identification of people with bulimia nervosa and binge eating disorder may be as low as 10% of actual cases. These low levels of treatment are influenced

by the nature of the illness, by the stigma associated with eating disorders, and by unsuccessful attempts to engage with health professionals.

“My eating disorder has cost me my whole life. I am isolated from all the normal activities of a woman of my age. In many ways my life got stuck in Year 8 at high school and I haven’t been able to move on. I still live with my parents because I can’t afford to pay rent. I work part time because I am physically too unwell to take on a full time job. I cannot get involved in the sort of social activities that my sisters and peers engage in”

Building on Existing Resources

Information and service models that address these gaps are already available in Australia. Training resources already exist, national standards and service models are emerging from the work of the NEDC; innovative approaches to service delivery, including outreach and access pathways, have already been developed to suit the Australian context; evidence-based prevention and early intervention programs are ready to be implemented. There is infrastructure in the general mental health sector, including prevention initiatives and rehabilitation support, which can be utilised as a platform for improved community-based access to eating disorder support, provided that such services are staffed by people trained at an appropriate level in eating disorders.

Australia is fortunate to have a mental health policy, plan and standards that promote recovery, early intervention, evidence-based treatment and consumer participation. The current policy environment offers a framework to develop an eating disorder system of care that is able to intervene early and provide integrated services across health and social domains that is consistent with the Fourth National Mental Health Plan (2009).

Building on the policies and expertise that we already have will require a commitment of resources. The alternative, however, is for individuals, families, communities and governments to continue to bear ever-increasing costs associated with not providing access to effective treatment.

The cost of untreated or inappropriately treated long term eating disorders is much greater for everyone involved than the cost of adequate provision of treatment.

“It is important to note that unless more effective treatment becomes more accessible and affordable, these sufferers will lean on the health system, often for a lifetime. Whilst our daughter is only 23, she maintains her anorexia, manages it, survives, but the side effects may only increase and become apparent as she gets older”

Identifying National Priorities

Action is required in all areas across the continuum of care, from prevention to recovery support, and in all states and territories, to address priority gaps. Action in all of these opportunity areas has the potential to reduce the impact of eating disorders.

Each state and territory has taken a different approach to the development of eating disorders services and therefore the next steps in development will look somewhat different in each area. It is difficult to recommend systematic approaches that are appropriate for implementation in the different health systems in each state and territory, particularly in the context of the very different stages of development of eating disorder services in each region. This report outlines models of service delivery for eating disorders that fit within a 'hub and spoke approach' as a source of guidance for the development of locally relevant solutions.

The intention of the Gap Analysis report is to outline a systematic approach to eating disorder service development that addresses national priorities and that can inform state and territory governments as they select the specific issues to target within their existing systems. The priority areas for action identified below provide the first steps towards the development of a nationally consistent approach to eating disorders that addresses the key gaps in current service delivery.

Identified National Priorities

1. Policy

Inclusion of eating disorders and the evidence-based standards for eating disorder prevention and treatment in all relevant health policies, plans, funding initiatives, Medicare Benefits Schedule and health promotion strategies.

Specific action is required to:

- Increase access to psychology, psychiatry and multidisciplinary services through the introduction of separate Medicare item numbers for eating disorders or adaption of existing access initiatives (e.g. BAMHS, ATAPS) to reflect evidence-based dosage and duration of treatment
- Prioritise mapping of eating disorder population health needs and service gaps in each community health region
- Include eating disorders in the development of national hospital reform and the move to activity-based costing to ensure appropriate remuneration for inpatient, residential and community treatment
- Integrate body image and eating disorder prevention at a policy level, recognising that body dissatisfaction is a risk factor for eating disorders
- Integrate eating disorder prevention strategies in health promotion and prevention initiatives that address general mental health, body esteem, nutrition, exercise and obesity

2. Workforce development

Implementation of core competencies and facilitated access to existing training for all health professionals and other professionals who work with high risk groups.

For early intervention and timely treatment to occur, it is essential that people who work with those at high risk of eating disorders proactively identify eating disorder symptoms and engage people in help seeking. It is essential that there are then appropriate treatments for those people to be

referred to. Without an active response from health professionals, supported by a knowledgeable community, early intervention will not happen.

Workforce development is a very high priority area for action. While other strategies are required (as outlined in this report), none of these strategies can successfully address the effectiveness of responses to eating disorders without the development of a skilled workforce.

Specific action is required to:

- Facilitate access to existing education and basic training resources
- Implement core competencies for all health professionals and other professionals working with people at high risk of eating disorders
- Resource existing centres of eating disorder expertise to enable better outreach and tertiary support for primary and secondary health services, especially in regional areas

3. Consistent national standards

Develop and implement national standards, clinical guidelines and decision support tools.

Nationally consistent approaches to eating disorders in Australia can only be achieved with the consistent implementation of shared standards. An immediate opportunity exists to build on the impetus and expertise of the NEDC to review existing guidelines and decision tools and develop them into one consistent national suite of standards.

Specific action is required to:

- Review existing clinical guidelines and develop:
 - Australian clinical guidelines that cover the full spectrum of eating disorders
 - Implementation guidelines that address the uptake, usage and medico-legal implications of national standards and clinical guidelines
 - Decision support tools relevant to each discipline in the multidisciplinary team
- Ongoing review of emerging evidence and translation into practice

4. Community access

Resourcing existing eating disorder services (government and non-government) to extend the reach and capacity of services as soft entry points for rapid and appropriate assessment and referral.

Specific action is required to:

- Disseminate existing assessment and referral tools
- Review roles and capacity of existing information and 'point of entry' services
- Develop collaborative links between information services and eating disorder service providers to ensure streamlined, timely referrals
- Review and build the capacity of existing information services to provide immediate access to short term professional intervention as an early intervention strategy and to maintain motivation while people wait for access to other services

5. Integrated approaches to prevention

Implement an integrated cross-sector approach to address the complex and interrelated problems of eating disorders, body dissatisfaction and obesity.

Specific action is required to:

- Implement existing evidence-based prevention and early intervention programs on a consistent basis, using existing mental health promotion initiatives as a platform for dissemination
- Provide training in the delivery of evidence-based prevention programs for teachers, sports coaches and other professionals working with young people
- Collaborate with health promotion campaigns to develop safe and effective approaches to weight management, with an emphasis on healthy lifestyle modification for children and young people
- Facilitate access to mental health literacy and Mental Health First Aid training for parents and professionals who work with people at high risk of eating disorders
- Implement the NEDC guidelines on safe weight related messages for all weight related health promotion strategies
- Convene a national expert panel to review the role of dieting in obesity, body dissatisfaction and eating disorders and develop long term strategies to promote healthy environments
- Provide online access to professionally facilitated self-guided early intervention programs under the auspice of one or more existing eating disorder service providers

6. Data collection

Inclusion of all diagnoses of eating disorders in health and welfare data collection and mental health surveys as a first step towards developing a detailed profile of eating disorders in Australia



There is an immediate need to improve access to eating disorder treatments in order to reduce inequities in regional access to all levels of treatment, improve access to early intervention, recovery support and treatment for mild to moderate presentations of eating disorders in community settings and improve access to intensive outpatient programs (including day programs and residential programs) in all states and territories.

However, on the basis of current data, it is not possible to accurately establish benchmarks for the capacity of eating disorder services or estimate the level of future need for eating disorder specialist services.

A priority area for action should therefore be focused on more detailed data collection to support decision making.

Specific action is required to:

- Include all diagnoses of eating disorders as distinct categories in national data collection activities including the Australian Health Survey
- Include BED as a condition in the International Classification of Primary Care
- Include eating disorders as a national research priority and support a National Research Agenda for the eating disorder sector
- Develop a detailed map of existing service capacity and resources for potential development in all community health regions
- Review of the role, capacity and sustainability of current state-based non-government community organisations providing support to people with eating disorders and their families.

Outcome	Nationally consistent standards are implemented in all health care services to ensure the provision of safe, multidisciplinary, evidence-based treatment	All Australians have access to a full continuum of care provided on a flexible basis to meet changing individual needs	All health professionals and other professionals who work with people at high risk of eating disorders are able to identify and appropriately support people with eating disorders	People with eating disorders are supported to actively participate in the decisions that affect their lives. Families and carers are educated and supported as important members of the treatment team	Health promotion and prevention initiatives provide safe and appropriate messages that support eating disorder prevention	Accurate data supports a national research agenda to improve the evidence for effective eating disorders prevention and treatment
	Develop and implement national standards, clinical guidelines and decision support tools	Resourcing existing eating disorders services to extend the reach and capacity of services as soft entry points for rapid and appropriate assessment and referral	Resource existing centres of eating disorders expertise to enable better outreach and tertiary support for primary and secondary health services	Resource community-based organisations to provide accessible support services	Implement an integrated cross-sector approach to address the complex and inter-related problems of eating disorders, body dissatisfaction and obesity	Inclusion of all diagnoses of eating disorders in health and welfare surveys and data collection
Priority Actions	 Workforce development Implementation of core competencies and facilitated access to existing training for all health professionals and other professionals who work with high risk groups					
	 Policy inclusion of eating disorders and the evidence-based standards for eating disorders prevention and treatment in all relevant health policies, plans, funding initiatives and health promotion strategies					
Gaps	Standards Consistent standards of treatment	Access Access to a full continuum of evidence based treatment	Workforce Skilled, knowledgeable workforce that is confident to treat	Support Support for consumer participation and recovery; Support for families and carers	Prevention Consistent access to prevention and early intervention programs; Integration of prevention with other health initiatives	Evidence Australian data to inform system development

Eating Disorders: the facts.

9% of people in Australia, over 2 million, will get an eating disorder in their lifetime.



Up to 1 in 10 people with an eating disorder may die as a result of their illness.



Only 22% of people with an eating disorder have access to specialist treatment.



Approximately half of children aged 10 & 11 want to lose weight and 3/4 of them have attempted to diet in the last 12 months.



Men make up 25% of people with anorexia or bulimia and 40% of people with binge eating disorder.



It is estimated that 30% of people seeking weight loss treatment have binge eating disorder.



iii. The Impact of Eating Disorders

Eating disorders are a group of serious psychiatric illnesses resulting in significant physical complications and impairment. During episodes of illness, people with eating disorders experience extreme psychological distress.

“Sufferers describe having a tyrant yelling abuse, threats and instructions in their head 24 hours a day”

In the longer term, people with eating disorders experience an increased risk of chronic illnesses, including risk of common non-communicable diseases such as heart disease, renal failure and osteoporosis as well as an increased risk of premature death.

The long term risks are different for each type of eating disorder but are potentially equally significant in terms of the impact on health, wellbeing, quality of life and life expectancy.

Life Expectancy

The risk of premature death is increased for people with all types of eating disorders (Arcelus et al. 2011), in part due to medical complications and in part due to an increased rate of suicide (Pompili et al., 2006). Young people with eating disorders are over 10 times more likely to die prematurely than their peers who are without an eating disorder (Steinhausen, 2009). Statistically, a woman who has had anorexia nervosa from the age of 15 (the average age of onset) is likely to live 25 years less than predicted for the normal population (Harbottle, Birmingham & Sayani, 2008).

This association between mental illness and increased risk of premature death has been demonstrated for other mental illnesses, even at low levels of psychological distress (Russ, Stamatakis et al., 2012). However, eating disorders, and in particular anorexia nervosa, have the highest mortality rate of any psychiatric illness. The Standardised Mortality Ratio (the ratio of observed to expected deaths) in anorexia nervosa has been shown to be as high as 12.8, which compares with a ratio of around 2.5 in schizophrenia and 1.6 in major depression (Arcelus, Mitchell, Wales & Nielsen, 2011).

Eating Disorders

Eating disorders include anorexia nervosa, bulimia nervosa, binge eating disorder, and eating disorders not otherwise specified (EDNOS). People with eating disorders have disturbed eating behaviours and distorted beliefs, with extreme concerns about weight, shape, eating and body image. Symptoms can also include driven exercise.

Eating disorders are very individual and complex illnesses. In practice, this means that individuals will present with variations in the typical symptoms. People with variable symptoms are usually diagnosed with eating disorders not otherwise specified.

People with these illnesses may have some but not all of the diagnostic signs for anorexia nervosa or bulimia nervosa or they may experience a combination of symptoms. People with EDNOS who have symptoms of anorexia nervosa, bulimia nervosa or binge eating disorder are susceptible to the same health complications as individuals who have been diagnosed with those disorders.

During the course of illness, an individual's presentation of symptoms will often change and so may their diagnosis. The diagnosis is not a measure of the severity of illness or the potential long term impact of the illness.

More people are diagnosed with binge eating disorder or EDNOS in Australia than either of the other eating disorder diagnoses. People with EDNOS are at equal risk of experiencing the adverse effects of eating disorders as those with more specific eating disorders. The risk factors may be increased when these disorders are not diagnosed and treated appropriately and in a timely manner.

One in five deaths from anorexia nervosa is due to suicide. Death from suicide is 32 times higher than expected in the general population. By comparison, people diagnosed with major depression are 20 times more likely to die from suicide (Steinhausen, 2009).

Long Term Impact

Recovery from an eating disorder is possible, especially with early intervention. Without early intervention, the long term prospects are relatively poor. Approximately 50% of individuals with anorexia nervosa and bulimia nervosa will recover. Of the remaining 50%, 20%–30% will continue to experience persistent sub-clinical symptoms, and 20%–25% will have a severe and enduring disorder (Steinhausen, 2009). Approximately 18% of people with binge eating disorder may experience a long term eating disorder of clinical severity (Fairburn, Cooper et al., 2000). Research into binge eating disorder has identified that this disorder is at least as chronic and stable as anorexia nervosa and bulimia nervosa (Hudson et al., 2007).

Eating disorders have been shown to have one of the highest impacts on health-related quality of life of all psychiatric disorders (AIHW, 2007). All eating disorders have potential long term health consequences (Harbottle, 2009).

For the individual, the impact may include psychiatric and behavioural effects, medical complications, social isolation and disability. People who develop eating disorders in childhood or adolescence may experience interrupted physical, educational and social development and a long term risk of significant medical complications (NEDC, 2010).

“Having an eating disorder is like being in a personal hell, where no matter what you do or don’t do, everything is wrong. It involved a lonely, isolated world of shame, guilt and a feeling of utter failure”

For families, the impact may include carer stress, loss of family income and disruption to family relationships (Treasure et al., 2001; NEDC, 2010).

Economic Impact

The cost of eating disorders is substantial. Eating disorders are the 12th leading cause of mental health hospitalisation costs within Australia, and the expense of treatment of an episode of anorexia nervosa has been reported to come second only to the cost of cardiac artery bypass surgery in the private hospital sector in Australia. Bulimia nervosa and anorexia nervosa are the 8th and 10th leading causes, respectively, of burden of disease and injury in females aged 15 to 24 in Australia, as measured by disability-adjusted life years (NEDC, 2010).

People with severe and enduring anorexia nervosa are often under-employed or unemployed, receiving sickness benefits, and suffering from multiple medical complications requiring primary, secondary and specialist medical care (Birmingham & Treasure, 2010).

The provision of treatment for eating disorders at current levels may appear costly. A recently released report from Deloitte Access Economics (2012) estimates the total annual expenditure on

eating disorders in 2012 at \$99.9 million, based on AIHW reports for 2008-2009. These health system costs are primarily borne by the Australian government (\$42.6 million) and state, territory and local governments (\$26.4 million). Individuals contribute \$10.4 million, while family/friends and carers make up the remaining \$20.5 million (Access Economics, 2012).

The cost of untreated or inappropriately treated long term illness, however, is much higher for everyone involved.

Added to the need for repeated access to treatment for the disorder and for treatment for all of the physical health consequences of the disorder over many years, are the costs of loss of productivity, loss of quality of life, health impacts on family and carers and out of pocket expenses. The Deloitte Access Economics report estimates the productivity impacts of eating disorders in 2012 to be \$15.1 billion, similar to the productivity impacts of anxiety and depression, which were estimated at \$17.9 billion in 2010 (Access Economics, 2012).

The “burden of disease” from eating disorders is estimated as \$52.6 billion, which is comparable with the estimated value of the burden of disease for anxiety and depression of \$41.2 billion, and for obesity at \$52.9 billion (Access Economics, 2012).

The total financial cost of eating disorders in Australia in 2012 was estimated as \$17.18 billion. If the burden of disease is included, valued at \$52.6 billion, then the total socio-economic impact of eating disorders is \$69.7 billion (Access Economics, 2012).

The majority (\$9.97 billion or 58%) of this cost is borne by individuals, mainly through lost earnings. If the value of healthy life lost (burden of disease) is included, then the total share of costs borne by individuals rises to 90% (Access Economics, 2012).

The Australian Government is the second largest bearer of the financial costs of eating disorders, with \$4.89 billion (29%) of these costs. This is mostly from taxation revenue lost because of productivity impacts, rather than from funding for the current health system approach to eating disorders.

These are conservative estimates of the cost of eating disorders. The estimates of prevalence used in these calculations are lower than those from Australian studies of prevalence and the costs of treatment are based on limited Australian data collection. Studies suggest that only 22% of people with eating disorders access specialist treatment for their illness (Swanson, Crow et al., 2011) and identification of people with bulimia nervosa and binge eating disorder may be as low as 10% of actual cases.

Increasing Incidence

Eating disorders are relatively common in the community when compared with other priority health issues (such as diabetes or asthma) and their peak age of onset in childhood and youth has significant implications for the individual’s long term health and, therefore, for the burden of disease.

Eating disorders are estimated to affect approximately 9% of the total population (males and females of all ages). During the course of a lifetime, it is estimated that approximately 15% of Australian women experience an eating disorder (Wade et al., 2006). These estimates do not fully take into consideration the frequent under-reporting and under-treatment of eating disorders, especially in men (Hudson et al., 2007).

The impact of sub-clinical eating disorders is even higher, with an estimated 20% of females being affected and again, these estimates may be understated due to the secretive nature of the disorders (O'Dea, 2005). The incidence of risk factors in the Australian population is higher still, with disordered eating and body dissatisfaction being common occurrences especially in adolescence (Russell-Mayhew, 2007). Many studies show that disordered eating is now normative in Australian society. Dieting and fasting has been documented as being in between 50% (10-11 year olds) and 90% (12 to 17 year olds) of children and young people.

The rate of eating disorders in the Australian population is increasing (Hay, Mond, Buttner & Darby, 2008). This trend has paralleled the increase in childhood obesity (O'Dea, 2005) and it is probable that there is a relationship between the increase in concerns about obesity and an increase in extreme weight loss behaviours and body dissatisfaction (O'Dea, 2005).

The National Report Card on Mental Health and Suicide Prevention (2012) identifies that “enduring mental illness has the same impact as other chronic diseases and needs to be dealt with in the same manner.” Eating disorders warrant the same level and breadth of health care coverage as other conditions currently categorised as serious mental illnesses (e.g.: schizophrenia, bipolar disorder, depression, obsessive-compulsive disorder) in order to reduce the impact on the individual, their families, communities and the health system.

iv. The Eating Disorders Gap Analysis

Purpose and Scope

A gap may be defined as the difference between a perceived need, an agreed standard and actual practice including available resources and utilisation of those resources. The brief for the NEDC Gap Analysis was to analyse and identify gaps in services and information available to people with eating disorders and to identify strategic options to address the findings of this analysis process.

The NEDC is tasked with the development of a nationally consistent approach to the prevention and management of eating disorders. Working towards this goal, the NEDC has developed the eating disorders National Framework, *An Integrated Response to Complexity*, and the Communication Strategy Report, *Clarity in Complexity* (both published on the NEDC website in August 2012), to provide a frame of reference for consistent evidence-based responses to eating disorders.

The gap analysis was conducted in the context of these reports, drawing on the principles and recommendations of these reports to provide the agreed standards which are required to define gaps.

At the recommendation of state government representatives, the inquiry focused on current achievements and opportunities for future development, including opportunities to leverage from existing service models and resources.

The purpose of the gap analysis process was therefore framed as identification of opportunities for practical action to implement a nationally consistent approach¹ to eating disorders, which can be implemented in the context of current policy, resources and practice.

The objectives of the NEDC Gap Analysis were:

1. To develop an overview of services in Australia that address eating disorders
2. To evaluate the effectiveness of information resources on eating disorders
3. To profile current state and territory initiatives that have the potential to provide strategic options for the development of eating disorders approaches in Australia
4. To prioritise gaps in current practices as the basis for achievable strategic action

¹For the purposes of the Gap Analysis, a nationally consistent approach is defined as one in which approaches to eating disorders are developed within a common framework of national standards

Methodology

The gap analysis was conducted using a mixed, though largely qualitative methodology implemented in stages throughout 2012.

In brief, the social inquiry process for the gap analysis focused on:

- Collating currently available information on the range, type and extent of services and information resources available for people with eating disorders in each state and territory
- Surveying key stakeholder perspectives on what is currently provided
- Comparing current practice and perspectives with the national standards outlined in the National Framework
- Developing consultation papers to facilitate broad stakeholder consultation
- Managing an iterative process of participatory analysis of information

Exclusions: The NEDC did not have the resources or authority to conduct the following activities:

- The Gap Analysis is not a service mapping project. Service identification formed part of the activity, drawing on information already published and feedback from stakeholders
- The analysis was not a qualitative evaluation of individual services or practices
- The Gap Analysis did not compare activities between states in order to make qualitative judgements about each states performance in the delivery of eating disorder services

The following outlines the key inquiry activities undertaken for the Gap Analysis.

Literature and information review

Relevant research on the eating disorder sector in Australia was identified through searches of biomedical and social sciences databases. To supplement this search and to incorporate any relevant unpublished information, members of the NEDC were also asked to provide relevant information and literature. Finally, a comprehensive search was made of Internet resources in Australia and internationally. This review was conducted on each of the following topics:

- Service mapping and service gaps in Australian eating disorder sector
- Best practice and promising practice in eating disorder services
- Professional development and training needs of clinicians
- Portrayals of body image and healthy eating behaviours in popular media
- General evidence base on eating disorders, body image, prevention and early intervention

Consultation through questionnaire

A variety of stakeholders in the eating disorder sector were consulted through an online and paper-based questionnaire. This methodology was implemented to gain access to a large volume of stakeholders within a limited timeframe. It also provided an opportunity to participate for those who

had barriers to attending other NEDC activities or who were not currently engaged as active members of the NEDC.

With all consultations, questionnaires were developed in collaboration with relevant working groups within the NEDC and experts on the NEDC steering committee. Questions were designed based on previous surveys conducted by the NEDC and other organisations in the eating disorder sector, as well as resources on best practice in survey design. Validated questions (or questions based on validated question structure) were used wherever possible.

Two separate questionnaires were conducted with clinicians who work with clients who have or are at risk of eating disorders. Participants came from a variety of professional backgrounds and spanned a broad spectrum of experience with eating disorders. The first was implemented as a brief interview with participants attending eating disorder conferences; this resulted in 22 responses from clinicians. The second was implemented as an online survey targeted at clinicians engaged with the NEDC; this resulted in 212 responses (163 completed).

An online service review was conducted, targeting organisations providing direct service to eating disorder clients. The survey allowed services to provide quantitative information about the size of their service and activities undertaken with clients, as well as providing qualitative comment about their service and eating disorder services generally. 95 individual responses were received for this survey, of which 71 were completed for a total of 60 identifiable services.

Questions used in the consultation process may be found in Appendix D.

Formal Consultation Forums

The NEDC arranged group forums of professionals in or engaged with the eating disorder sector to promote intra and inter-personal discussion and debate, and recorded these conversations. Each forum was chaired by a member of the NEDC with particular expertise in the relevant clinical area. Gap analysis consultations were held with the following groups:

- Interdisciplinary Advisory Group
- Prevention Advisory Group
- Mental Health Contact Group (state and territory government representatives)

Details of the membership of these groups appears in Appendix B.

Informal Face-to-Face Consultation and Observations

Researchers observed a variety of NEDC member activities, including the National Workshop and Consumer and Carers Participation forum and engaged with participants in informal face-to-face consultation.

A series of guidance questions were developed for conversations with conference and workshop participants to direct conversation in a semi-structured way. The structure of the questions generally followed the questions also posed in the clinicians survey.

Conversations initiated outside of the semi-structured interview methodology were also recorded and used as general observations and anecdotal support for evidence from other sources

Case Study

Where consultation identified evidence-based or promising practices, these services were subject to further literature review, information review and, in some cases, interview, to form illustrative examples of opportunities for best practice and sector development.

Part A

Bridging the Gaps

Standards, Practice and Opportunities for Development

1. Evidence-Based Treatment

Eating disorders are a distinct group of complex illnesses with characteristics and treatment requirements that are different to other types of mental illness. The medical complications of eating disorders are wide ranging and have an impact on the way in which the disorders are treated, requiring an integration of physical and mental health services.

Standards outlined in this report apply to all eating disorders unless otherwise specified.

Standards for evidence-based treatment

The NEDC National Framework identifies the following principles needed to achieve quality treatment for eating disorders:

- Person and family-centred care that addresses the needs of individuals
- Safety and flexibility in treatment options
- Partnering to deliver multidisciplinary treatment in a continuum of care

In addition to these principles, the Worldwide Charter for Eating Disorders also indicates that treatment should include:

- Comprehensive assessment and treatment planning
- Accessible, high quality, fully funded, specialised care
- Respectful, fully informed, age appropriate, safe levels of care

Safe, effective treatment for eating disorders addresses all of the aspects of illness: physical, behavioural and psychological. To achieve best practice, evidence-based treatment should include:

- Access to a range of safe treatment options that meet different needs at each stage of risk, illness and recovery
- Flexible and appropriately supported entry, exit and transition between services supports and individually tailored care planning
- A multidisciplinary team who work in partnership with the person, their family and other health and support providers, including treatment of comorbid issues. The multidisciplinary team will assist clients to meet physical, mental, nutritional, occupational and social needs. Individuals with an eating disorder require individual care plans and access to a designated case coordinator
- Treatment plans for people with eating disorders that always assess the need for physical, psychological and nutritional intervention

- Assessment that takes multiple parameters into consideration rather than any single parameters, such as weight
- Access criteria for services that support simultaneous and sequential service delivery from multiple providers
- Treatment plans that provide for a minimum of 24 months' access to treatment and support
- Treatment provided in a sufficient dosage, taking into consideration the type of disorder, duration of disorder, comorbid conditions and outcomes of previous treatment interventions, with access to a minimum of 20 sessions of therapy
- Access to more intensive and longer treatment, with access to at least 50 sessions of therapy for people with persistent or complex illness, people with low BMI (<17.5), and people who do not respond to treatment
- Mechanisms for hospitalisation of patients with anorexia nervosa before the onset of medical instability
- Duration of inpatient treatment that is flexible in meeting individual needs with an expected period of hospitalisation between 3 and 7 weeks
- Health care settings that have mechanisms to facilitate access to more intensive levels of specialist treatment in response to a patient's changing needs
- Scheduled follow-up after treatment for individuals
- Transition and discharge plans which are developed in collaboration with the individual, their carer or family and all related service providers. These plans should include a re-admission plan with agreed criteria for re-admission, agreed monitoring criteria, referral to appropriate treatment or support services within their community and plans for ongoing collaboration between health professionals
- Access to a full range of health and community services that meet long term needs for people with enduring illness
- Monitoring of physical and mental health for an average of 5 years post treatment
- Policies and protocols which support multidisciplinary care and collaboration at all levels of treatment
- Shared standards and clinical guidelines implemented across all disciplines
- Protocols which support a coordinated team approach engaging the person, their family and support network
- Specialised eating disorders case coordination for individuals with complex needs

1.1 Aims of Eating Disorder Treatment

The overarching aims of treatment for all eating disorders are:

1. Reduction in eating disorder behaviours
2. Restoration of nutritional health
3. Treatment of physical complications
4. Enabling of family support through the provision of family education, counselling and therapy as appropriate
5. Enhancement of the patient's motivation to engage in treatment and recovery
6. Provision of education regarding healthy nutrition and healthy relationship with food and development of regular and healthy patterns of eating
7. To help patients to identify and change dysfunctional thinking, attitudes, beliefs and emotions and development of new coping mechanisms
8. Reduction in extreme weight and shape concerns
9. Treatment of associated psychiatric conditions, including low mood, anxiety and impulse regulation
10. Prevention of relapse

The goals and length of treatment for a particular person are dependent on their presentation and should be tailored to their individual needs.

1.2 A Complete Continuum of Care

Treatment of eating disorders requires a clearly identifiable continuum of care providing flexible, stepped care options to meet the physical and mental health needs of people presenting with varying levels of risk, severity, complexity and acuity. Delivery of this continuum of care involves non-government agencies, primary care professionals, local mental health services, hospitals and specialised services.

While hospitalisation is essential in the most severe cases, most people with eating disorders may be treated successfully by appropriately trained health professionals in community settings.

Intensive eating disorder-specific treatment, provided through intensive outpatient, day programs and residential programs, ensures the continuum supports the essential step up and step down access to treatment during the course of illness. Without these intermediary levels of treatment, more people will require hospitalisation.

The necessary continuum of care includes six core components with access at all levels to tertiary consultation and support:

1. Primary, secondary and tertiary prevention
2. General outpatient support provided in both hospital and community settings, with flexible access to a range of services delivered, variable frequency of access and particular emphasis on relapse prevention/early intervention

3. Intensive outpatient support for people living with their family or other support structures who require intensive clinical support
4. Day programs, providing a more structured program, including group therapy
5. Residential programs, providing 24 hour support ideally located in the community. This level of care provides a step down or step up level following or before hospitalisation and is imperative for those who may not have a significant support structure in their homes
6. Inpatient services for medical intervention and stabilisation; intensive, structured inpatient programs to address severity and comorbidity

(National Eating Disorders Framework, NEDC, 2012)

Access to a continuum of care is a priority action area in the Fourth National Mental Health Plan (Priority Area 3; 2009), with an emphasis on appropriate levels and a mix of services to provide continuity of care. Implementation of the full continuum of care for eating disorders would contribute to achievement of this priority.

1.2.1 Safe Multidisciplinary Treatment

For people with eating disorders, safe treatment requires access to skilled professional treatment for the psychological, physical and nutritional aspects of their illness.

In determining a patient's level of treatment, assessment should include their physical condition, psychology, eating disorder behaviours and social circumstances. It is unsafe to rely on a single parameter, such as weight, to determine the type and level of treatment required. Treatment guidelines recommend the regular monitoring of clients' mental and physical status (APA, 2006; National Institute for Clinical Excellence [NICE], 2004).

Both the National Report Card on Mental Health and Suicide Prevention (2012) and the National Mental Health Service Standards (Standard 2: Safety, 2010) emphasise the importance of safety and wellbeing. For people with eating disorders, these require an integrated delivery of both physical and mental health care.

Standard 6 of the National Mental Health Service Standards (2010) identifies that consumers have the right to receive care that is both comprehensive – meeting all their needs – and integrated in order to achieve the best possible outcomes. Implementation of the safety principles for eating disorders will assist mental health services to meet this standard.

1.2.2 Long Term Pathways from Treatment to Recovery

Sustained engagement with eating disorder services is an essential feature of an eating disorder model of care.

Eating disorders often persist (Wade et al. 2006) for extended periods during a person's lifetime. Up to 50% of people receiving treatment for anorexia nervosa and bulimia nervosa have symptoms for at least five years.

Unlike some mental illnesses, such as mild to moderate depression, eating disorders do not respond to short term treatment. A longer course of treatment with recovery support is required to address all aspects of the illness and reduce the risk of relapse and chronicity. Failure to access long term coordinated treatment early in the course of illness or episode directly contributes to the persistence of the illness and the potential for other health complications and their impact on the consumer's quality of life.

People who have experienced an episode of an eating disorder are at high risk of a recurrence of the same or a related illness. Relapse is a significant issue for people with eating disorders, with rates of relapse ranging from 22% to 51% across studies of Anorexia Nervosa and Bulimia Nervosa (Keel et al. 2005).

Long term treatment requires sustained engagement between patient and health care providers to ensure recovery. Sustained engagement with coordinated treatment and support should be available for a period of at least 24 months to reduce the risk of relapse.

Recovery from an eating disorder must happen in the context of daily living. Contributing factors in sustained recovery include the support available and the person's sense of control and personal confidence (Leung, Ma & Russell, 2012). The person with an eating disorder must actively engage, be motivated for change and interact with their treatment team and their social world.

Recovery support, therefore, includes helping people build functional capacity, autonomy, and a sense of personal effectiveness in order to set personal goals, make positive choices and restore independent living and quality of life. Recovery support services are, therefore, best provided in the local community. Assessment of support needs and referral to support services should be included in individual treatment plans.

Even at the mild to moderate levels of illness, people with eating disorders require access to recovery support on a flexible basis for a sustained period of time to help them to avoid or effectively manage relapse and establish healthy patterns of behaviour. Medical monitoring and the opportunity for ongoing engagement with recovery support services is recommended for an average of 5 years, post treatment.

Development of a recovery-oriented approach that prioritises the most effective treatment to prevent recurrence of illness is an aim of the Fourth National Mental Health Plan (2009).

Implementation of these principles will enable mental health service providers to achieve Standard 10 *Delivery of Care* in the National Mental Health Service Standards (2010), with particular reference to Standard 10.1 *Supporting recovery* and 10.4.8 *Individual interdisciplinary treatment, care and recovery plans*.

1.2.3 Sufficient Treatment Dosage

The minimum course of treatment for eating disorders supported by evidence (FBT; CBT) comprises at least 20 sessions, usually delivered over a 4 to 6 month period. This recommendation is based

both on clinical experience and the existing scientific literature (ANZAED, 2011). Shorter periods of treatment are not supported by research evidence and are inadvisable, except as a preventative approach.

A course of 20 sessions of therapeutic intervention is a relatively short term approach for the treatment of eating disorders. When recovery is achieved through this type of short term therapy, further therapeutic and rehabilitation support is likely be required to prevent relapse (Pike, 1998).

Treatment for Bulimia Nervosa and Binge Eating Disorder

Cognitive behavioural therapy is the leading treatment for bulimia nervosa and is effective for approximately 40–60% of individuals receiving treatment (Hay & Touyz, 2012). The length of treatment recommended by the treatment outcome literature for binge eating disorder and bulimia nervosa is 20 sessions (Fairburn, Marcus & Wilson, 1993; Mitchell, Agras & Wonderlich, 2007) delivered as either individual or group therapy (Hay, & Touyz, 2012). This treatment dosage is consistent with the NICE guidelines (2004).

Treatment for Anorexia Nervosa

A Cochrane review (Hay et al., 2003) indicated that minimum treatment period for patients with anorexia nervosa who are being treated in outpatient settings is 20 sessions. Of the studies included in this review, the number of sessions provided ranged from 20 – 50 sessions.

The shortest models of treatment that have demonstrated success for patients with anorexia nervosa include:

- **Early Intervention:** Family-based therapy (Maudsley approach) for children and adolescents, delivered as an early intervention for people with illness less than 3 years – a minimum of 20 sessions or six months' duration, with review and opportunity for longer engagement (Lock, le Grange et al., 2010; le Grange, Rathouz & Leventhal, 2007; Couturier, Isserlin & Lock, 2010; Treasure & Russell, 2011)
- **Relapse Prevention:** Cognitive Behavioural Therapy for adults – CBT has shown promising results in the prevention of relapse (Hay, Touyz and Sud, 2012). Minimum 20 sessions with an expectation of a further period of therapy after review

However, for people with more complex or persistent illnesses, where early intervention is not possible or not successful, a longer course of treatment is required.

The duration of illness, the presence of comorbid conditions, and physical health are all key issues in determining the length of treatment that may be required. Data from studies using CBT-E (Cognitive Behavioural Therapy – Enhanced) completed after the Cochrane review indicate that 20-25 sessions may be appropriate for people with a BMI greater than 17.5 (Fairburn, Cooper et al., 2009; Byrne, Fursland, Allen & Watson, 2011), while people with a BMI of 17.5 or lower require longer treatment of between 40 and 50 sessions to achieve good outcomes (Fairburn, 2011).

The Children's Hospital at Westmead in NSW has found that an average of 30 sessions of Maudsley Family Based Therapy is effective in improving outcome for children and adolescents with anorexia nervosa. Provision of this number of sessions has halved rates of re-admission to their inpatient unit (Rhodes & Madden, 2005; Wallis, Rhodes, Kohn & Madden, 2007).

Studies have indicated that the provision of higher treatment dosage (more sessions) is associated with a reduction in the rate of relapse. The provision of a further 50 sessions after discharge from hospital has been shown to decrease the risk of relapse, thus reducing the need for further treatment and hospitalisation in the future (Carter, McFarlane et al., 2009).

Duration of Hospitalisation

Duration of treatment in hospital will vary depending on the physical and psychological needs of the individual. A review of hospital admissions in the UK (Health and Social Care Information Centre, October 2012), where no time limits are placed on the duration of hospitalisation, demonstrates variable lengths of hospital admissions from one day to six months' duration. An average period of hospital treatment is 7 weeks (based on hospitalisation statistics from Queensland and Northern Ireland).

The National Mental Health Services Standards (Standard 10.5, 2010) require that treatment and support reflect the best available evidence. The standard would be achieved by the implementation of the principles of safe, multidisciplinary treatment for eating disorders in sufficient evidence-based dosage and duration.

Discharge Planning

Ideally, a patient should experience their care as connected and coherent and delivered in a logical and timely fashion that is consistent with their medical and personal needs (Haggerty et al., 2003).

There is a need for strong discharge planning from emergency, hospital inpatient and specialist outpatient programs that ensures that all patients have:

- A re-admission/call back plan that clearly defines for the individual the criteria for seeking help and for the service when to prioritise re-admission. A risk with strict entry criteria to limited places in specialist treatment is that people have to be very ill before they gain entry. If the person who has been discharged has to meet those criteria for re-admission, then the benefits of the first episode of treatment may largely have been lost; both individual and treatment team are starting over again. If a person can be re-admitted (or get in to see their treating clinician) early in the next episode of illness, there are good prospects for a relatively short period of treatment to achieve improvement in health and reduce the risk of further relapse
- A follow-up plan with agreed criteria for monitoring an individual's health and a delegated person or agency to perform the monitoring. This may be achieved through an eating disorder-specific service, but can also be achieved by the development of shared treatment

plans with primary care clinicians

- Referral to recovery support or the next level of treatment required by the individual. Again, this may be provided as part of an eating disorder-specific service or may be provided by primary or secondary care services or by community agencies. No one should leave treatment without an appointment arranged with an appropriate service as the next step in the treatment plan. For people who are deemed to be fully recovered, establishing a connection with a community agency providing recovery support is advisable so that the person has ready access to help if the need arises

1.3 A Profile of Current Treatment Services

The details of treatment and support services have been informed by two consultation surveys conducted by the NEDC, consultation with individuals and advisory groups, and a review of published information on available services and service mapping activities. A list of services included in the review is attached at Appendix B.

Services have been considered across the spectrum of treatment for eating disorders: from community-based support services to inpatient hospital treatment. It includes both public and private services. Although the focus is on organisations and services that specifically address eating disorders, attention has also been paid to the role of general mental health services, which provide services to clients with eating disorders, and the experience of individual clinicians supporting clients with eating disorders.

Treatment service providers comprise public, private (for-profit and not-for-profit), and non-government organisations (NGOs). The services provided across Australia span the continuum of care in eating disorders and include inpatient, day programs and outpatient models of care.

Australia has examples of some of the best available approaches to eating disorder prevention, treatment and recovery support. These services have developed on an opportunistic basis in isolation from each other and other health sectors, and have been driven by individual expertise, perceived local need and funding opportunity.

However, there are marked differences in the provision of eating disorder services, and access pathways to those services, between states and territories. While population size and differences in health systems may explain some of these differences, there are anomalies, particularly regarding access to adult treatment services.

Services are provided for three diagnoses: 98% of services consulted by NEDC provided programs addressing anorexia nervosa, while 94% provided services for bulimia nervosa. 71% stated they provide services for binge eating, including a significant proportion of outpatient and community-based services.

1.3.1 Specialist Eating Disorders Inpatient Programs

Access to both medical and mental health beds continues to be difficult for people with eating disorders. Evidence from consultation with treatment providers and people with lived experience demonstrates that while some states (e.g. QLD) have mechanisms in place to ensure that general hospital admissions meet the needs of patients with eating disorders, many hospitals will not admit patients with eating disorders and do not have or have access to staff trained in the provision of eating disorder treatment.

The NEDC identified 32 inpatient beds in public health services designated for adults with eating disorders in Australia. These beds are located in six services across the country, three of which are in Victoria. There are no designated public beds noted in ACT, WA or NT. Several of the beds designated for adults in the public system are in fact co-located with potentially unrelated health services (such as Mothercraft) or are also available for people with other mental health issues, such as mood disorders.

In private services there are approximately 78 beds across Australia available for adults with eating disorders (including, in some cases, adolescents over the age of 16 and/or young adults over the age of 18). Additionally, some private hospitals list eating disorders as one of the conditions they treat in their general mental health units. Access to these beds is dependent on a patient meeting the financial costs through personal means or health insurance and meeting entry criteria, which generally includes stable physical health.

Services consulted by the NEDC indicated that inpatient services primarily provided medical monitoring (90%), nutritional rehabilitation (90%) and psychiatric care (90%). Other program elements frequently provided by inpatient services include:

- Medical stabilisation (70%)
- Nutritional counselling (85%)
- Psychological services (75%) and psychosocial interventions (70%)
- Cognitive Behavioural Therapy (60%)
- Social Work services (60%)
- Other specific service models (e.g. creative therapies, family therapies)

Private services indicated that they were less likely than public services to provide medical stabilisation or monitoring, but were more likely to include psychological services and Cognitive Behavioural Therapy. This highlights the different roles between these two health systems and the challenges of engaging in the private system when a client is medically fragile. Lack of integration between physical and mental health services and between private and public health services leads to fragmented treatment that does not safely address all aspects of the disorder; physical, psychological, nutritional and social.

From a consumer perspective, private health services are not necessarily providing evidence-informed models of treatment. Feedback provided to the Butterfly Foundation and to the NEDC as part of the gap analysis consultation indicated that many consumers feel they have little choice in

treatment and that the treatment they access does not reflect specialist knowledge of eating disorders.

“Even though they say they are eating disorder specialists, they don’t get it”

Beds available for children and adolescents are more difficult to quantify. In some respects, children and young people are better served by programs in place in general adolescent medical and psychiatric wards where specialist teams provide a continuum of care from outpatient to inpatient programs. However, not all Child and Adolescent Mental Health teams are equipped to manage the specific needs of eating disorders.

The NEDC acknowledges that calculation of beds or bed-days is not compatible with all health systems; however, at this time it provides the best method of comparison available. Calculations of capacity are confused by a move in some states from designated beds, to access for eating disorder patients, to general hospital beds. The NEDC proposes that a bed is only accessible for people with eating disorders if it is supported by an appropriately skilled treatment team and access criteria facilitate the admission of people with eating disorders.

A particular challenge for the delivery of specialist inpatient treatment for eating disorders is the need to have a sufficient intake capacity in order to support a full multidisciplinary team. Clustering beds in specialist service units provides one way of achieving the ‘economy of scale’ that facilitates the provision of expert multidisciplinary care.

Many treatment services in Australia, even the few available programs that offer a high-intensity model of care, do not include the full range of professionals that a person with an eating disorder needs during the course of their illness.

Duration of Hospitalisation

In Australia the average length of stay in public acute hospitals for separations providing specialised mental health care varies from 11.7 days in the Northern Territory to 18.5 days in Western Australia (AIHW, 2012). The most common length of stay for a completed residential episode is 2 weeks or less, compared to the average of 7 weeks for patients with eating disorders in Queensland and a reported overall average hospital stay for people with eating disorders of 19.5 days (Deloitte Access Economics, 2012).

The average public patient admitted for the ‘eating disorders/obsessive compulsive disorders’ cost \$21,565 in 2009-10. In private hospitals, the stay is typically of longer duration and the costs, on average, are somewhat lower at \$17,333 (Deloitte Access Economics, 2012). However, these costs must be met by the consumer, through independent means or sufficient health insurance.

Discharge Planning

Hospital discharge criteria that focus on weight, rather than on mental health outcomes and healthy eating behaviours, lead to increased risk of relapse.

“Probably the biggest problem was discharging her because her BMI was fine! One hospital discharged her because she was medically stable - even though she had not eaten or drunk anything for 24 hours”

Consultation has demonstrated a lack of structured discharge plans with limited assessment of family or social supports available for the person after discharge.

“I was sent home from hospital in a taxi because there was no one at home to come and get me. I had no follow-up appointment and no information on how to get help, other than going back to emergency the next time I got sick”

1.3.2 Eating Disorder Intensive Outpatient Programs

Outpatient services are aimed at various levels of intensity, for people to be referred to as a step down from inpatient treatment or as an opportunity to treat without the necessity of hospital treatment.

Outpatient programs can be linked to inpatient programs in a spectrum of care model or can be stand alone services for those not requiring a higher level of care. Outpatient services are most commonly located in metropolitan areas which can create barriers to attending for those in regional and remote areas.

Services consulted by the NEDC indicated that the majority of outpatient services utilise Cognitive Behavioural Therapy (84%) and psychological services (78%). Outpatient programs also commonly provide:

- Psychosocial intervention (50%)
- Family therapy (47%)
- Nutritional counselling (44%)
- Case management (40%)
- Individual intervention models, e.g. group therapy, creative therapies.

In general, the majority of outpatient services catered to those over the age of 18 of either gender. 18 services also catered to young adults over the age of 16 years. Eleven services catered to children under the age of 14 years of any gender. Three services indicated that they provided outpatient services to women only.

There are no known residential programs in a community setting in Australia. Residential programs are important where care in transition between home and hospital settings is required. Consumers and carers consulted frequently highlighted the lack of this kind of service in Australia.

Five respondents to the NEDC consultation indicated that their organisation provides day programs to eating disorder clients. Collectively these services represent 32 places, with an average of 10 per service. All day programs provide CBT, group therapy and education. Three provide nutritional and other psychological services.

1.3.3 Community-Based Treatment and Services

Community services deliver a range of primary health and social support services with programs varying according to local need and resources. These services may be delivered in single sessions with individual practitioners or through group programs. They often target specific groups (e.g. disorder, gender and age-specific services) with the objective of promoting health and wellbeing and improving early access to health services when required.

While it is difficult to tell the extent to which people with eating disorders access Community Health Services, information from services and individual clinicians indicate that allied health professionals, particularly in areas such as dietetics and counselling, are often the 'frontline' of eating disorder identification and treatment.

NEDC consultation surveys were completed by 17 community-based services, which together represented approximately 430 places available for clients within in a 12 month period, with an average of 87 per service. These services catered to a range of age ranges and both genders; although some services indicated that they targeted a particular consumer population, for example, young people or women.

The majority of these services focus on providing psychological services and psychosocial interventions, particularly using Cognitive Behavioural Therapy. In addition to these program elements, community-based services provide:

- Psychological services (87%) and psychosocial intervention (80%)
- Education (60%)
- Case Management (53%)
- Nutritional counselling (47%)
- Carer Support (47%)
- Other allied health services (e.g. OT 13%, social work services 27%)
- Other therapeutic methods (e.g. group therapy 13%, creative art therapy 7%)

Community-based services accept a wide range of consumers and often have specific criteria for admission that relate to the program and its aims. Some of the common criteria indicated during the NEDC consultation with services were:

- Participation by the consumer should be voluntary and the consumer should be motivated to engage with the particular model of intervention offered by the service
- Potential participants should not be at acute risk of physical harm from either medical or psychological symptoms; this includes medical instability and risk of suicidal behaviour
- Potential participants should not be in need of a higher level of care than can be provided in a community setting

While many community services offer promising practices, these services are often not consistently evaluated for their effectiveness and do not make the research supporting their service models explicit.

1.3.4 General Health Services

Many people who need treatment for eating disorders and related physical symptoms are ultimately seen in non-specialist services, emergency departments, and general medical or mental health services.

Without specific strategies to provide integrated, holistic treatment for eating disorders across disciplines, treatment in general health services often results in a 'revolving door' experience for people with eating disorders, exiting a service once medically stable and being without follow-up support until they are next medically compromised.

Child and Adolescent Mental Health Services (CAMHS) have a particularly important role in diagnosing and treating eating disorders, as many eating disorders emerge in the teenage years. The core features of the usual CAMHS approach to clients with eating disorders are a multidisciplinary team approach, work with families and collaborative work with paediatricians.

While many CAMHS units have specific eating disorder services, many may not have clinicians with the right expertise to provide individual assessment and treatment for eating disorders. This is particularly true for regional and remote areas. Other youth mental health services, such as Headspace and Orygen, are also providing important information sharing functions, as well as providing general mental health services to young people who may have or be at risk of an eating disorder.

General Adult Mental Health Services are less likely to have designated eating disorder services and have identified a particular difficulty in treating people with moderate to severe eating disorders. This is due to the level of expertise required to treat eating disorders effectively. People with moderate to severe eating disorders are typically only accepted as AMHS if they have a comorbid condition, such as major depression. The consequence of this is restricted access to adult public mental health services for people with eating disorders and potentially ineffective care for clients who are in the care of Adult Mental Health Services and do have an eating disorder.

The issue of how these two systems interact and feed into each other is also important to those at risk of or who have an eating disorder, particularly as the onset of eating disorders often occurs during the transition period from adolescents to early adulthood.

The experience of these related health services for many consumers has been negative. Consumers and carers have provided feedback on the lack of awareness among general medical and mental health staff, from individual health practitioners and services generally, resulting in insensitive and inappropriate care.

1.3.5 Services Provided by Individual Clinicians

General Practitioners

For many, the first point of contact regarding their eating disorder is their GP. Consequently, GPs have an important role in recognising and assessing people who have or are at risk of an eating disorder. A well-resourced GP can assess symptoms, perform physical examinations and provide referrals to other health care professionals.

According to the AIHW (2012), the most common mental health related problems managed by GPs in 2010-11 were depression, anxiety and sleep disturbance. A GP was most likely to prescribe, supply or recommend a medication for the management of mental health related problems. GPs also provided management through referral for counselling, advice or other treatments. In this context, it is noted that pharmacological management for eating disorders is not strongly supported by evidence, that assessment of eating disorders requires specific knowledge and skills and referral requires knowledge of services and access pathways.

Across Australia, there are GPs whose professional experiences and interests have led them to develop skills in identifying, assessing and addressing eating disorders in their patients. However, many consumers and carers have reported that GPs' responses to their needs were often inadequate and highlighted a misunderstanding of eating disorders, their risks and symptoms. A lack of awareness among the general GP profession results in:

- GPs not identifying risk factors in their patients
- GPs being unclear on the services available and how to make appropriate referrals to those services
- Patients being inappropriately referred to services or not getting the most effective use of Medicare subsidised services
- GPs being unable to provide effective ongoing management of community-based clients with an eating disorder

"In the early part of her disease, GPs and specialists (including dietitians and psychologists) failed to recognise her eating disorder, even though she was significantly underweight and with amenorrhoea"

"I was misdiagnosed for six years - told I had hypoglycaemia and other illnesses..."

"Being an adult male, it was very difficult to be taken seriously; I had 3 GPs and a nutritionist all fail to diagnose the condition"

"Most medical people have little idea or understanding of eating disorders"

Other Clinicians

There are individual practitioners with clinical expertise in the treatment of eating disorders providing community-based treatment in both the public and private sectors.

Individual health clinicians include psychiatrists, psychologists, dieticians and a wide range of allied health service practitioners who specialise in the management of eating disorders or actively treat clients with eating disorders. Clinicians who provided feedback to the NEDC on their experiences of treating eating disorders included: dieticians, psychologists, occupational therapists, nurses, dentists, social workers, counsellors, psychiatrists, physiotherapists, GPs and speech therapists.

While most clinicians indicate that they use evidence-based models of intervention, many use a mixture of interventions when treating eating disorders based on their own preferences, interests and beliefs, rather than evidence-based practice.

Most clinicians surveyed indicated that addressing healthy eating and eating disorders in their work is important to them. 87% considered healthy eating important to address and 85% considered eating disorders important to address. Although fewer clinicians considered body image important for them to address in their work with clients, it was still considered important by over 75% of respondents. Clinicians consulted had all previously identified a level of interest in eating disorders and this result should not therefore be interpreted as typical for all clinicians. The majority of clinicians also highlighted that their professional fields did not place enough importance on prevention and intervention of eating disorders.

It is evident from clinicians' responses that their experiences with eating disorders varied widely; some worked within a specialist eating disorder service, while others acknowledged that they had not yet managed a client with an eating disorder. 77.4% of respondents said they provided clinical services in their professional field to clients with eating disorders and 54% said they provided a specialist eating disorder service. Only 43% used clinical guidelines or protocols for working with clients with eating disorders.

Many clinicians are aware of eating disorders and able to screen for eating disorders, but are not willing or not confident enough to treat eating disorders and are quite anxious when faced with a client with an eating disorder, referring a client on and reducing the opportunity to capture their motivation at the time.

Most respondents could describe at least one risk factor or symptom of eating disorders. At least 29 separate factors were described and reflected the participants' level of experience, professional area of expertise, and in some cases, the case history of specific clients they had come into contact with. Although the question asked for risks, most responses identified behaviours typically present as symptoms of an already present eating disorder.

Factors relating to anorexia were more commonly discussed than other eating disorders. For example, 39% of respondents listed weight loss as a risk factor, while 11% considered weight gain a risk. Likewise, restricting food intake was considered a risk factor by 23% of respondents, while binge eating was listed by 6% of respondents.

The most common factors listed by clinicians as indicating that a client may have an eating disorder are detailed below:

- Negative body image (39% of respondents)
- Weight loss (39%)
- Dieting behaviour and/or disordered eating (27%)
- Pre-occupation with weight (23%)
- Restriction of food intake (23%)
- Excessive exercise (22%)
- Low self-esteem (18%)
- Depression/anxiety (17%)
- Low BMI (17%)
- Family issues (15%)

Less than half of respondents indicated that they screen clients for eating disorders in their professional practice. Of the 78 (37%) who did screen, 45 provided additional comment on this process. These qualitative responses painted a picture of screening processes, which are generally informal and undertaken at the time of assessment/intake or when an eating disorder is already suspected in the client.

Only 27% of respondents were aware of or used prevention information and resources. Those resources were most typically; websites (8), support groups (2), programs/workshops (5), manuals/tools (5), handouts (5), and books (5). Resources specifically mentioned by name were developed by; The Butterfly Foundation (9), CCI (8), CEED (3), EDOS (3), EDV (3), Beyond Blue, EDA, EDA QLD, DAA EDSIG, Mandometer Melbourne and SANE.

When they would refer a client with an eating disorder depended on multiple variables, including their own level of expertise, the nature of the disorder, the other services available to the client, the wishes of the client, and so on. Clinicians discussed referring clients who were medically at risk, who acknowledged they required further assistance and agreed to a referral, who were beyond the professional capabilities of the clinician and who had other service options available to them for referral.

Clinicians also provided a wide variety of examples of where they would refer clients, again depending on the severity of their illness and the services available in their community. Only 3% of respondents indicated that they were not aware of where to refer a client with or at risk of an eating disorder, and a further 5% indicated that they worked for a service where an internal referral could be made to an appropriate specialist. Of those who identified that they would refer a client with an eating disorder on for specialist care, the most common referral pathways identified were:

- 32% would refer to a specialist eating disorder service
- 31% would refer to a mental health service, including a public psychiatric service
- 25% would refer to a GP
- 25% would refer to a hospital or medical service

- 23% would refer to a private practitioner in psychology, nutrition or other allied health services
- 12% would refer to a dietician
- 9% would refer to an eating disorder information service
- 7% would refer to a community service

This is a largely private sector and without sufficient support from public funding, referrals and treatments are unaffordable for a large portion of the community, particularly if they are without private health insurance and/or in need of an ongoing treatment plan.

1.3.6 Treatment Duration and Dosage

In policies and funding initiatives for community-based care reviewed in the NEDC Gap Analysis, no mention is made of the differences between eating disorders and other mental illnesses or of the specific skills required to prevent or treat this group of disorders.

Inpatient services in private health do not consistently provide an evidence-based dosage of treatment.

For general mental health initiatives eating disorders are typically grouped with mild to moderate levels of anxiety and depression and general youth mental health (e.g. Better Access, ATAPS, Headspace, ReachOut). This contributes to a pattern of treatment made up of unconnected, short term episodes of treatment with limited or no support between those episodes.

There is an underlying assumption that eating disorders are:

- The same as other common mental illnesses and will therefore benefit from the same approach to treatment
- Only of significance at the acute stage where hospitalisation is required and
- That health professionals, particularly GPs and Mental Health professionals, are familiar with and able to diagnose and treat eating disorders

The Access to Allied Psychological Services (ATAPS) initiative is frequently suggested as an appropriate vehicle enabling people with eating disorders to access services. ATAPS relies on GPs to refer patients to community-based psychologist services for short term therapy. The initiative is designed to be of benefit to people with mild to moderate disorders, specifically anxiety and depression, for which short term therapy has been identified as being of therapeutic value.

Short term treatment is inadvisable, except as a preventative approach for people at high risk of developing an eating disorder. Even at the mild to moderate levels of illness, people with eating disorders require access to recovery support on a flexible basis, for a sustained period of time (2 years), to help them to avoid or effectively manage relapse and establish healthy patterns of behaviour.

“Expensive and stop-and-start nature of treatment limits the amount of change possible, particularly cognitively”

“Medical practitioners are not familiar with treatments and causes of eating disorders and treat only the physical symptoms, not the emotional or associated symptoms”

The MBS Better Access Program (BAMHS) currently subsidises GPs in development of a mental health treatment plan and in line with this plan, provides for 10 allied mental health services sessions, with up to 6 extra sessions where exceptional circumstances apply and a further 10 group therapy sessions. In January 2013, this will change to an initial treatment course of 6 sessions with further scope to access an additional 4 sessions if required, as well as 10 group therapy sessions per calendar year. This does not guarantee access to 20 sessions for each individual.

Although the BAMHS was neither designed nor intended to provide intensive, ongoing therapy for people with severe and persistent mental illness, the Australian Government has acknowledged that there are some people with more complex needs who are using the services provided under the BAMHS initiative for care and support.

While some people are accessing eating disorder treatment through initiatives such as ATAPS and BAMHS, neither initiative is able to guarantee access to an informed diagnosis and a sufficient dosage of treatment to achieve evidence-based standards. Many consumers consulted for this report noted that they often require counselling on a weekly basis.

GPs can also continue to refer people with more severe ongoing mental disorders to Medicare-subsidised consultant psychiatrist services, where 50 sessions can be provided per year. The limitation to this service is that treatment must be provided by psychiatrists and there are very few psychiatrists providing eating disorder treatment and generally, very limited access to psychiatrists in regional and rural areas. 89.5% of psychiatrists work in major cities (AIHW, 2012).

“Finding qualified psychiatrists for the treatment of patients suffering from eating disorders is a nightmare. There are very few skilled in this area of mental health and who have a solid understanding of this illness”

The strategic opportunity is to extend access to this item to allow patients with a diagnosis of anorexia nervosa and bulimia nervosa to access 50 sessions of treatment from a Clinical Psychologist as well as from psychiatrists. This will improve access to an evidence-based dosage of treatment and improve access generally to treatment for people in rural and regional areas.

1.3.7 A Continuum of Care

While some people in Australia have a positive experience of eating disorder treatment, gaining rapid access to treatment delivered by skilled professionals, the majority of people seeking eating disorder treatment experience a number of barriers to effective treatment that contribute to the severity, longevity and socio-economic impact of their illness.

“Given my sister primarily accessed her care through the public health system, I was surprised by how quickly her case was referred and she received an appointment to begin treatment. When she was referred to see a paediatrician, again access was relatively easy to obtain” (

“In the early stages, it was difficult to obtain treatment. Firstly, because the illness was not diagnosed by GPs and other health professionals and secondly because the eating disorder psychiatrist books were full”

No region in Australia has access to a fully coordinated continuum of care for eating disorders. The majority of eating disorder specialist services are provided in metropolitan areas. Significant gaps in the continuum exist in intensive outpatient treatments and day and residential programs for adults and in community-based services for people with mild to moderately severe eating disorders.

Lack of clinicians in local health regions with the knowledge and experience to treat eating disorders, together with insufficient specialist programs with the capacity to support treatment in general health care, has led to a lack of access to treatment in people’s local communities.

“Due to rural location, effective hospital treatment was 700kms away”

“Living in a rural area there are no choices in treatment at all. Only other treatment clinics were in Melbourne and this meant splitting the family for an extended length of time and I still had other children to consider”

Lack of coordination between specialist services and primary and secondary health services further weakens the potential for any patient to access flexible, stepped care delivered on a continuum.

“The GP that I initially presented to at my university health service had no idea about eating disorders and referred me to a generalist psychiatrist who also wasn’t appropriately supported or connected (with an ED unit) to treat EDs”

Clinicians consulted by the NEDC identified a wide range of gaps in the continuum. Their responses generally indicated service gaps in the clinician’s own local area:

- Specialist inpatient programs (28 respondents)
- Outpatient or day programs (22)
- A multidisciplinary team to refer clients to (21)
- Local services to refer clients to (20)
- More public, financially accessible services available to clients (17)
- Community-based programs (16)
- More places in services already available to avoid delay or exclusion (14)
- More specialist psychological services (10) and more specialist GPs (9) available to their clients

Thirteen clinicians also noted a lack of diversity in the models of intervention available to their clients. Having access to a single type of service does not meet the requirements for individual treatments that address the specific presentation of the eating disorder and the person’s strengths and social context.

Eating disorders occur across the lifespan from childhood to adulthood and treatment is highly likely to involve multiple sectors in the health system, as well as multiple disciplines. Even in situations where services are available, individual patients are experiencing gaps in service because they do not have the effective case coordination, which would facilitate access to services.

Gaps in the continuum of care, particularly in intensive outpatient programs and day and residential programs for adults, lead in some instances to the necessity of seeking treatment interstate or overseas.

“We have had to search the country looking for support. We had to fly weekly to the Oak House in Melbourne until it closed down due to [lack of] funding. We have had to relocate to Sydney so that she could be an inpatient at Wesley Hospital”

Specialist tertiary-level programs vary in availability across states and territories. Tasmania and the Northern Territory have no specialised eating disorder programs at this point in time. For individuals wanting access to a particular model of care, in a particular geographic region – even metropolitan regions – choice is either very limited or non-existent.

1.4 Examples of Current Resources

There are a number of examples of program innovation for the treatment and support of people with eating disorders. The following selection highlights the diversity of strengths, which can be used as a foundation for development of nationally consistent approaches to eating disorders.

Body Esteem Program – Women’s Health Works, WA Community-Based Program

The Body Esteem Program offers peer-facilitated, self-guided recovery groups for women over the age of 18 who are living with an eating disorder. The program was born out of an unmet need for self and peer-supported eating disorder services in Western Australia and a desire to have community-based support that integrated and worked together with clinical professionals in the eating disorder sector.

A unique and integral aspect of the programs delivered through Body Esteem is that the groups are facilitated by professionals who also have the lived experience of having an eating disorder themselves. The facilitators offer their own experiences within a structured program. Each program is delivered by two facilitators, each who share their own unique story and support participants to take their own steps towards regaining health and wellbeing. Facilitators are provided with formal training and supervision as part of the program.

Anorexia Nervosa/Bulimia Nervosa 20 Week Program: This program is delivered once a week (2.5 hours per week) over a 20 week period and provides insight, education, support, and guidance for women wanting to move forward on their recovery journey. This program is for women who have the desire to live a life which is free of negative thought patterns and self-destructive behaviours, which are associated with anorexic and bulimic eating disorder/s.

Binge Eating/Compulsive Overeating 20 Week Program: This program is delivered once a week (2.5 hours per week) over a 20 week period and provides insight into the emotional aspects of overeating. Please note that this is NOT a weight loss program; it is a program which takes a holistic view of why binge/overeating behaviours occur. The program explores different strategies that can be used, which can support the individual’s recovery, and provides a supportive, caring environment where re-learning can occur.

At the time of writing, the cost for the Body Esteem programs is \$350.00 (\$18 per session), payable by the participant.

After initial piloting of the program, it has been evaluated and found to be effective in engaging women in treatment and improving their coping and living skills. The program has gained funding through the Mental Health Council. It has recently published its program documentation to allow for replications of the program to be piloted in other locations.

Sydney Children's Hospital Network - Westmead Campus Eating Disorders Program Inpatient & Outpatient Child & Adolescent Service

Based in Adolescent Medicine, in conjunction with Psychological Medicine, this program provides joint medical and psychiatric assessments of new patients, with ongoing individual and family work, by the psychosocial team. The service provides:

- Child and adolescent outpatient services with a weekly new patient clinic and a weekly follow-up clinic
- Child and adolescent inpatient services with up to 4 beds on a medical ward for re-feeding and medical treatment program
- Outpatient family therapy delivering Maudsley Family Therapy treatment, including intensive family therapy, is provided for families whose adolescent has been in the eating disorder inpatient program upon discharge

The family admission program is an innovation in the implementation of Maudsley family-based treatment (MFBT) and increases the level of therapeutic intensity compared to standard outpatient MFBT. Complete with a kitchen and dining table, the Butterfly Wing is designed to allow families to prepare meals and eat together and to help set boundaries and re-establish eating patterns.

The 2 week, hospital-based residential program is designed as a step down from usual inpatient care or a step up if outpatient treatment is stalling. The program targets families who are responding poorly to standard MFBT treatment because of complex family dynamics, the severity of the illness or their remote location. Through a structured daily program and a shift in the locus of control from hospital staff to the child's parents, the program aims to reduce length of stay in the acute inpatient environment, reduce re-admission rates and improve outcomes for patients and families.

Family admissions have been developed at the CHW to extend its capacity to meet the needs of complex patients. This has been done in line with the core principles of MFBT and has endeavoured to utilise the same initial leverage of MFBT. However, the additional intensity of a 2 week residential program has allowed families to focus on issues that may have prevented them responding as outpatients and has created an additional level of engagement with the therapists via their shared experience. This augmentation to the model utilises the advances others have implemented, such as multiple family group therapy, separated family therapy and parent-to-parent consultation, and allows interventions to be tailored to the individual family.

The introduction of family-based treatment programs in 2002 led to a significant reduction in children and teenagers needing repeat admissions.

*Andrew Wallis, Colleen Alford, Aimee Hanson, Joanne Titterton, Sloane Madden and Michael Kohn Journal of Family Therapy (2012) **Innovations in Maudsley family-based treatment for Innovations in Maudsley family-based treatment for anorexia nervosa at the Children's Hospital at Westmead: a family admission programme***

Body Image Eating Disorders Treatment & Recovery Service (BETRS), Victoria Community-Based Continuum of Care Service

BETRS is a community-based outpatient service for people with eating disorders, their families and carers. The service contributes to a continuum of care between primary, tertiary, inpatient and community-based services and the BETRS Inpatient Specialist Eating Disorder Unit located at Austin Health.

1. Intake service

Provides phone based assessment, brief intervention, support, referral and appropriate communication with treating health professionals. BETRS provides a smooth 'easy in, easy out, easy back' approach to accessing services.

2. Assessment and treatment planning service

Comprehensive assessments conducted by clinical professionals within the multidisciplinary team inform tailored treatment plans. The treatment plans specify the range of interventions required to best meet the needs identified throughout the assessment. Assessment by the team precedes access to any of the treatment services at BETRS.

3. Group therapy

The following groups are offered over the course of the year:

- Family and carer education and support (FACES)
- Bulimia nervosa/binge eating
- Motivational Enhancement
- Psychoeducation
- Severe and Enduring Eating Disorder(SEED)

4. Day program

The Day Patient Program (DPP) is an alternative to inpatient care and can also be a useful step in the transition to and from home after intensive inpatient treatment. How long participants stay in the program is determined by individually established goals and progress. The DPP facilitates the recovery process for people with a low BMI who are motivated to undertake health restoration and the management of disordered eating behaviours.

The program is an open, structured group program that supports participants to achieve individually negotiated health restoration goals. Groups focus on supporting motivation and managing feelings while working on health related goals.

The DPP runs three times on weekdays. The hours are 9.45am until 4.00pm. There are some small costs for participants.

5. Inpatient unit

A specialist inpatient service is available for people whose symptoms have not been met in a community-based treatment management setting. The purpose of admission is weight gain and management. The beds are located in the acute unit at the Austin Hospital.

Southern Health Butterfly Day Program, Victoria Community-Based Day Service

The Southern Health Butterfly Eating Disorders Day Program is a joint project between The Butterfly Foundation and Southern Health, the first of its kind in Victoria, with funding from government and philanthropic organisations. The program provides specialist, intensive treatment for individuals aged 12-24 years who require more intensive support than can be achieved through outpatient treatment alone. It is staffed by a multidisciplinary team consisting of a Director Psychiatrist, Program Manager and Clinical Psychologist as well as a Family Therapist and consultant health professionals including a paediatrician, dietician, teacher and creative therapist.

The service operates from 9.30am to 3.15pm, 5 days a week, with the option of part time or full time attendance. The program follows an intensive timetable with three group therapy sessions and three meals each day.

Day Program participants take part in group therapy specifically designed to assist with recovery from their eating disorder, in combination with dietetic and meal support and supervision. Referrals can be accepted from Public Mental Health Case Managers or Private Mental Health Clinicians via our Psychiatric Triage Service.

The Southern Health Butterfly Day Program is an open program and recognises that length of stay in treatment varies depending on the unique needs of individual participants. The program's multidisciplinary team works with participants to achieve nutritional rehabilitation and normalisation of eating behaviour. There is also a strong focus on identifying and managing thought processes around food, eating and weight, improving body image and assisting participants to identify, understand and manage issues that have contributed to the development and maintenance of their eating disorder. Participants attending the day program are required to be medically monitored by their GP/Paediatrician.

1.5 Recommendations Relating to Treatment

In summary, the key gaps identified in the provision of treatment for eating disorders include:

- Gaps in the full continuum of care in all health regions
- Gaps in treatment coordination across health sectors and disciplines
- Typical dosage and duration of treatment that is less than that supported by evidence
- Gaps in health professionals knowledge, skill and confidence to treat eating disorders

The suggested first step to address gaps in treatment is to ensure that eating disorders are clearly identified as core business for health systems and services. Policy is therefore identified as an area of national priority for action: inclusion of eating disorders and the evidence-based standards for eating disorder prevention and treatment in all relevant health policies, plans, funding initiatives, Medicare Benefits Schedule and health promotion strategies.

Based on the standards for best practice and building on the promising approaches, the following details key strategic opportunities for development to address the gaps identified in current practice.

Immediate Opportunities Ensure that policies and health funds specify long term treatment at a sufficient evidence-based dosage to be effective

Information and resources are already available to support these actions Ensure that policies and health funds include the following in recognised treatment for eating disorders:

- Early intervention for people at high risk
- Community entry services, initial counselling, early intervention and psychiatric services
- Recovery support
- Family support and education
- Case coordination
- Case follow-up and monitoring
- Multidisciplinary treatment

Medium Term Planning Review hospital admission criteria and private health insurance funding criteria to ensure that people with eating disorders can receive treatment in their local health region

Further development of information and resources is required to support these actions Develop protocols for shared provision of care between health disciplines and between health service providers, including public and private health and NGO community-based services

Review hospital admission criteria and private health insurance funding criteria to ensure that people with eating disorders can receive sufficient evidence-based treatment in their local health region

Develop cost-effective models of service including early intervention and recovery support for implementation in areas that do not currently have access to these services.

Optimal Model Criteria for inclusion or admittance to services support, early intervention and prioritise access to service as close as possible to the person’s home community

Eating disorders are clearly identified in mental health policies and initiatives and have specialised responses reflective of the complex nature of the illness

2 Equity of Access

The National Mental Health Policy (2008) ensures that, “people with mental health problems and mental illness will have timely access to high quality, coordinated care appropriate to their condition and circumstances, provided by the most appropriate services.”

2.1 Standards for Equity of Access

The NEDC National Framework identifies the principle ‘equity of access and entry’ as necessary in achieving best practice in care for those with or at risk of an eating disorder.

In addition to this principle, the Worldwide Charter for Eating Disorders also indicates that treatment models should include specialist services that are accessible, high quality and fully funded.

To achieve best practice standards in ensuring equitable access to all those in need of treatment, services and systems should ensure:

- People have access to treatment and support services when and where they are needed, early in the illness and early in each episode of illness
- The requirements of regional and rural areas are recognised and technological solutions to providing accessibility are included
- The entry requirements and the costs, subsidies or fee rebates for treatment take into consideration the long term and complex nature of eating disorders and the need to ensure they are accessible and affordable to all
- Clearly identified entry points, ideally located in the community, to assist people in making informed decisions about treatment options and enable them to engage with accessible and affordable services
- People in high risk groups are screened for eating disorders as part of routine health checks
Referral processes and entry criteria for access to services enable early intervention
- Access to eating disorder-specific services is available in all areas including rural and regional
- Information and service entry points are easily identifiable at national and local community levels
- Health fund criteria for treatment of eating disorders reflect the duration, complexity of the illness and the standards for safe, flexible treatment
- Entry criteria for access to services enable early intervention
- Individuals and families have access to information and resources, including self-help early intervention resources.

2.2.1 Timely Access and Entry

Early detection of eating disorders and intervention is critical to successful outcomes. People who have had an eating disorder for less than 2 years are likely to respond more quickly to treatment and experience fewer physical health consequences (Berkman, Lohr & Bulik, 2007; Steinhasuen, 2009). This is particularly the case for people with bulimia nervosa and binge eating disorder.

Illness duration has been shown to be an important predictor of outcomes for people with anorexia nervosa. Illness for more than three years is associated with poor outcomes (Treasure & Russell, 2011).

Eating disorders have an impact on the individual's ability to engage with treatment. Self-awareness and motivation to engage in treatment are important contributors to successful treatment outcomes. The transient nature of illness awareness requires the capacity for an immediate treatment response (Schoen, Lee, et.al, 2012). The ability to respond rapidly when a person requests help is vital for the treatment of eating disorders. Strategies to enhance motivation are required throughout the course of treatment, from initial referral to recovery support (Waller, Schmidt, Treasure et al., 2009).

The need to have patients on a waiting list potentially increases the chronicity of illness. In order to maximise the outcomes of treatment, eating disorder treatment services need to ensure that treatment is provided as early as possible in the course of illness and as a timely response whenever the person is motivated to engage in change.

Timely access and ease of entry to mental health services are requirements of the National Mental Health Service Standards (Standard 10.2 and 10.3, 2010), with an emphasis on the provision of clear entry pathways (Standard 10.2.2, 10.3.2, 10.3.4). Increasing access to timely and appropriate mental health services is a recommendation of the National Mental Health Report Card (NMHC, 2012).

2.1.2 Location of Treatment

Eating disorders are best treated in community settings wherever possible. However, the complexity of eating disorders and the potential for rapid deterioration in physical health mean that close links must be maintained between local service providers and tertiary expertise.

Eating disorders can be treated in any health care setting provided that there is access to skilled staff to deliver treatment in that setting and that the mechanisms exist to facilitate access to more intensive levels of specialist treatment in response to a patient's changing needs.

For people with severe anorexia nervosa (e.g. extreme weight loss and medical complications), intensive treatment is required to stop the progress of the illness. Hospitalisation should occur before the onset of medical instability. Weight levels should not be used as the sole criterion for access to or discharge from inpatient or intensive treatment programs.

Most people with bulimia nervosa and binge eating disorder do not require hospitalisation. Indications for the hospitalisation of patients with bulimia nervosa and binge eating disorder include failure to respond to outpatient treatment, suicidality, serious concurrent general medical problems or comorbid psychiatric or substance disorders that would otherwise require hospitalisation.

National Mental Health Service Standards (Standard 10.2.4, 2010) require that wherever possible, services are located to provide ease of access.

2.2 Profile of Current Access to Treatment Services and Support

Research suggests that access to treatment for eating disorders is alarmingly low, with only 22% of sufferers receiving specialist treatment for their eating disorder (Swanson, Crow, Le Grange, Swendsen & Merikangas, 2011).

‘Programs that are easily accessible, based in the community with strong links to existing universal services are likely to be the most acceptable, effective and least stigmatising’ 13 (WA Mental Health Strategic Policy, 2010).

For people with lived experience, getting an initial diagnosis and referral to appropriate services presents one of the biggest barriers to accessing treatment, often delaying access by several years. Even once engaged with a service, patients often have access to only one part of the appropriate care continuum. This is a result of too few services, located ad-hoc in a patchwork across the state, without an effective mechanism for ongoing care coordination.

The experiences of clinicians highlight the challenges faced by consumers attempting to access services. More than 60% of clinicians consulted had faced difficulty accessing services for their clients. Most commonly, this was to do with the service not having the capacity to take on the client or having long waiting lists. Other difficulties encountered included:

- Clients not meeting strict inclusion/exclusion criteria, particularly relating to BMI
- Clients not being financially able to access private services
- Having no local service to meet the particular need of the client

2.2.1 Access to Treatment

Admission Criteria

Admission criteria play a crucial role in determining whether people with eating disorders gain access to appropriate treatment early in the course of illness.

Although many services indicated that they have standardised criteria for admission of patients with eating disorders, particularly those engaged with the Eating Disorders Outreach Services in Queensland, these criteria are largely locally determined and can vary widely, even between hospitals providing similar services. The most common admission/exclusion criteria for both hospital and outpatient programs relate to body mass index (BMI), medical stability and comorbid

conditions. For private services, patients may require appropriate private health insurance coverage in order to participate in a program.

Generally, hospital psychiatric inpatient services will not admit a person with a BMI below 12-14. Patients with very low BMI are admitted to general medical services for weight restoration. Without coordination between psychiatric and medical services, this may result in disconnected episodes of treatment which do not safely address all aspects of the eating disorder.

As with inpatient services, outpatient services, including day programs, have particular exclusion criteria when determining the admission of a consumer to the program. Services consulted gave the following examples of criteria for inclusion in their outpatient programs:

- The potential participant must be medically stable and in no immediate risk of physical or psychological harm as a result of their eating disorder or any other comorbid disorder
- The potential participant must be under the care of a GP or other coordinating health professional (in services where this is not provided internally)
- The consumer must have a diagnosis of an eating disorder and a certain BMI, which varied according to services but was generally over 15, 16 or 17.5
- Not having comorbidity with drug and alcohol

Consultation with consumers and carers indicates that many patients ‘fall between the cracks’ of the different service admission criteria. For example, a patient may be too underweight to access outpatient treatment, but not deemed to be sufficiently at medical risk to warrant admission to inpatient treatment, therefore being denied any treatment.

“Instead, they are told they are not sick enough to be referred to appropriate care. I think that the emotional costs/impacts of this experience cannot be overstated”

“Specialist care was refused until recently as I was told I would never get better”

“People with eating disorders should not be discriminated against because they have eating disorders. So many hospitals and treatment programs say they don’t treat eating disorders, but there needs to be places where people can actually go to access appropriate care, and at this stage there isn’t – people are falling through the cracks in the system, many are dying, while others exist with the torment of an eating disorder”

Admission Criteria for People with Eating Disorders with Comorbid Conditions

97% of people with an eating disorder have a comorbid condition. Having an eating disorder with a comorbid mental health condition has a profound impact on access to services. Many eating disorder programs, particularly those in private health, exclude patients with comorbid conditions or self-harming behaviour.

Seeking treatment for the comorbid condition isolates people from eating disorder treatment. Services that specialise in treating other conditions do not have the expertise or the protocols to treat eating disorders. Patients receive reactions from staff such as: *“We don’t treat eating disorders here – if you’re not eating that’s your fault”* and, *“you can’t stay here and lose weight, so we have to discharge you.”*

Timeliness of Access

Insufficient places in specialist programs contributes to long waiting times for some patients.

“GP needed to refer quicker. Waiting time to first available appointment at eating disorder clinic was 5 weeks. My daughter needed urgent admission via A&E prior to her first appointment date”

40% of hospitals and 60% of outpatient programs indicated that they do not maintain waiting lists. It is not possible in these circumstances to assess the number of people seeking treatment who are not able to access that treatment.

For those services that do maintain waiting lists, 20% of hospitals and 28% of outpatient programs indicated that they have waiting lists of up to 3 months. Several services noted that, as their group programs only run at specific times during the year, a client may have to wait for service even though there is a place available for them.

A number of factors impact on waiting lists, including admission criteria. Highly restrictive admission criteria reduce the number of people actively seeking treatment. There are suggestions that this is intentional for some services when very limited resources are available. The question was posed by one clinician consulted by the NEDC, *“how do you prioritise access when you only have two beds?”*

Any amount of waiting time may place a patient in danger, either because their health will deteriorate or because they will lose the motivation to engage in treatment. If their health deteriorates, this may result in emergency hospitalisation or it may mean that the person is defined as ‘too ill’ to meet the service access criteria. This is an issue of relevance to other mental health sectors. For example, consultation to support the WA Mental Health Strategic Policy (2010) found evidence of *‘carers forced to watch consumers wait until their conditions become sufficiently florid to demand the attention of the largely hospital-based acute care system currently in place.’*

Every health service should have strategies to ensure that patients requiring treatment for an eating disorder receive some level of care immediately, even if it is limited to regular follow-up checks to monitor their progress while they wait for other services.

Timely Access for People With Enduring Illness

Feedback from people with eating disorders suggests that long waiting lists for access to private health services are usual, particularly for adults who have experienced long term illness. While it is important to prioritise early intervention for young people in their first episode of illness, this should not be at the expense of older adults with enduring illness.

Older people with persistent eating disorder symptoms require a different approach and a different environment to engage with treatment. At present there are no specialist treatment services for people with enduring eating disorders. Some community-based recovery support programs provide group support for people with enduring illness.

"I have been suffering from anorexia for 26 years. I spent the first 23 years in denial, refusing to access treatment, as it was too scary for me. In 2009, at age 36 I was literally on my death bed. I was so weak I needed to hold onto walls to support myself when I walked, I was even too weak to sit upright in a chair. I was fainting frequently and too ill to drive. My life had completely fallen apart. My anorexia had cost me everything. I had been kicked out of uni, as I was an insurance liability due to my fainting. I couldn't dance or work. I had lost what few friends I had. As I got physically sicker, I became more and more isolated and depressed. I lived for my baby niece and nephews, but I had become too ill to play with them and too weak to even carry my six month old niece.

At this stage, being bed ridden and unable to do anything, I knew the time had come to address this problem. I thought everyone would be so happy that I had finally made the decision to address my eating issues. However, I was shocked to find that despite having private health insurance, no matter where I turned I seemed to fall through cracks in the system.

I was told I was "far too ill" to be admitted to any private hospitals, including those specialising in eating disorders. I was advised to attend the local public hospital. I was told I was too medically unwell to be admitted to East Wing – the psychiatric division of the local public hospital, and too mentally unwell to be admitted to the medical wards: "We can't have a self-harmer on the wards." I asked, "where do I go?" I was told I would be referred back to my Doctor. My Doctor referred me to RPA, and after months waiting to receive an initial appointment, I was told that I had had anorexia for too long and would never get better, and that the few beds would go to younger patients, with a better chance of recovery.

Unfortunately, there are many people in the position I was in 2009. Ready to access care, but unable to access care due to the lack of specialised services. People are dying on waiting lists. This should not be allowed to happen. When people finally make the decision to get better, it is important that they are able to access care."

Cost of Treatment

The majority of people with eating disorders receive treatment through individual clinicians in private practice and through private hospitals.

Lack of recognition of eating disorders in private health insurance, Medicare benefits and other funding initiatives leads to difficulties in accessing treatment, particularly for people who are reliant on public health services.

Lack of access to financial support reduces or delays access to treatment and increases family stress.

“There is very limited financial support available for those who suffer from eating disorders. Centrelink does not provide disability or illness support unless you either have a full time job to return to or have had the illness for at least two years. This leaves a lot of people falling through the cracks”

Access Pathways

Lack of information on referral pathways has led to inappropriate referrals and delays in accessing appropriate treatment.

“When I finally got the right treatment it was highly effective; however, the 5 years prior to this, treatment was either ineffective or made the condition worse”

The NEDC consultation identified that eating disorder specialist services often do not receive referrals from GPs and other primary care professionals, reflecting the lack of awareness of eating disorders and of treatment options amongst these groups. 60% of clinicians indicated that they had experienced difficulty finding a service to refer people to.

Families and adults with eating disorders also struggle with a lack of information on how to access services.

“Parents had no idea what was available and thought what we were given was all there was. Later in my illness they realised there was other treatment available and that they would need to search around and find what suited me specifically”

“Provide a helpline which would enable sufferers to obtain low cost immediate counselling and contact rather than endure long waiting periods for costly appointments and by which time their condition has exacerbated”

There is a need to provide personalised information to people who are seeking help for eating disorders. Support services and tertiary consultation services (e.g. Butterfly Foundation, EDV, CEED, CEDD, NEDC) provide information on available services, either through their websites or by telephone. Generally, these information services are not integrated with the health service providers and information may be limited.

2.2.2 Access to Support Services

A review of services available in Queensland (EDA, 2012) found that the top three services considered to have the best understanding of eating disorders were all support and information services, which also provide some level of direct service to clients with eating disorders.

Community-based services and support and education services are key places that people with or at risk of an eating disorder seek information. Outside of these services, the Internet has proved to be a popular source of initial information. Generally services are well known in their local regions and

provide online and telephone access to information and support, as well as centre-based and outreach services.

Support services have a role in:

- Dissemination of information; research, best practice, guidelines, education materials
- Advocacy; individual and sector wide
- Referral
- Facilitation of best practice in local services
- Provision of community-based support services for consumers and carers
- Community awareness.

There is a distinction between services which primarily meet the information and support needs of people with eating disorders and their families, and services which primarily meet the information and professional support needs of clinicians and health services.

Community-Based Support Services

These organisations serve community needs at all levels, from health promotion, prevention, early intervention to acute illness, recovery and relapse prevention. They assist carers and families of people with eating disorders to access support and information. At optimum capacity, they offer peer support groups, community training and education programs, telephone and online counselling, resource libraries, prevention programs for schools and the community, carer support and training programs, training and treatment sponsorship, media advocacy and public awareness to reduce stigmatisation of body image issues and eating disorders.

Community-based organisations are located across various states and territories within Australia, with large and critical differences in resources and sustainability. These include:

- The Butterfly Foundation (national service, offices in Melbourne and Sydney)
- Eating Disorders Foundation of the ACT (ACT)
- Eating Disorders Association Incorporated (QLD)
- Gold Coast Eating Disorders Association (QLD)
- Panic and Anxiety, Obsessive Compulsive and Eating Disorder Associations (ACEDA) (SA) *(note that ACEDA closed in December 2012. In 2013, Centacare were provided funding to provide Eating Disorders services in SA)*
- Tasmanian Eating Disorders Support Service (TAS)
- Eating Disorders Foundation of Victoria Incorporated (VIC) Bridges Association Incorporated (WA)

These organisations seek to provide valuable and wide-ranging community services, such as telephone helplines, advocacy, recovery-oriented support groups for individuals with eating disorders, education and skills-based support groups for carers and families, school-based training and education programs, and information resources. In most instances, these are the only organisations in the sector that are seeking to meet some of the needs of carers and families of sufferers.

Some of these community-based organisations are partly supported by state funding, while others receive no state or other regular funding support, relying solely on fundraising.

Regardless of funding support, maintaining operations for community-based organisations is challenging and heavily reliant upon volunteers. Volunteers are generally individuals with lived experience of an eating disorder, health professionals, student health professionals and carers or family members.

2.2.3 Access to Information

59% of clinicians consulted provide health information resources about eating disorders to clients. Many of these resources are sourced from support services or from websites.

There has been a strong uptake of mental health information online, especially amongst young people (Rickwood, 2011). There are indications that people with the greatest wellbeing problems are the ones who are searching online for health information (Drentea, Goldner, Cotten & Hale, 2008). Health professionals also use online search engines to find medical literature (Cummings, 2009).

One study has shown that 68% of young people would use online mental health information if they needed it; however, the same study found that 79.4% would still prefer face-to-face support (Horgan & Sweeney, 2010). People accessing information about eating disorders do so in the context of the complexity of eating disorders, along with difficulties in accessing knowledgeable primary care and early intervention and the barrier of stigma and misconceptions about eating disorders. Providing access to information in a personalised way that can answer an individual's specific questions may be an essential component of an early intervention approach. Building capacity into community-based support services and youth health services, such as Headspace, may provide one option to achieve this. The provision of telephone and email support services may also provide an accessible and cost-effective alternative.

The Australian Government e-Mental Health Strategy seeks to capitalise on this trend by improving access to professional and reliable mental health information, support and therapy through online portals.

Evidence-based information on eating disorders can be accessed from a wide variety of online sites, including eating disorders and body image support services, private clinical practices, youth mental health services and the NEDC website.

The first phase of the NEDC reviewed websites of relevant Australian organisations providing information on eating disorders included:

- Australian and New Zealand Academy for Eating Disorders (www.anzaed.org.au)
- Bridges Association Incorporated (www.bridges.net.au)
- The Butterfly Foundation (www.thebutterflyfoundation.org.au)
- Centre for Clinical Interventions (www.cci.health.wa.gov.au)

- Centre for Eating and Dieting Disorders (www.cedd.org.au)
- Eating Disorders Association Incorporated (Queensland) (www.eda.org.au)
- Eating Disorders Association of South Australia (www.edasa.org.au)
- Eating Disorders Foundation of Victoria (www.eatingdisorders.org.au)
- ISIS Centre for Women's Action on Eating Issues Incorporated (www.isis.org.au)
- Women's Healthworks (www.womenshealthworks.org.au)

Evidence-informed fact sheets on eating disorders may also be found on relevant youth health websites, such as Headspace and ReachOut.

Although the Internet has information available defining eating disorders, accessing practical information on local, relevant services proves more difficult. The volume of information on eating disorders and body image is now so great that selecting the right information can be confusing. Although the credibility of the website should assist people in the selection process, websites have not been shown to consistently meet quality standards.

A review of websites on diet and anorexia or bulimia (using Google as a search engine) has found that the credibility of websites covering these issues is still poor. Factors such as identifying authorship, referencing of content and updating of content were identified as areas for improvement (Guardiola-Wanden-Berghe et al., 2011).

Usage patterns for the NEDC website indicate that while people may enthusiastically search the website for resources, they do not necessarily remember those resources at later times when the information would be of immediate use. There is a need to either assertively disseminate information (e.g. through email) or to provide more personal information (e.g. through telephone support).

Information that promotes help seeking for medical treatment is not always welcome. Many people prefer not to seek medical help and people with eating disorder experience additional barriers to help seeking, including failure to recognise their condition as a health problem, reluctance to change, and fear of the stigma associated with eating disorders. In this context, the solutions offered by less credible sites may be more appealing than the right answer or the most accurate information.

Social Media

The advent of social media has given rise to many new and innovative ways for people with or at risk of an eating disorder to access information and support. It also provides a unique environment to disseminate population-wide and targeted messaging about healthy eating and body image. However, social media also provides a forum for people to share their unhealthy views on eating and body image, and creates a community of acceptance and support for symptoms of eating disorders. It also allows for the easy spread of misinformation about healthy eating, body image and eating disorders.

The following are some examples of the information contained in social media:

- **Facebook:** The social networking site has many pages devoted to unhealthy eating behaviours and weight loss programs, some with hundreds of thousands of fans. These pages often perpetuate misinformation about eating disorders and support dangerous, restrictive dieting behaviours
- **Twitter:** A review of Twitter hashtags and the accounts that have frequently used them highlights a pervasive use of Twitter updates to share thoughts and experiences on disordered eating behaviour. Twitter also provides communities of 'support' for people engaging in unhealthy eating behaviours and eating disorder symptoms. While these updates seem to be specific to people already suffering from disordered eating and thinking regarding body image, they are often also tagged with more general terms such as *#fat* and *#loseweight*, which gains them a wider audience with people interested in general weight conversations
- **Tumblr:** This free blogging website includes pages which contain graphic images of underweight men and women, along with personal experiences of eating disorders and self-harming behaviours. It also contains explicit information on how to engage in disordered eating behaviours and employs derogatory language towards people who are not restricting and/or purging their food intake. Many of the people responsible for these pages purport to be young women, often under the age of 18

Information services and campaigns should have an active, well-monitored presence in social media spaces and should look at the roles and risks of social media as part of early intervention and prevention programs with young people. Organisations and initiatives providing online information about eating disorders must continuously review and develop their resources in order to maintain their currency and quality.

2.3 Examples of Current Practice in Access and Equity

There are a number of projects in Australia that seek to improve access to information and services for clinicians, families and people with eating disorders. These include government initiatives, such as CEDD (NSW) and CEED (VIC), which place an emphasis on information, training and professional consultation, as well as non-government support services, such as the Butterfly Foundation's National Support Line and the Eating Disorders Victoria Helpline and Helpfinder Service.

Centre for Eating and Dieting Disorders (CEDD), New South Wales

CEDD is funded by the Mental Health and Drug & Alcohol Office, NSW Department of Health. It is an academic and service support centre based in Sydney, resulting from collaboration between the Sydney Local Health Network and The Boden Institute of Obesity, Nutrition, Exercise & Eating Disorders in the Faculty of Medicine at the University of Sydney.

The Centre has a number of key functions to:

- To promote awareness of eating disorders as serious mental illnesses, which require treatment and which, in many cases, can be cured
- To contribute to policy development for the treatment, prevention and cure of eating disorders
- To improve access to services for people in NSW who have an eating disorder and their carers
- To provide support to clinicians in NSW who have taken on the care of patients with an eating disorder
- To conduct and foster research into eating disorders, their aetiology, treatment and cure
- To educate and train the health workforce in evidence-based medicines and treatments for people with eating disorders
- To support other organisations working for the betterment of those afflicted by these mental illnesses
- To contribute to the development of prevention and early intervention policy and interventions to reduce the incidence, duration and burden of eating disorders
- To collaborate and develop ideas with experts in the fields of obesity, body image and other related disciplines in order to promote broad spectrum Public Health

The Victorian Centre of Excellence in Eating Disorders (CEED), Victoria

CEED was launched in January 2002 as part of the Victorian government's commitment to improving health care for people with eating disorders. CEED aims to reduce the risk, duration and impact of eating disorders in people of all ages by building Victoria's capacity to undertake effective prevention, early intervention and clinical care.

CEED's objectives are to:

- Provide leadership in research, education, training and consultation in the field of eating disorders
- Enhance the capacity of primary care and specialty services to respond to the early intervention, treatment and rehabilitation needs of people with eating disorders through training, education, research and consultation
- Identify, develop and support the implementation of evidence-based best practice across the spectrum of care, including early intervention for primary care and specialist services
- Act as a resource and clearing house for contemporary approaches to prevention, early intervention and treatment of eating disorders across the life span
- Identify and respond to particular service provision issues as they relate to regional and remote areas through the development and/or support of appropriate service models
- Improve partnerships and linkages between primary care, specialist services and other service sectors, including welfare, education and employment, in the interests of developing a comprehensive response to the needs of people with eating disorders
- Ensure that those with eating disorders and their families are actively represented in the work of CEED

CEED senior clinicians provide consultation to specialist public mental health services (Child & Adolescent and Adult Mental Health Services) and clinicians working with clients who have an eating disorder or an emerging eating disorder. CEED is unable to provide consultation to health professionals working in the private sector.

The Eating Disorders Helpline

The Eating Disorders Helpline provides information, guidance and support via a telephone helpline and an online email service to anyone whose life is affected by an eating disorder, body image issues or disordered eating

The Eating Disorders Helpline is currently a shared service for three state-based eating disorder support services: Eating Disorders Victoria, the Eating Disorders Association Inc (QLD) and ACEDA (SA) – formerly the Eating Disorders Association of South Australia. Calls are transferred and answered by the organisation in each caller's state. Calls from other states are answered in Victoria.

The Eating Disorders National Support Line

The Butterfly Foundation's National Support Line (1800 ED HOPE), as well as their web-based and email service, provides access to professional and confidential support for people with eating disorders, families and clinicians.

Professionally trained counsellors, who are experienced in dealing with eating disorders, provide personalised support, advice on coping strategies and eating disorder information. The program can also offer guidance on treatment options and connections with other services and specialists.

The Butterfly Support Line expanded in early 2013 into the Butterfly National Teleweb Counselling Service.

A different, more intensive and targeted approach is provided by the Eating Disorders Outreach Service (EDOS) in Queensland, which provides streamlined access to eating disorder specialist inpatient treatment at the Royal Brisbane and Women's Hospital and outpatient services and professional support for people accessing treatment in general health services.

Eating Disorders Outreach Services (EDOS), QLD

The Eating Disorders Outreach Service (EDOS) supports clinicians in the treatment and management of eating disorder patients across Queensland. The service has become an integral part of the RBWH Adult Eating Disorders Service, providing state-wide assessment and treatment recommendations, consultation liaison services and specialist intervention programs.

EDOS provides services in four key areas:

- Facilitation of intake to specialist eating disorder inpatient and outpatient programs at the Royal Brisbane and Women’s Hospital
- Service capacity development through the provision of support to primary and secondary care clinicians working with eating disorder patients across Queensland
- Education and training, including assessment, treatment and prevention workshops and facilitation of networking between clinicians
- Consultation liaison and the development of decision support resources, including an inpatient management toolkit

This model is supported by a staff unit of two permanent specialist clinicians (social worker and psychologist), dieticians, a nurse, a specialist psychologist, a psych registrar and a team manager. The service provides a specialist outpatient clinic, state-wide education and a consultation liaison service, as well as state-wide policy development and a state-wide intake service to support access to public services and ensure access to the RBWH service.

EDOS has been successful in facilitating patient access to local, general medical and psychiatric facilities. EDOS also plays a significant leadership role in the development of effective state-wide networking forums for clinicians and key stakeholders, in in-service delivery and in the provision of evidence-based educational opportunities, each of which has contributed to improved access to services for eating disorder patients. EDOS has also established decision tools, practice guidelines and training resources, which may be transferrable to other state and territory contexts (*Painter, Ward, Gibbon, Emmerson, 2010*)

2.4 Recommendations Relating to Access

Community access is identified as a priority area for national action. While the issue of access is addressed in very different ways in each state, clear points of entry and referral pathways remain a consistent gap for most states. The priority action is identified as resourcing existing eating disorder services (government and non-government) to extend the reach and capacity of services as soft entry points for rapid and appropriate referral.

Based on the standards for best practice outlined in this chapter and building on the promising approaches relating to access, the following table details key strategic opportunities for development that address the gaps identified in current practice.

Immediate Opportunities	Review roles and capacity of existing information and ‘point of entry’ services Dissemination of existing assessment and referral tools
Medium Term Planning	Develop a detailed map of existing service capacity and resources for potential development in all community health regions
<i>Further development of information and resources is</i>	Review access pathways into and between services and utilise national framework to improve coordination between services

required to support these actions

Develop collaborative links between information services and eating disorder service providers to ensure streamlined, timely referrals

Review and build the capacity of existing information services to provide immediate access to short term, professional intervention as an early intervention strategy and to maintain motivation while people wait for access to other services

Develop protocols for shared provision of care between health disciplines and between health service providers, including public and private health and NGO community-based services

Implement intensive, community-based services in all areas that are currently underserved

Support and monitor the consistent implementation of assessment and referral tools

Review access pathways into and between services and utilise national framework to improve coordination between services

Map existing evidence-based family and consumer education programs to facilitate sharing of resources between service providers

Review the roles and funding arrangements of existing support organisations in each state

Optimal Model Mental health policies and initiatives that provide for early intervention, safe multidisciplinary treatment and a sufficient dosage of treatment to promote recovery

3 Flexible, Person-Centred Models

3.1 Standards for Person-Centred Models

The NEDC National Framework identifies the following principles needed to achieve quality treatment for eating disorders:

- Person and family-centred care that addresses the needs of individuals
- Safety and flexibility in treatment options

Eating disorder programs take a person-centred approach in which the patient is an active agent in improving their own health and wellbeing. Person-centred services:

- Prioritise engagement and retention
- Provide multiple options for treatment that facilitate individual choice

- Take the person's values, preferences, resources, resilience and choices into consideration in planning treatment
- Make optimal use of family and community resources, coordinating and integrating treatment in partnership with the patient, family, and health care professionals
- Provide for sustained engagement, including recovery support and long term care of stabilised individuals with complex comorbidity or enduring illness

To achieve effective person-centred models of care, services should ensure:

- Individual treatment plans are developed within a person-centred, family and culture-sensitive and recovery-oriented framework
- Services are delivered with a strengths-focused approach that supports long term recovery and that is tailored to meet an individual's decision making capacity and other needs as they develop over the course of the illness
- A choice of treatment approaches is available
- Policies and protocols enable staff to identify and work with family members or carers
- An individual treatment plan is developed for each person, taking into consideration individual strengths and resources
- Treatment plans include long term support for recovery, criteria for re-admission, and post treatment follow-up
- Planned treatment and support is specific to the person's disorder and to their individual circumstances
- Professional support is provided to enable people with eating disorders to actively engage in their own treatment decisions
- Support for self-advocacy includes pre-treatment engagement information and support, motivational enhancement and education and support for self-advocacy
- Consumer participation in research, evaluation and service development is supported with training and debriefing
- Organisations working with people with eating disorders have clear guidelines and protocols to support consumer self-advocacy and participation

3.1.1 Individual Pathways to Recovery

An eating disorder is a complex interaction of distorted eating behaviours, psychological distress and physiological disturbance. A further level of interaction occurs with comorbid conditions; eating

disorders commonly occur with other mental and physical illnesses. Comorbid conditions may increase the severity and chronicity of the eating disorder (Blinder, Cumella, & Sanathara, 2006).

Societal factors, such as cultural standards, personal relationships and community attitudes, play an important role in the prevention or heightened risk for the development of eating disorders, and in early intervention and support for people who have the illness.

The interplay between all of these factors results in a dynamic illness that can change the way in which it manifests throughout its duration. The presentation of an eating disorder may vary over time (Wade et al., 2006). Approximately half of individuals with anorexia nervosa will experience bulimia nervosa or EDNOS at a later stage in life. The presentation of people with bulimia nervosa and binge eating disorder may also change over time to EDNOS (Steinhausen, 2009).

All types of eating disorders present within a wide range of severity. At one end of the spectrum, some people may experience mild to moderate episodes of an eating disorder, while others may experience severe and persistent disorders with life threatening consequences.

People may experience an unstable pattern of illness, with alternation between periods of remission and new episodes of illness. Progression along the continuum is not linear and response to treatment is individual and variable. There is no predictable or normative long term course associated with eating disorders.

The experience of an eating disorder is highly individual and as a result, eating disorders are amongst the most difficult psychopathologies to treat. No single treatment will be effective for every person with an eating disorder. The complexities of eating disorders require a multidisciplinary team and a supportive environment with the capacity to provide collaborative intervention for an extended period of time (NEDC, 2012).

Without treatment for an eating disorder, the prognosis is relatively poor. For example, without treatment, up to two thirds of people with bulimia nervosa will have an eating disorder of clinical severity after five years (Fairburn, Cooper et al., 2000).

A person with an eating disorder requires treatment that is specific to their disorder, specific to their individual circumstances and delivered by health professionals who have been trained in the delivery of evidence-based approaches.

3.1.2 Consumer and Family Participation

There is a strong evidence base to show that involving and engaging consumers in the provision of their care has significant overall benefits in improving the quality and appropriateness of individual service and health services as a whole. Participation is a right and a key enabling strategy in improving health outcomes for the community.

Participation in decisions that personally affect an individual may present significant challenges for a person with an eating disorder. Professional support is required to enable the person to actively engage in their own treatment decisions. This would include the provision of pre-treatment

engagement information and support, motivational enhancement and education and support for self-advocacy.

Consumer participation for people with eating disorders, especially for those who are not yet fully recovered, will preferably occur in an environment in which support is available for:

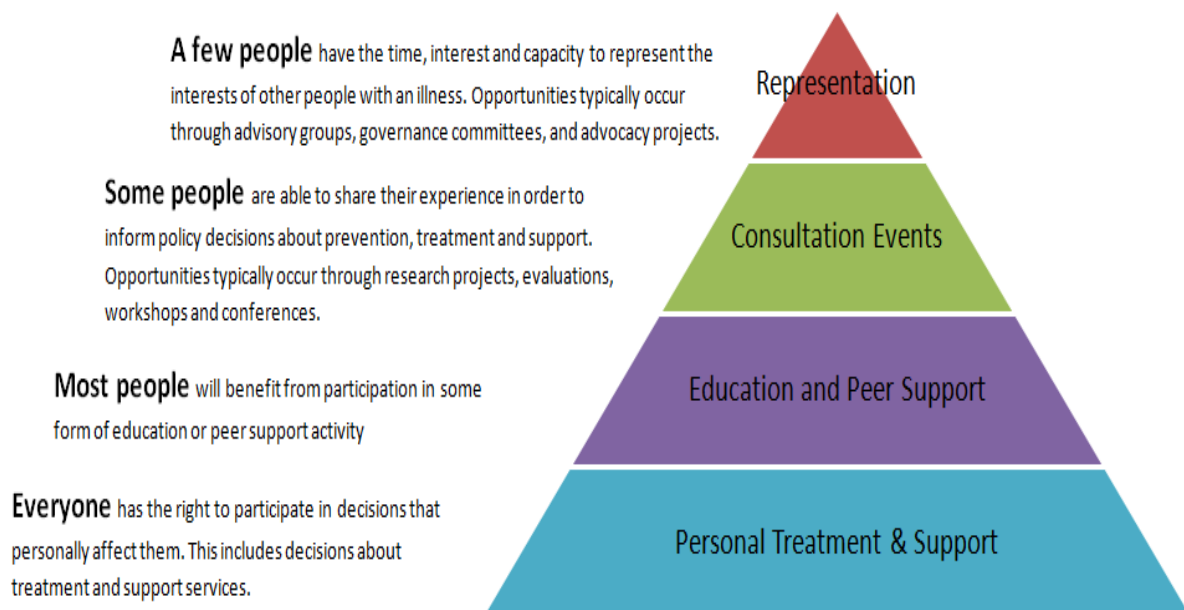
- Selection of safe and appropriate events for participation for the individual's stage of recovery
- Development of coping plans and skills to enhance the experience of participation and minimise risk of harm
- Debriefing after participation and for long term recovery

The NEDC Gap Analysis has identified four different types and levels of participation for both consumers and carers (see diagram below).

At each of these levels, consumers and carers require education and support to assist them to make the most effective use of opportunities. Participation activities require clear guidelines to ensure that people with eating disorders are able to safely participate with undue stress that may trigger further illness.

Implementation of family support and consumer participation support strategies would contribute to achievement of Standard 3 of the National Mental Health Service Standards (2010), which includes reference to the provision of training and support for consumers, carers and staff.

Education and support for consumer participation should form an integral part of an eating disorder service model.



3.2 Current Practice in Person-Centred Models and Participation

The NEDC model of participation clearly identifies that participation in public events and as a representative of others is not necessarily helpful for everyone with a lived experience of eating disorders. The ability to participate and the benefits of participation are dependent on the individual's circumstances, including their stage of recovery.

For many people, participation is an important part of the journey of recovery. Information collected by the NEDC indicates that some people choose to participate in any event that identifies eating disorders as a core issue in a search for information and help in their recovery; others avoid participation as a source of stress or as potentially stigmatising.

A review of motivation to participate conducted by Trowse, Cook and Clooney (2012), on behalf of Children Of Parents with Mental Illness (COPMI), found that people are primarily motivated by a desire to help others and improve services and this is consistent with the responses collected by the NEDC. Feedback from the participants in the 2012 Evidence from Experience forum, and from previous NEDC forums, identified the primary motivation to participate as the desire to:

- Share their experience in order to inform clinicians about the impact of treatment and service practices and to improve health practices
- Give support to and receive support from others with lived experience

While both of these activities are vital to the process of participation, they are also relatively high risk activities for participants with a potential to increase stress and, in some instances, trigger eating disorder thoughts and behaviours that can develop into a full relapse.

For some people with eating disorders, engagement in consumer participation and, in particular, self-advocacy, is a part of achieving wellbeing. This encompasses the ability to ask for what they need, particularly in treatment relationships, and the ability to contribute something of value to their community from their own experience.

Participating – being involved in meaningful activities that increase feelings of personal efficacy and dignity – may be a part of a person's coping plan for recovery and yet at the same time, it may expose the person to increased risk of relapse if the participation is perceived as being unsuccessful.

3.3 Examples of Current Practice

Some state health services have developed strategies for involving consumers and carers; for example:

- The Eating Disorders Program at Princess Margaret Hospital for Children in Western Australia; this service operates consumer and carer advisory groups and works with a consumer participation coordinator to carry out initiatives from consumers and carers, such as producing youth-friendly resources and peer mentoring

- Queensland has carer and consumer representation on the State-wide Mental Health Network Eating Disorders Sub Network; the Royal Brisbane and Women’s Hospital (RBWH) Eating Disorders Service employs carers and consumers to review their clinical and operational management on a regular basis
- At the Austin Hospital in Victoria, an eating disorders working group comprised of carers and practitioners together devised a short practical information booklet to assist families of patients in understanding aspects of the Austin Hospital treatment process, as well as provide home management tips to families, such as meal planning

The following guidelines address the actions that any agency can put in place to facilitate participation by people with lived experience of eating disorders.

Choosing to Participate

Consumers and carers have unique expertise as a result of their experiences. Consumers and carers have a right to participate and have a direct and active role in all processes that affect their lives. How they choose to participate is an individual decision.

The choice to participate can be facilitated by providing a range of different methods of participation including direct personal participation and opportunities to provide information in written form. For example:

- Suggestion boxes
- Questionnaires
- Individual goal setting for treatment and support
- Choice of treatment and support activities
- Group meetings of different sizes held in different environments to increase the experience of personal comfort

“Any small amount of choice is better than none”

Decisions about who should participate at levels beyond personal treatment and support should be made collaboratively between professionals with knowledge of eating disorders and consumers. The involvement of professionals in this process is desirable to support both the safety and wellbeing of the person choosing to participate and the safety and wellbeing of others who may be participating.

Issues for discussion to support individual decision making could include:

Personal Experience of Recovery

Discussion could explore:

- Whether the person is currently receiving treatment
- Their current physical health
- Their feelings regarding their illness or experience as a carer
- Their concerns, especially regarding ‘triggering’ events
- Setting clear boundaries for personal safety and risk management

Motivation to Participate

Exploring what the person hopes to achieve from participation:

- Their goals for the specific participation activity
- Whether the motivation is primarily about personal recovery or about providing information for others
- Comparing this with the purpose and content of the participation activity
- Consideration of alternative opportunities for participation, if appropriate

Behavioural Requirements of Participation

It should also be assessed whether participation requires the person to be able to:

- Travel
- Listen to others, consider different points of view and accept these differences
- Engage in collaboration with clinicians, carers and/or researchers
- Sit in meetings for long periods of time
- Eat meals with other people
- Participate in noisy, crowded or unfamiliar environments
- Commit a specific amount of time and energy

Support for Participation

Exploring the sort of support the person would like to receive to facilitate participation. For example:

- More information about the participation activity
- Opportunity to meet other participants before an event
- Training to develop skills for participation at the appropriate level
- A 'buddy' or support person
- Debriefing after participation and referral to appropriate support or treatment options where there is a risk of actual relapse

General Guidelines to Support Consumer Participation

The following guiding principles are suggested for organisers of events at which people with experience of eating disorders are invited to participate. These principles are consistent with the general standards for consumer participation. They specifically address the issues of recovery from eating disorders, which may lead to different participation support needs for people who have experience of eating disorders.

All levels of participation

Consumers and carers have varying communication styles and participation needs and every effort should be made to accommodate individual need provided that the activity will be safe and positive for the person concerned and other consumers they may be engaging with.

At all levels of participation, the person with an eating disorder, and their family or carer, should be able to access:

- Clear information on the purpose of the participation activity and what can be expected to happen during participation. This should include identification of what will be discussed and how

any information collected during participation will be used

- Support, if required, from a person or persons experienced in the provision of eating disorder information and support before, during and after participation
- Education or training on how to participate at the relevant level, including how to manage their own responses to participation

Group Meetings

For group events (such as group meetings, peer support events, education and conferences), planning should take into consideration the way in which food and support services are provided:

Active Participation

- Invite participation from more than one person with lived experience to participate
- Engage people with lived experience in the planning and evaluation of participation events
- Include representation from lived experience in the leadership of the meeting (e.g. include as facilitators or presenters or include on question panels)

Food Presentation

People with lived experience of eating disorders may experience anxiety in social situations. Depending on their personal experience, this can be exacerbated when in the presence of health specialists or carers. People with experience of eating disorders may also be stressed by the presence of food, other people eating or the expectation that they eat in front of strangers. This can be further aggravated if the group includes sufferers of different forms of eating disorders, such as those suffering from restrictive anorexia nervosa and those suffering from bingeing and purging bulimia nervosa. The following strategies may assist people to manage these anxieties. They are particularly relevant to longer meetings (such as conferences, day-long workshops):

- Avoid making food a focal issue of any meeting (e.g. avoid holding 'lunch meetings' or 'afternoon teas')
- Provide a range of healthy food options (e.g. avoid serving one food type, such as sandwiches for lunch or cake for morning tea). Enable people to make personal food choices from a range of items, such as fruit, salads and nuts.
- Serve food in a separate area to the main meeting wherever possible. If food must be served in the meeting room, remove the food before the meeting recommences.
- Provide spaces away from the main meeting rooms where people can withdraw if they choose to do so to eat in private or to have some quiet time between sessions or interaction with others

(e.g. provide a separate quiet room or ensure that there is access to outside space or encourage people to go out for a walk and explore the local area)

Sharing Personal Stories

If the purpose of the participation event is to share personal stories and experiences, consideration should be given to:

- Clearly identifying in all preparatory materials that the event will involve or is appropriate for personal storytelling
- Providing guidelines on what may and may not be safely talked about Providing separate meetings or break out groups for people with a lived experience of eating disorders and their family and carers
- Providing alternative approaches for storytelling and story collection (e.g. writing stories, individual interviews, video recordings) to help people manage the stress and risks associated with telling or hearing personal stories about eating disorders

When engaging people to speak from lived experience, organisations are advised to:

- Identify the target audience for the meeting. Appropriate presentation content for audiences of clinicians or researchers will be different to safe and appropriate content for people who have or are at risk of developing an eating disorder
- Provide speakers with guidelines on safe content for presentations to audiences that include people who have or have had an eating disorder
- Select speakers who are 'highly recovered' - in general, this means they should be out of treatment for at least 12 months and preferably for at least 2 years
- Brief speakers verbally on the aims and objectives of the presentation and the target audience; the brief should include details about their role, how long they have available to speak and whether they will be expected to answer questions or not
- For vulnerable audiences, request an indication of what the speaker intends to say before the presentation
- If the person is speaking for the first time, ensure that they have support to prepare and rehearse their presentation. Provide mentoring support to assist people to adapt their story to suit the purpose of the meeting and the audience's needs

Support Services

Ensure that a support person with knowledge of eating disorders is accessible during group meetings for anyone who would like support.

4 Support for Families and Carers

The National Mental Health Policy (2008) ensures that, *“The crucial role of carers in prevention, early intervention, treatment and recovery will be and provided with appropriate support to enable them to fulfil their role.”*

4.1 Standards for Supporting Families and Carers

Families can play a critical role in identifying eating disorder symptoms, supporting help seeking and engagement and supporting treatment and recovery between meetings with clinicians. Families require education, resources and support to enable them to sustain their role throughout the treatment and recovery process (Treasure, Smith & Crane, 2007).

Family involvement is essential for children and adolescents. For adults with anorexia nervosa, family involvement may be useful and should be considered on a case-by-case basis. Involving spouses and partners in treatment is highly desirable.

Adults with other types of eating disorders may benefit from the involvement of family if their condition is complex, requires long term treatment or if family patterns of behaviour may contribute to relapse or recurrence of the illness.

People who do not have access to family support require access to other forms of professional support as an essential part of treatment engagement and relapse prevention.

Families are significantly impacted by eating disorders even when they are not actively involved in supporting treatment. Carers of people with anorexia nervosa, for example, experience significant levels of distress (Whitney, Murphy et al., 2012). Family education and support is integral to long term treatment of eating disorders and the prevention of eating disorders and other mental health problems in family members.

Information, engagement, education and support for self-advocacy, along with education and support for recovery for both consumers and their carers, may be provided as an integral part of specialist eating disorder treatment programs or by community-based services working collaboratively with treatment services.

The National Report Card on Mental Health and Suicide Prevention recommends investment in healthy families and communities (Recommendation 7: NMHC, 2012). For families affected by eating disorders, the range of support provided for families and carers should include individual or group information, education, engagement in therapeutic processes, peer support and facilitated access to mental health and other support services to meet their own needs.

Standard 7 (Carers) of the National Mental Health Service Standards (2010) includes the recognition of the role of carers in the wellbeing, treatment and recovery of people with mental illness and requires policies and protocols to enable staff to identify and work with carers. Expansion of the

level and range of support for families and carers is an aim of the Fourth National Mental Health Plan, 2009).

The NEDC National Framework identifies the following principles needed to achieve effective support for carers and families:

- Person and family-centred care that addresses the needs of individuals
- Support for families and carers as integral members of the team

In addition to these principles, the Worldwide Charter for Eating Disorders also indicates that treatment services and systems should include accessible, appropriate support, education and resources for carers.

To achieve best practice, services should ensure:

- Families and carers, where available, are recognised as integral members of the treatment and support team and receive support, skills and strategies, education and information to enable them to support the person with the eating disorder and to maintain personal good health themselves
- Where support of a family or carer is not available, this gap in the team and support structure is taken into account and addressed by the service providers
- Family education and support is integral to long term treatment plans
- The range of support includes individual or group information, education, engagement in therapeutic processes, peer support and facilitated access to mental health and other support services to meet their own needs
- Policies and protocols enable staff to identify and work with family members or carers
- Family or other nominated support persons are educated and supported to act as integral members of the treatment team
- Education for families is integrated into treatment – either as part of treatment programs or provided separately on referral from treatment programs
- Families, including partners, children and siblings, have access to education and support to manage their own stress and mental health
- A range of service options, including telephone support and day and residential programs, meets the needs of adults who do not have family support

4.2 Current Practice in Providing Support for Families

From a consumer perspective, one of the biggest gaps to be addressed is the lack of access to community-based recovery and rehabilitation support and family support.

“We have had no family support; my parents have had nothing. The amount of stress this has caused over the years has sometimes been overwhelming and has caused rifts between family members”

During and after treatment, people with eating disorders need to learn how to respond to their normal living environments, particularly in relation to food, without the eating disorder. This takes time, education, encouragement and support. It must be carried out as close to home as possible to enable people to continue or resume their normal life activities and relationships. Professionally facilitated peer support is also an important contributor to recovery. As the experience of an eating disorder is very isolating, these services ideally provide support for social inclusion to help people to establish relationships and engage in a range of social activities.

Some specialist eating disorder services provide recovery and family education as part of the treatment program, however, this is not consistent across all specialist programs and does not appear to take place for people accessing treatment through general primary care services.

Lack of integration of motivational engagement, recovery support and family education and support in the treatment process reduces effectiveness of treatment and increases family stress. While most (but not all) specialist eating disorder programs address the full treatment pathway, people accessing treatment outside specialist services do not readily gain access to these essential components of treatment.

There are some examples of recovery support for eating disorders in Australia (see examples in Chapter 1). There are also examples of recovery support for people with other mental illnesses, which are mostly provided by non-government organisations. These services potentially provide the infrastructure for delivery of more eating disorder recovery programs. This would require skilling staff in these services to work with people with eating disorders.

Caring for the family, whether they are active participants in the treatment process or not, is an essential part of the clinical role and therefore a part of service planning for eating disorder management. This need continues into adulthood, when adults with eating disorders are living with parents or other extended family members or have a spouse, partner or children.

“Not only are more hospital beds required, but it is important that more community services are available to assist people before they get to the point of needing hospitalisation, and to assist in the maintenance of gains made in hospital, after discharge. Community support should address independent living skills, helping people manage their eating, cooking and shopping in the community. Appropriate community support would reduce the burden on the hospital system”

4.3 Recommendations for Supporting Person and Family-Centred Services

The key gaps for support for person and family-centred services are consistent access to support services in the local community and integration of those services with treatment. Based on the standards for best practice and building on current approaches in Australia, the following table details key strategic actions for development to address the gaps identified.

Immediate Opportunities	Encourage implementation of NEDC participation guidelines and NMHC participation guidelines in all levels of participation
<i>Information and resources are already available to support these actions</i>	<p>Incorporate training to support consumer and carer participation in core competencies for staff working with people with eating disorders</p> <p>Promote implementation of NEDC participation guidelines and NMHC participation guidelines for all levels of consumer and carer participation</p>
Medium Term Planning	Map existing evidence-based family and consumer education programs to facilitate sharing of resources between service providers
<i>Further development of information and resources is required to support these actions</i>	<p>Create structured opportunities for participation at a representative level</p> <p>Develop training and support mechanisms for consumers and carers engaging in participation at a representative level</p> <p>Resource community-based organisations to provide accessible support services including maintaining an active, relevant online presence and online support services</p> <p>In collaboration with providers of consumer, carer and family education, identify strategies to ensure access to consumer, carer and family education in all states and territories, including regional areas</p> <p>Integrate family and recovery support in existing eating disorder services where this is not currently the service model</p> <p>Establish online and telephone support services to improve access to early intervention and self-management support</p>

5 A Skilled Workforce

5.1 Standards for a Skilled Workforce

The National Mental Health Policy (2008) ensures that, “the supply and distribution of appropriately trained workers in the mental health sector and other relevant sectors will be adequate to meet the needs of people with mental health problems and mental illness.”

The NEDC National Framework identifies the following principles needed to achieve quality treatment for those with eating disorders:

- Partnering to deliver multidisciplinary treatment in a continuum of care
- Tertiary consultation accessible at all levels of treatment
- A skilled workforce

Effective treatment for eating disorders needs to be evidence-informed and delivered by specifically trained health professionals with fidelity to the evidence-based treatment model (ANZAED, 2011).

An effective model of care is one that is founded on a skilled and supported workforce. To achieve this for eating disorders would require all health professionals to be trained in eating disorders in order to raise their awareness of the serious nature of eating disorders and to enable them to identify, assess and contribute to the treatment of eating disorders. Training would include the development of attitudes and practices that support early identification and intervention, recognition of the ambivalence and fear that is prevalent in this population and a person-centred and recovery-oriented approach.

In order to gain access to effective treatment, eating disorder expertise must be developed in five key areas:

1. Primary Care - Recognition & Assessment

Clinicians and allied professionals in primary care who work with people at high risk of developing an eating disorder have the knowledge and experience to recognise people at risk, assess their needs and refer to or consult with eating disorder specialist services.

This group includes but is not limited to: GPs, paediatricians, dietitians, psychologists, school psychologists, social workers, dentists, nurses, mental health nurses, emergency department personnel and specialists treating potentially related conditions, including obesity, obstetrics, diabetes and substance disorders.

2. Eating Disorder Treatment Teams (Non-Specialist)

Clinicians with knowledge and experience in the treatment of eating disorders, from disciplines representing physical, psychological and nutritional health, working together in a team approach to deliver a coordinated individual treatment plan.

This group includes but is not limited to treating clinicians such as: GPs; paediatricians, dietitians, psychologists, psychiatrists, occupational therapists, nurses and mental health nurses.

3. Tertiary Treatment Teams (Specialist)

Clinicians working in specialist programs from disciplines representing physical, psychological and nutritional health, developing expertise in the delivery and evaluation of evidence-based treatment and the provision of professional support to providers of non-specialist treatment.

4. Family Support

Clinicians, health and community services have the capacity to provide education, support, and mental health services for family members.

5. Sustained Recovery Support and Secondary Prevention

Access to ongoing support, including individual professional support, group support, peer support and self-help education. Both recovery and family support require skilled professionals working in health and community services in disciplines such as: psychologists, social workers, occupational therapists, nurses, educators and trained peer supporters.

To achieve best practice, systems should ensure:

- Core competencies that are defined for all relevant professions are included
- Access to appropriate and relevant training for everyone who works with people at high risk of developing an eating disorder
- Health and allied professionals who work with high risk groups are trained in screening, assessment, referral and support for people with eating disorders
- Health professionals who provide treatment are trained in the delivery of evidence-based treatment and have access to tertiary support and supervision
- Non-health professionals who work with high risk groups have training in eating disorder Mental Health First Aid or equivalent
- Clinicians, health and community services have the capacity to provide education, support, and mental health services for family members
- Every mental health hospital and youth medical service has the capacity to treat eating disorders, with at least one nominated role having responsibility for eating disorders, including liaison with tertiary consultation services
- Every medical hospital has at least one nominated role with responsibility for ensuring that patients with eating disorders access appropriate and evidence-based treatment

- Health professionals with eating disorder expertise are employed in every primary health care region and in every major (primary referral and large regional) hospital

Individuals with eating disorders are typically first seen by their family or primary care physician (Clarke & Polimeni-Walker, 2004), even if they may not receive treatment for their eating disorder from these health care providers. GPs, paediatricians and nurse practitioners are therefore a priority group for access to training.

Where existing policies and protocols indicate that all staff in general services (e.g. CAMHS) have a responsibility to treat eating disorders, all staff should be trained. In other contexts, every hospital and youth medical service should have the capacity to treat a person with an eating disorder, with at least one nominated role having responsibility for eating disorders, including liaison with tertiary consultation services.

Tertiary Consultation

Education alone has proven to be insufficient to remove access barriers, as evidenced by a continuing reluctance by some services to provide ongoing treatment to eating disorder patients. Where barriers have been successfully removed, this has been attributed to the provision of ongoing support post-training, delivered through tertiary consultation (Painter, Ward, Gibbon & Emmerson, 2010).

Professional development to enhance knowledge skill and confidence to treat comprises of a number of factors, such as training, decision support tools, access to practical experience, supervision and peer support.

Access to expert consultation is required at the earliest possible point to ensure appropriate and early intervention. Whenever treatment occurs in the continuum of care, from early intervention to recovery support, there must be access to tertiary-level expertise for consultation, supervision, guidance and referral.

To enable effective tertiary consultation, services require the following:

- Clinicians from all disciplines required in the multidisciplinary team have access to expert advice, case review and supervision when required, regardless of their geographic location
- Expert advice is available for every clinician and every patient regardless of their geographic location or source of service provision
- Every health region has formal connections with a tertiary service that is resourced to provide training, supervision and shared care

5.2 Current Practice in Developing a Skilled Professional Workforce

There is an expectation implicit in all current funding models and general health service protocols that all qualified health professionals are able to treat eating disorders.

In secondary mental health services, specific policy and protocols for the delivery of services to people with eating disorders do not specify that treating professionals require specific knowledge or skill in eating disorders. A significant barrier to developing services is the lack of appropriately trained staff.

There is an expectation in community health initiatives that GPs will be knowledgeable and skilled in identifying, assessing and appropriately referring people with all forms of mental illness, including eating disorders. However, mental health seems to be undervalued in medical school curricula and GPs, as discussed previously in this chapter, are often insufficiently trained and resourced to undertake this role (Wallace & Ransom, 2012).

Research and NEDC consultation identify that eating disorders are not included (or not sufficiently included) in undergraduate qualifications to enable a health professional to treat with confidence. Voluntary participation in professional development is not regulated and when based solely on training, appears to build knowledge but not confidence to treat. Some clinicians are providing treatment for eating disorders without professional development or supervision in this field and without the use of clinical guidelines.

Research has demonstrated that Australian health professionals generally have higher levels of nutrition knowledge than health professionals in studies in other countries. However, apart from dietitians, the level of health professionals' nutritional knowledge was very similar to that of patients with eating disorders (See Long Ho, Soh, Walter & Touyz, 2011) and does not, therefore, necessarily contribute to improved treatment or patient education.

Most clinical service providers report they use empirically supported treatments in treating eating disorders, but these are often folded into eclectic approaches, rather than used in forms that had been evaluated in research trials (Wallace & Ransom, 2012).

People with an eating disorder come in to contact with a wide variety of clinicians from medical and allied health fields. Although these clinicians may not have received adequate professional training in responding to eating disorders, they are often put in a position of needing to identify, assess and treat eating disorders and their symptoms.

These clinicians acknowledge their professional limitations in providing effective, holistic support to clients experiencing an eating disorder. However, with appropriate training, ongoing supervision and support from a multidisciplinary team and eating disorder experts, it appears clinicians are eager to work with other professionals in identifying and treating eating disorders.

Almost half (82) of clinicians consulted by the NEDC indicated that they received no formal instruction about eating disorders during their formal, professional training. The 47% who did receive training as part of their professional qualification described the training as minimal, basic or inadequate. Only 3 respondents described the training they were provided as 'good' and these respondents indicated they had an eating disorder expert in their teaching or training team.

“Whilst admitted to an adolescent psychiatric unit due to her eating disorder, we were often told staff were not trained in this area, even though at the time of our daughter’s admission, 5 of the 8 patients in the unit had an eating disorder”

This information is supported by a review of university courses in Australia relevant to the allied health services engaging with eating disorder clients. Eating disorders are rarely specifically covered at an undergraduate level. Obtaining training in eating disorders during professional qualifications relies heavily on the research interests of a particular faculty.

For non-health professionals working with people at risk of eating disorders, the situation is similar. Vocational training and accreditation programs in the areas of fitness and sports coaching, for example, do not include content on the identification and support of people with eating disorders in the context of their profession.

To compensate for this, it appears that many clinicians sought out professional development training after they had completed their mandatory training:

- 64% had completed external training
- 52% received supervision
- 60% were involved in a peer support network
- 29% received external supervision
- 38% had completed training provided by their organisation
- 5% had attended conferences
- 5% had attended workshops
- 3% had obtained further information from journals and independent research.

Respondents provided information about what they believed to be the most useful aspects of training in preparing them to identify and treat eating disorders in their professional field. Of those, the most commonly listed aspects were:

- Models of intervention (23% of respondents)
- Opportunity to engage with a specialist in eating disorders (18.5%)
- Assessment (15%)
- Gaining practical experience (15%)
- Formal supervision (15%)
- Identifying risk (11%)
- Receiving resources to utilise later (11%)
- Skills in engaging clients (7%)

- Networking opportunities (6%)
- Opportunity to hear from/engage with people with lived experience (6%)

Clinicians identified a wide range of measures which would assist them in feeling better prepared to manage clients with eating disorders, reflecting on their wide range of skills and experience, and their roles in addressing eating disorders. Most commonly, respondents indicated the following would be beneficial:

- Practical skill-based training (32% of respondents)
- Professional development opportunities (18%)
- More services to refer clients to and support their own work (13%)
- Access to specialists in order to provide expert advice and/or support (12%)
- Being part of a multidisciplinary team (12%)
- Having resources and tools to reference in their day-to-day work (12%)
- Having professional supervision (11%)

Most clinicians (53%) had experienced barriers to accessing training or professional development. Several barriers were consistently raised by respondents:

- Financial barriers (44% of respondents)
- Time barriers (35%)
- Lack of support from employer to attend training (24%)
- Competing priorities (e.g. need to staff service) (21%)
- Unable to travel (17%)
- Residing in a remote location (15%)
- Lack of training opportunities available (15%)

Several respondents indicated that providing training or training materials in a web-based format would circumvent many of the common barriers to clinicians attending training and professional development programs.

At present, professional development in eating disorders is accessed on a voluntary basis by clinicians. Access is limited by the reach and resources of the organisations that provide expert training (see list of training providers below), as well as the general barriers to accessing professional development, such as cost, time, availability and location of training. It is vital that GPs and other professionals who work with very high risk groups receive eating disorders training. Existing training resources, especially those available in an online format, provide a strategic opportunity to improve professional capacity to recognise and treat eating disorders.

5.2.1 Core Competencies

All health professionals who have a responsibility for assessment and diagnosis and who come into contact with high risk groups for eating disorders should be able to demonstrate knowledge and skill in the assessment, diagnosis and care of people with eating disorders.

There are currently no defined core competencies or skills sets for the treatment of eating disorders and this directly contributes to the failure to identify the need for trained staff in existing policies and protocols.

The development of core competencies for eating disorders is consistent with the implementation of the National Mental Health Workforce Strategy (Priority Area 4, Fourth National Mental Health Plan, 2009).

5.2.2 Tertiary Specialist Service and Consultation

Walker and Lloyd (2011) suggest health professionals feel they do not adequately understand the eating disorders experience and fear worsening the condition. It is important to give clinicians further training in evidence-based approaches, eating disorders and appropriate pathways and available services.

There is a lack of integration between specialist eating disorder services, general hospitals and Medicare local regional services, as well as a lack of capacity in existing specialist services to provide outreach and supervision for other health professionals.

The confidence to treat is as important as knowledge. Most clinicians in primary and secondary care services will only occasionally see patients with eating disorders. It is difficult to maintain and develop confidence to treat when working with small case numbers. Access to tertiary expertise to inform and support treatment is a key factor in building confidence to treat.

People from specific high risk groups may first seek help from professionals in very different fields, for example, athletes may first seek help from specialists in sports medicine or physiotherapy, whilst people who frequently use self-induced vomiting purging techniques may first be identified by a dentist and will access help through that dentist.

For specific at-risk groups, specialist health service providers may represent the first point of contact. For example, for women presenting with eating disorder symptoms later in life, the first point of contact may be a gynaecologist or midwife (Newton & Chizawsky, 2006); men and women may present for infertility treatment (Ogg, Millar, Edit, Pusztai, & Thom, 1997); for people seeking treatment for diabetes or obesity, an endocrinologist or a diabetes educator may be the first point of contact (Pereira & Alvarenga, 2007).

5.2.3 Community Outreach Education

A study in Western Australia has found that outreach community-based training in eating disorders is an effective approach to improve skills in gatekeepers in rural communities and to introduce systemic benefits in improved use of tertiary consultation and improved referral processes.

“This study quantitatively confirms that community-based training on eating disorders improves regional capacity to manage eating disorders in regional Australia” (McCormack, Watson, Harris, Potts & Forbes, 2013).

The study demonstrated a link between outreach training and a reduction in hospital admissions and better uptake of local services by patients after discharge from hospital (McCormack, Watson, Harris, Potts & Forbes, 2013).

5.3 Examples of Current Practice in Professional Development Training

The following table details current specialist professional development training in the area of eating disorders.

Provider	Course	Target Audience	Location	Information
Centre for Eating and Dieting Disorders	5 module learning program in eating disorders	Health Professionals in NSW and other jurisdictions	Online	www.cedd.org.au
Centre for Excellence in Eating Disorders	A variety of specialist workshops and seminars on eating disorders	Varies depending on content; generally mental health or general health practitioners	Victoria, Online	www.ceed.org.au
Centre for Excellence in Eating Disorders	Training in eating disorders assessment and treatment	Individually designed to meet needs of Area Health Services	Victoria	www.ceed.org.au
The Butterfly Foundation	Workshops for frontline professionals to equip them to screen and intervene accordingly (e.g. Dove BodyThink)	Teachers, youth and community professionals working with young people	Australia wide	www.thebutterflyfoundation.org.au
Mental Health Academy	Course focuses on the various eating disorders and the range of approaches available to treat eating disorders	Mental Health professionals	Online	www.mentalhealthacademy.com.au
Northside Clinic	Workshop on identification and treatment of eating disorders	GPs	New South Wales	www.northsideclinic.com.au
Children's Hospital Westmead	CD Rom and Educational Resources to improve the identification, assessment and management of children with an eating disorder	Health Professionals	Computer-based	
The Eating Disorders Outreach Service	A variety of specialist workshops and seminars on eating disorders	Health Professionals	Queensland	
Women's Health	This workshop demonstrates how to present the teen body image lesson to female students from years 7 to 10	School Based Youth Health Nurses	Queensland	www.womhealth.org.au

Eating Disorders Victoria	Variety of workshops and professional development tailored to suit the needs of participants	For people working in education and other professionals working with young people	Victoria	www.eatingdisorders.org.au
Centre for Clinical Interventions	Introduction to Eating Disorders	Clinicians	Western Australia	www.cci.health.wa.gov.au
Eating Disorders Training and Evaluation Centre	A variety of general and specialist training courses covering introduction to eating disorders, therapies, supporting parents and carers, prevention and promotion	Clinicians	Western Australia	www.pmh.health.wa.gov.au/

Professional Associations: ANZAED

Professional associations build community capacity to address health issues by improving the skills and practices of health professionals.

The Australia and New Zealand Academy for Eating Disorders (ANZAED) is a peak, professional body for eating disorders in Australia and represents the interests of a variety of professional disciplines. It contributes to the eating disorders sector by providing advocacy, networking, public education and training and education for professionals working within the sector. ANZAED's management executive is multidisciplinary and includes professionals who work within the fields of psychiatry, clinical psychology, nursing, medicine, dietetics and social work across public and private treatment facilities within Australia.

Some States are also funding specialist teams with a focus on improving clinical resources and professional development in the sector: the Centre for Eating and Dieting Disorders in New South Wales; the Victorian Centre of Excellence in Eating Disorders; the Eating Disorders Outreach Service in Queensland and the Eating Disorders Training and Evaluation Centre (EDTEC) in Western Australia.

Eating Disorders Training and Evaluation Centre

EDTEC provides training workshops for the public, education professionals and health professionals throughout the year. The workshops cover foundation-level courses, such as early identification, assessment and management of eating disorders and advanced level workshops covering different psychological treatments, as well as dietetic and nutritional management and prevention courses. EDTEC also brings national and international speakers to Western Australia, sometimes in collaboration with others services. EDTEC also provides training on request to schools, community settings and hospitals. Supervision and consultation is available for practitioners working directly with eating disorders. Peer networks are operated through EDTEC and include videoconferencing for regional professionals.

CEDD Eating Disorders Online Learning

The CEDD, in partnership with NSW Health, has developed an online learning program in eating disorders for health professionals. The interactive online course provides comprehensive training in the medical, psychological and dietetic management of these mental illnesses. This online training program provides relevant professional development in the area of eating disorders suitable for medical practitioners, nurses, dietitians, psychologists and other allied health professionals. The course has been designed to meet the CPD requirements of the bodies governing these professional groups and is registered with a number of them. It offers a flexible and effective way to meet CPD requirements.

Learning occurs through five, self-paced modules. Each module equips participants with up-to-date knowledge, an understanding of the central issues in the field and the skills required in each step of the diagnosis, assessment and treatment of clients, for both children and adults, across all major eating disorder diagnoses.

A flexible learning format allows individuals to tailor their learning experience to a basic or more challenging level. Each module provides access to a range of learning formats, from interactive text, to lectures and role plays conducted by renowned Australian and international specialists in the field. Feedback from sufferers and their families is also included as part of the learning process.

Topics are varied and include:

- Background and diagnostic issues
- Medical, nutritional and mental health assessment and the considerations that are unique to the assessment process in eating disorders
- Planning and preparation for treatment
- The different techniques and treatments suitable for different eating disorders
- Key concepts in treating clients in different service settings

Course content ranges from the introductory, for those who are new to the field, to the advanced, for those wanting to consolidate and build on their existing abilities. Each module contains a Core curriculum (which is required to pass the assessment), an 'In Practice' section offering a more in-depth view of the topic and clinical tools and a Resources section with key readings and materials, which can be beneficial in the clinician's immediate practice, and which can also be kept by the participant as an ongoing reference resource.

The following draft competency statements for frontline and non-specialist treating clinicians has been reviewed by the NEDC and by ANZAED. Further work will be required to refine these statements before implementation.

Core Competencies for Frontline Health Professionals

Patients with eating disorders often present with complex psychological needs, risk of physical complications and elevated mortality rates. An extensive knowledge and skill base is required to manage and treat eating disorders, including those related to medical and nutritional issues, assessment of physical and psychiatric health and a need to be able to work in a multidisciplinary and often multi-agency team.

All health professionals who have a responsibility for assessment and diagnosis and who come into contact with high risk groups for eating disorders should be able to demonstrate knowledge and skill in the assessment, diagnosis and care of people with eating disorders.

Screen, Assess and Refer

1. Demonstrate knowledge of evidence relating to eating disorders

- Describe normal healthy eating, nutritional principles and healthy relationships with food
- Recognise the signs of disordered eating and describe the associated health risks
- Describe the risk factors that contribute to eating disorders
- Describe the eating disorders, their progression and impact on psychological health and quality of life
- Demonstrate awareness of the overlapping nature of eating disorders and the prevalence of atypical presentations
- Describe the range of physical issues related to eating disorders
- Demonstrate awareness of a variety of health conditions, which can co-exist with eating disorders
- Discuss the barriers to self-disclosure that a person with an eating disorder may experience and identify strategies to help a person disclose

2. Identify and screen people at risk

- Identify high risk groups
- Identify warning signs and typical presenting symptoms of eating disorders
- Initiate discussion about eating habits with a patient
- Use evidence-based screening questions for eating disorders
- Assess for risk of suicide and self-harm

3. Conduct assessment and document clinical history

- Take a clinical history for a person with a suspected eating disorder
- Discuss the importance of involving family members or supporters in assessmentDescribe the systematic assessment of children, adolescents and adults in relation to eating
- Use assessment tools and tests as appropriate for the person and the professional discipline e.g. Mental State Assessment, Physical assessments, Common medical investigations, Risk

assessment, Psychometric assessment, Dietary assessment

4. Refer patients appropriately

- Refer patients to relevant services to address their physical, psychological and nutritional needs
- Identify when a patient should be referred to a Hospital Emergency Department
- Identify when a patient should be referred to an eating disorders specialist service
- Explain the risks of rapid deterioration of health in people with eating disorders
- Explain the impact of very low BMI on cognition and discuss the role of mental health legislation and compulsory treatment for some patients

Contribute to Treatment and Management of Eating Disorders

In addition to demonstrating knowledge of screening, assessment and referral, all health professionals who contribute to treatment for people with eating disorders should be able to demonstrate the ability to:

5. Work collaboratively with patients and their families

- Discuss the importance of a family and person-centred approach to treatment
- Provide information and support to the patient
- Explain the role of families in assessment, engagement, treatment and recovery support
- Engage the patient, and where possible their family, in collaborative decision making
- Discuss strategies to enhance motivation for change
- Identify and respond to patient ambivalence about treatment and engagement difficulties
- Model an understanding and supportive attitude
- Demonstrate awareness of personal attitudes, values and beliefs (e.g. regarding body shape) to manage counter transference or collusion with client
- Explain the range of education and support needs a patient and their family may require and refer to appropriate support services

6. Develop and implement a treatment plan

- Work with a patient to identify their strengths and resources for goal setting
- Describe the standards for safe treatment (National Standards Schema)
- Describe the medical care that may be required to treat eating disorders
- Describe the role of intensive treatments, including hospital admission
- Describe the purpose of weight gain for patients with very low BMI
- Describe re-feeding syndrome and strategies to reduce the risk of re-feeding syndrome
- Apply Clinical Practice Guidelines
- Implement a management plan
- Demonstrate awareness of when and how to refer to other professions or services
- Monitor progress and measure outcomes (relevant to own professional discipline)
- Describe evidence-supported treatment modalities for eating disorders and their relevance to individual patient needs, including: CBT, Guided Self-Help CBT, FBT

7. Contribute to collaborative interdisciplinary treatment

- Describe the roles of key professions in the multidisciplinary team, including: GP, psychologist, psychiatrist, dietitian, dentist, mental health nurse
- Collaborate in implementing recommendations/treatment with professionals from other disciplines (e.g. nutritionists, physicians etc.)
- Describe collaborative strategies to reduce the risk of a patient “splitting” health care providers
- Discuss referral pathways and the planning required for transfer between services
- Support transfer between services and provide appropriate follow-up of patients

8. Support recovery

- Describe physical, psychological and personal understanding of recovery
- Discuss the risk of relapse and recurrence and the importance of recovery support
- Describe secondary prevention strategies
- Demonstrate awareness of community-based support services and resources
- Discuss issues in the care of adults with long term eating disorders

5.4 Recommendations for a Skilled Workforce

Workforce development is identified as a priority area for national action: implementation of core competencies and facilitated access to existing training for all professionals who work with very high risk groups.

The widespread delivery of training in eating disorder assessment and treatment is essential. Existing training resources (e.g. CEDD online training, EDOS training workshops, CEED training workshops) and training for other frontline professionals, such as teachers (e.g. EDOS, Children’s Hospital Sydney, the Butterfly Foundation) could be utilised to rapidly address the knowledge deficit in a cost-effective way.

Local health region coordination provides a platform for the identification of professionals in each health region with an interest in and a need for professional development in eating disorders.

In the longer term, a review of all current training programs and development of an accreditation process or standardised core content would contribute to a nationally consistent approach.

To ensure national consistency in the provision of training, nationally agreed core competencies will be required.

Based on the standards for best practice and building on promising approaches, the following table details key strategic opportunities for development to address the gaps identified in professional development.

Immediate Opportunities	Improve access to existing training resources (e.g. CEDD online training)
<i>Information and resources are</i>	Within local community health care regions, map existing workforce capacity and identify priority areas for delivery of training

<i>already available to support these actions</i>	Review and develop existing protocols and policies on eating disorder treatment to include reference to training requirements
<i>Medium Term Planning</i> <i>Further development of information and resources is required to support these actions</i>	<p>Further develop draft core competencies for implementation</p> <p>Resource existing eating disorder specialist services to include (or increase) outreach capabilities</p> <p>Develop online/videolink approaches to improve tertiary consultation access for rural and regional areas</p> <p>Develop an accreditation process for training and education course content in eating disorders to promote evidence-based knowledge and skill in the treatment of eating disorders</p> <p>Review existing information resources and decision tools for treating professions in consultation with the relevant professional bodies and develop or endorse resources for national dissemination</p> <p>In collaboration with providers of consumer, carer and family education, identify strategies to ensure access to consumer, carer and family education in all states and territories, including regional areas</p>
<i>Optimal Model</i>	<p>Access to tertiary support and supervision for all health professionals working in early intervention and treatment of eating disorders to enable accessible, community-based service delivery</p> <p>Every primary care clinician who works with high risk groups is trained within the scope of their professional discipline to identify, diagnose, assess, refer and manage patients with eating disorders</p> <p>Every hospital-based mental health service has staff trained to provide treatment</p> <p>Every medical hospital has at least one nominated role with responsibility for ensuring that patients with eating disorders access appropriately skilled professionals and evidence-based treatment</p>

6. Prevention and Early Intervention

6.1 Standards in Prevention and Early Intervention

Prevention and early intervention are critical components of a continuum of health care. The purpose of prevention and early intervention is to reduce the incidence of illness and the impact of illness on individuals, families, communities and health care systems.

Prevention focuses on the modifiable risk factors that precede the development of illness. Reducing causal risk factors for an illness is expected to break the developmental sequence leading to a reduction in the frequency and intensity of the illness (Jacobi, Hayward et al., 2004). Independent, meta-analysis studies have found prevention initiatives to be effective in influencing eating disorder related knowledge, attitudes and behaviours (Fingeret et al., 2006).

Individuals who are identified and treated early in the course of an eating disorder have a better chance of recovery compared to those with a longer history of illness (Berkman, Lohr, & Bulik, 2007; Steinhausen, 2009). Early intervention provides interventions that are appropriate for and specifically target people displaying the early signs and symptoms of eating disorders.

Prevention, early identification and prompt intervention are necessary to reduce the severity, duration and impact of the illness. Early intervention for eating disorders includes strategies that enable people to access services as soon as they are needed: early in the development of the illness, early in help seeking and early in recurrent episodes of illness, with immediate access to treatment and support. Early intervention critically depends on early detection of risks and symptoms (McGorry & Yung, 2003; Marshall & Lockwood, 2004).

The National Mental Health Policy (2.2-2.4, 2008) identifies the following in relation to prevention and early intervention:

- Mental health promotion activities will support de-stigmatisation and assist Australians to become emotionally resilient, cope with negative experiences and participate in their communities
- The proportion of Australians with mental health problems and mental illness and who are at risk of suicide will be reduced
- People with an emerging mental health problem or mental illness will be identified and treated as early as possible in the initial phase and any subsequent episode to minimise the severity and duration of the condition and to reduce its broader impacts

To achieve good practice, prevention and early intervention activities should ensure:

- Consistent and appropriate messages are provided to make sure that the community is aware of eating disorders as serious mental and physical illnesses

- Frontline professionals and adults with a duty of care and who influence young people (e.g. parents, school counsellors, teachers and youth workers) are trained to recognise and respond appropriately to eating disorders
- Eating disorders are consistently represented in media and health promotion campaigns as serious, complex illnesses that can be treated
- Criteria for safe health promotion messages for eating disorders inform all universal health communications and promote safe and consistent community messages
- Accurate information on the risks of dieting is consistently represented in media and health promotion campaigns
- Families are actively encouraged to develop mental health literacy and other strategies to support resilience in children and young people
- Communication actively encourages clinicians and professionals who intersect with people at high risk of eating disorders to access appropriate training
- Evidence-based prevention programs are delivered on a consistent basis over time, as part of a long term coordinated approach to prevention
- Prevention and early intervention programs are delivered by appropriately trained facilitators
- The content of prevention and early intervention programs is developmentally appropriate for the target audience
- Prevention and early intervention programs are delivered in the context of a supportive environment (e.g. a 'whole of school' approach)
- People in very high risk groups and those with early symptoms have access to early intervention programs (e.g. guided self-help, online programs)
- Prevention and early intervention initiatives include monitoring of implementation fidelity and evaluation
- All parents and professionals who intersect with high risk groups have access to training in Mental Health First Aid or an equivalent
- People in high risk groups are screened as part of general primary care
- Frontline clinicians are trained and skilled to screen, assess, diagnose and refer people with eating disorders
- Entry criteria for access to services enable early intervention
- Prevention and early intervention for eating disorders is integrated with other health promotion and prevention initiatives whenever possible

- All mental health and obesity prevention initiatives that target high risk groups are evaluated for their impact on body dissatisfaction and disordered eating
- Content focuses on the key risk factors that precede the development of an eating disorder: body dissatisfaction, dieting, thin ideal internalisation, negative effect, pressure to be thin and perfectionism
- Content builds healthy body satisfaction, media literacy (critical thinking and problem solving) and a healthy relationship with food

6.1.1 Target High Risk Groups

The two groups at highest risk of developing an eating disorder are children and young people, and females of all ages. However, more specific target groups can be defined with particular vulnerabilities and intervention needs and these must be taken into consideration in developing prevention approaches. Eating disorder prevention and early intervention initiatives target:

- Adolescents and young adults (ages 12-25)
- Females
- Athletes engaging in competitive sport, fitness or dance
- People seeking weight loss treatment
- People with a personal or family history of eating disorders
- People with additional health risks or vulnerabilities:
 - Younger children
 - Pregnant women
 - People with specific health conditions – diabetes, PCOS, infertility
 - Males
 - Indigenous communities

6.1.2 Interactive and Socially Developmental Approaches

Effective prevention programs are timed appropriately, are socio-culturally relevant to their target populations, have well-trained staff and include outcome evaluation (Nation, Crusto et al., 2003).

Specifically, successful approaches are:

- Interactive, promoting experiential learning and social development
- Promotional of critical thinking and problem solving (e.g. media literacy)
- Dissonance-based, motivating change to attitudes and behaviours
- Multi-sessional, providing opportunities to practice and build on knowledge over time

6.1.3 Developmentally Appropriate Approaches

Preventive initiatives for children and young people should address the developmental stage, with each component of prevention building on the foundation of earlier stages in development.

Children under the age of 15 do not need information about eating disorders in order to benefit from prevention initiatives.

In general, children under the age of 12 years do not need information about eating disorders. Communication should focus on positive behaviours for good health, healthy relationships with food, positive body images and general mental health literacy.

Young people aged 10-14 years are in the critical transitional years of puberty. Communication should focus on media literacy, healthy eating, risks of dieting, natural changes and variations in body shape, peer pressure and building a supportive peer environment.

Young people aged 15-25 years may be at higher risk of developing an eating disorder, having already engaged in dieting and disordered eating. Communication should be tailored to meet the needs of high risk audiences and should include ways to challenge internalisation of the thin ideal. Universal awareness of eating disorders (literacy) is required to enable peer and partner support. Messages may target specific occupations and interests, such as sport, dance, modelling and the entertainment industry.

6.1.4 Program Delivery

Research findings support the importance of training and supporting teachers and other professionals who are expected to deliver prevention programs or source external presenters with expertise in the prevention of eating disorders. Providing professional development for teachers that is directly linked to programs and resources will increase the likelihood that programs will be implemented in schools in a 'whole of school' approach.

The long term impact of prevention messages may be strongly influenced by the social environment; therefore, to be effective, prevention programs should be delivered within a broader context of cultural change. Cultural change requires consistent responses across a wide range of communication channels.

The school setting has the potential to provide an environment that fosters resilience and a coordinated, whole of school approach is frequently identified as an effective means of addressing multiple risk factors for adolescent health concurrently (CEED & EDV, 2004). The proposed National Strategy on Body Image (Commonwealth of Australia, 2009) provides a checklist on whole of school approaches to promote positive body image and the checklist includes many recommendations appropriate to eating disorder prevention and early intervention.

A whole of school approach will ensure:

- A policy and environment that promotes resilience and complements eating disorder prevention programs
- Teachers and school staff are skilled to contribute to eating disorder prevention
- School curricula that appropriately teaches students about body image issues, healthy relationship with food and media literacy
- Communication of eating disorder prevention messages to parents

To be most effective, prevention initiatives must be delivered consistently over time, as part of a long term and coordinated approach to prevention and early intervention for eating disorders.

6.1.5 Coordinated & Consistent Messages

Coordinated strategies to prevent, identify and intervene early in the course of eating disorders are required and must work together with broader interventions that target the socio-cultural environment.

Addressing the complex socio-environmental risk factors for eating disorders will require a shared and consistent approach between obesity prevention, body dissatisfaction (body image) prevention, eating disorder prevention and general mental and physical health promotion. An integrated approach to prevention based on the shared risk factors for obesity, body dissatisfaction and disordered eating may provide the best opportunity to reduce the impact of all of these conditions on the health of Australians.

Collaboration is required across these sectors to ensure consistency of messaging. Evaluation of all mental health and obesity prevention initiatives in regards to their impact on disordered eating is essential to open up opportunities for shared approaches to prevention and health promotion. Implementation and evaluation of prevention and early intervention initiatives should monitor and ensure implementation fidelity.

Universal prevention initiatives, delivered as part of such an integrated approach, should include:

- A focus on a developing healthy lifestyles and a healthy relationship with food
- Promotion of modest, achievable health and weight goals
- Clear messages about the risks of restrictive and extreme dieting
- Development of media literacy and critical thinking
- Healthy body satisfaction and respect for body diversity

Initiatives should avoid the use of negative motivators such as comparison, fear, stigmatisation or social exclusion.

6.2 Gaps in Current Practice in Prevention and Early Intervention

There are evidence-based prevention and early intervention programs suitable for use in schools and other settings with children, adolescents and young adults. At present, these are implemented on an ad-hoc basis at the request of individual schools or local communities.

There are also evidence-based training programs available that are suitable for parents, young people and frontline professionals, such as teachers and primary care health professionals. These prevention programs are delivered on request and there is no consistent implementation schedule.

A lack of consistent implementation of prevention and early intervention programs and Mental Health First Aid training contributes to long delays in seeking treatment, as well as the duration and complexity of illness.

There are general mental and physical health initiatives targeting high risk groups for eating disorders. At this stage, with the exception of body image and media literacy initiatives, none of

these specifically address risk factors for eating disorders and none have been evaluated regarding their impact on disordered eating.

The primary gap in prevention and early intervention is consistent and coordinated health messages. There is an urgent need to develop integrated prevention initiatives that encourage body esteem, healthy eating and lifestyle behaviours, without prompting engagement in fad diets, weight loss attempts and the diet-binge cycle.

Prevention is a priority of the Fourth National Mental Health Plan (Priority Area 2: 2009). Eating disorders should be specifically referenced in action plans to address improvement of community understanding, delivery of programs in schools, implementation of targeted prevention and early intervention programs and the expansion of community-based youth mental health services. Action plans should:

- Improve community and service understanding and attitudes through a sustained and comprehensive national stigma reduction strategy
- Work with schools, workplaces and communities to deliver programs to improve mental health literacy and enhance resilience
- Implement targeted prevention and early intervention programs for children and their families through partnerships between mental health, maternal and child health services, schools and other related organisations.
- Expand community-based youth mental health services that are accessible and combine primary health care, mental health and alcohol and other drug services
- Provide education about mental health and suicide prevention to frontline workers in emergency, welfare and associated sectors (Fourth National Mental Health Plan, 2009)

There are continuing risks associated with the popular media interpretation of obesity prevention messages. Fears about weight gain develop within a cultural context that promotes the pursuit of thinness and engagement in dieting behaviours, both of which contribute to body dissatisfaction (Neugebauer, Mack, Roubin, Curiel, 2011). Wherever people look in the media, appearance criticism and dieting are popular topics. Regardless of the intention of health promotion messages that encourage weight loss, it is in the context of popular media that these messages are interpreted and internalised.

There are population groups for which no reliable evidence is available to guide prevention and early intervention. The indicators of risk suggest that Indigenous people are at high risk of eating disorders, but there is no evidence as yet on the most appropriate way to assist Indigenous communities to address these issues. This is a priority for further investigation.

6.2.2 Targeting Key Groups

People Seeking Help for Weight Loss

Weight issues and obesity are serious and common outcomes for people with bulimia nervosa and binge eating disorder (Fairburn, Cooper, Doll, Norman, & O'Connor, 2000). People with these disorders are more likely to seek help for weight loss than for psychological distress (Mond, Myers,

Crosby, Hay & Mitchell, 2010). However, people of healthy or low weight also seek assistance for weight loss and this can be an indication that the person is at risk of or has an eating disorder. Of particular concern is the impact of non-medically supervised weight loss programs on children and young people, whether it is the child who engages in the diet or the parent who role models the dieting behaviour.

There is evidence that professionally designed and administered weight management programs for children and adolescents have the potential to reduce both weight and eating pathologies (Hill, 2007). However, without an appropriate level of expert involvement from both physical and mental health sectors, dieting represents a risk for young people.

Two key issues are identified for the promotion of prevention and early intervention for eating disorders for people seeking help with weight loss:

- The lack of training and ability to use evidence-based screening tools, particularly for weight loss consultants who are not health professionals. This has an immediate impact on early identification and longer term implications for those vulnerable to eating disorders who engage unsuccessfully in weight loss programs. While no specific training has been identified for these professionals, mental health first aid training for eating disorders and introductory professional training in eating disorders (e.g. CEED online training) may provide an initial basis for improving workforce capacity in this sector. Training for staff would need to be supported by policies and procedures within each organisation or centre that aligned with the principles of eating disorder prevention.
- The lack of regulation of the weight loss industry, particularly in regard to the promotion of 'quick fix' diet products and diet plans, raises considerable concern. Unlike pharmaceuticals, diet products do not have to prove their effectiveness. Failure to lose weight leads product users to blame themselves, rather than the product, which leads to low self-esteem and the potential for increased health risks (Hill, 2007). There is scope for regulation regarding the way in which diets and diet products are promoted.

Resources are available to guide the development of safe health messages (e.g. the Academy for Eating Disorders' guidelines for the prevention of obesity in children, 2010; the NEDC Clarity in Complexity: Communication Strategy for Eating Disorders and the appendix, Healthy Weight Related Messages, 2012).

Screening people seeking weight loss treatment within the context of a more regulated weight loss industry would also contribute to early identification and early intervention for people with eating disorders, with no discernible negative consequences for the reduction of obesity.

Athletes

There is a priority need for resources and programs to target the specific needs of different codes of sport, fitness and dance. Each of these interest sectors has implemented initiatives to either prevent the development of eating disorders or to support identification of people with early symptoms.

These initiatives have developed in isolation from each other and hence have come to fruition without the opportunity to learn from and replicate effective approaches.

Coordination and evaluation of initiatives to prevent eating disorders is required to enable sectors to replicate successful tools and approaches in settings other than schools.

Mental Health First Aid training could be appropriate for coaches, teachers, fitness instructors, parents and young adult athletes, providing immediate access to an evidence-based training program.

There are also a number of evidence-informed resources available which could be utilised as the basis of prevention interventions in physical activity, such as Fitness First Australia's "Fitness Australia Guidelines" (Marks & Harding, 2004).

However, NEDC investigation has demonstrated that generic resources are not being extensively integrated into practice and resources developed for other sectors are not being transferred and adapted.

Information on eating disorders and prevention must be interpreted in ways that can integrate with the existing practices of a sector or code of sport. The degree of difference is not simply between sectors such as sport and education. The language and expectations of each sporting code and each type of dance are different. These differences must be reflected in the way that eating disorders are communicated and this can only be achieved through a partnership approach between eating disorder expertise and each sector to develop the resources that they need.

Adult Early Interventions

There is an increasing identification of eating disorders in older adults. Early intervention for adults – early in the development of illness or early in the current episode of illness – is a vital prevention strategy, both for the individual adults concerned and for the other people they may influence, such as children and grandchildren. This strategy can reduce the impact and duration of illness in these adults.

Few prevention interventions have been directed towards alleviating body image or disordered eating issues in the adult community. However, innovative approaches have been successfully trialled in the fitness sector (e.g. Lousie Wigg and Body Image and Health Inc approaches to changing the culture in gyms: Wigg, 2001) and amongst chronic dieters (Paxton, 2002).

Some interventions designed for children and adolescents have been shown to have positive effects on adults as well. For example, the program Student Bodies (discussed in Chapter 3 of this report) has been shown to be effective in improving knowledge for teachers and this may include improving the participant's own weight and dieting issues. As an online intervention, this approach could have broad appeal and accessibility for adults if appropriately promoted.

While successful, these approaches have not been widely adopted. Broader implementation of targeted interventions for adults is likely to be very valuable (Paxton, 2002).

Engaging Parents

While not a high risk group themselves, parents are consistently identified as the most influential group for children and young people and are, therefore, a primary target audience for prevention and early identification messages. It is essential that parents gain an understanding of eating disorders and how family activity can positively (or negatively) influence mental health. Mental Health First Aid training provides one evidence-based option for parents.

Specific training programs have been developed for parents, particularly in the area of body image, either as integral parts of prevention initiatives involving both children and parents (e.g. Neugebauer, Mack, Roubin, Curiel, 2011) or as standalone information sessions.

While resources exist, rates of engagement of parents remain very low. The adults in a young person's life reflect the broad values of their culture. While communication may be usefully targeted at specific groups, such as teachers, sports coaches or parents, it must also be supported by broader community awareness in order to be effective. Strategies that target limited groups of adults are unlikely to have necessary impact on their own.

Communication needs to focus on disordered eating, rather than the diagnosis of an eating disorder in order, to gain general public attention. This approach will help people to connect eating disorder issues with their own experience.

Making information readily available is important. Directly targeting parents and frontline professionals with evidence-based information may provide an immediate opportunity to raise awareness to the necessary levels in order to support prevention and early intervention.

6.2.3 Complementary Initiatives

There are a number of mental and physical health initiatives targeting children, young people and their parents that could provide useful platforms for the dissemination of evidence-based eating disorder prevention programs.

There is no evidence at this stage to suggest that these programs currently have the capacity to prevent eating disorders or contribute to early identification or early intervention for eating disorders. There is a need to add eating disorder expertise and evidence-based resources to existing programs to ensure effective prevention of eating disorders. Key areas for the addition of eating disorder-specific knowledge include:

- Professional development for teachers and others presenting body image, media literacy and eating disorder prevention programs

- Professional development for frontline clinicians, including psychologists and nurses working in schools and clinicians in youth health centres, to ensure that young people have access to knowledgeable clinicians able to identify, assess and refer people with eating disorders
- Programs and resources, ensuring that eating disorders and body image programs (that have been evaluated as successful) are available to all young people
- Design and evaluation of general mental health and nutritional health initiatives to ensure that these reduce the risk of harm and that they are evaluated in relation to their impact on disordered eating

Schools are making a commitment to health and wellbeing and implementing a variety of strategies to promote mental health and positive body image, including state and federal policy initiatives and locally derived strategies. However, schools experience significant barriers in supporting mental health, including time constraints, potential conflict between the instructional and social development roles expected of teachers and limited access to health services for referral of students.

While schools provide a convenient place for connection with children, young people and parents, they are not always best placed to influence the thinking and behaviours that may contribute to eating disorders. Instead, parent attitudes may be the most important influence. Parent attitudes can be affected by the perceived expertise of other professionals working with their children or directly with adults interacting with the family, including sports coaches, dance teachers and weight loss consultants. Prevention approaches should consider the full spectrum of opportunities to influence adult attitudes and behaviours, as well as connect with young people. There are many initiatives at a local level developed and disseminated by youth and family services and eating disorder support services that provide a platform for further development. These initiatives are largely unevaluated and have developed separately from each other. Creating links between these services, and with researchers, to improve sharing of resources and information, and implementation of evaluation, will enhance outcomes.

6.2.4 Consistent Implementation

To be effective, it is important that the evidence-based programs and resources currently available for prevention and early intervention are made accessible on a consistent basis to high risk groups. Existing complementary mental and physical health initiatives that target the same high risk groups should be utilised as platforms to ensure dissemination of resources.

While the range of evidence-based prevention initiatives available in Australia is small, there are programs and resources available, including some specifically developed for the local context. Consistent implementation of these resources to target high risk groups, together with collaboration between the body image, obesity and eating disorders sector for health promotion, provide immediate opportunities for strategic intervention to stop the spiralling costs of eating disorder management.

There are a small number of evidence-based prevention and early intervention programs predominantly developed for delivery in schools and universities. Additional prevention approaches are required to meet the needs of all high risk groups, particularly men, athletes, older women, people seeking weight loss help and vulnerable communities.

While there are identifiable gaps in prevention and prevention support services, the gaps in linkages between these existing resources is equally important. Positive actions are being carried out in every state and in both private and public health and education, but there are few links between these initiatives. Resources are used to 'reinvent the wheel' with each new initiative, rather than capitalising on what has already been achieved.

Sharing of information, replication and upscaling of current initiatives and coordination between initiatives will be an important part of any future approach to preventing eating disorders. A common and coordinated approach to evaluating effectiveness could significantly enhance the development of a uniquely Australian approach.

Most prevention initiatives provide a short term program delivered once in a child or adolescent's school life or on a more targeted basis, delivered once to young adults with very high risk. The information, beliefs and behaviours developed during these short term interventions must compete with a barrage of other messages received through the media, the school or work environment, as well as through family and peer relationships.

To be most effective, prevention initiatives must be delivered consistently over time as part of a long term and coordinated approach to prevention and early intervention for eating disorders. Organisations and initiatives providing online information about eating disorders must continuously review and develop their resources in order to maintain their currency and quality.

Opportunities to improve the dissemination of information about eating disorders to support prevention, early identification and access to early intervention include:

- Coordination of quality websites to link to each other
- Coordination of the development of resources to ensure that initiatives act synergistically and the development of clear links between credible sites may enhance access to reliable information
- Provision of opportunities for personal contact

6.2.5 Innovative and Flexible Approaches

There is an urgent need to replicate some of the innovative approaches to prevention and treatment that have been developed to meet local, regional and specific sector needs in Australia. These innovative approaches are evidence-based, but have not yet generated evidence of their own effectiveness.

Approaches to prevention must include evaluation strategies. This applies to the implementation of eating disorder prevention programs, the adaptation of these programs to new contexts, to general

health initiatives that are intended to build resilience and to early access initiatives intended to assist people to seek help early in illness.

Prevention approaches must be flexible and adaptable to the context in which they will be delivered. No two schools or sports, and no two adult work or recreation contexts, should be expected to have the same needs or have the ability to utilise exactly the same thing. There is a need to work with each specific sector to develop their approaches, rather than simply providing them with guidelines that have already been determined. Prevention initiatives should be developed in close consultation with each target audience and sector.

6.2.6 Knowledge of Frontline Workforce

Early intervention is dependent on the capacity of community members – including professionals, laypeople, people with symptoms of eating disorders and their supporters – to recognise and act on the health problem. A trained and resourced professional workforce, which includes health professionals and professionals in gatekeeper roles (e.g. teachers, school counsellors and physical activity instructors), that is able to identify and respond to people at risk is essential, as is extensive community education to develop mental health literacy about eating disorders.

The process of identification by health professionals is a key problem for eating disorders. International and Australian studies have found very low rates of identification of people with eating disorders in health care settings (Hay et al., 1998, Mond et al., in press) and delayed presentation of the seriously ill to specialist services (Madden, Morris, Zurynski, Kohn, & Elliot, 2009).

The majority of people with eating disorders have contact with health professionals, but do not specifically talk about their eating problems. The majority of adolescents with eating disorders (72.6% to 88.2%) have contacted services for emotional problems (Swanson et al., 2011). A variable but significant proportion of people with eating disorders (30% to 73%) contact health professionals for help with their weight (Hay et al., 2011).

For many people with eating disorders, their first attempt at seeking treatment is a test of attitudes and responses. If the first help seeking experience is positive, the person is more likely to engage successfully with future treatment. The knowledge of the clinician is critical to this engagement process. People who have a positive first encounter with health professionals note the benefits of having a knowledgeable and non-judgemental therapist (Schoen, Lee et al., 2012).

Recognition requires knowledge of the illness and various warning signs, as well as knowledge of pathways, to access appropriate professional intervention, positive attitudes towards people with eating disorders and a belief that acting on this knowledge will have a positive outcome (Jorm, Korten et al., 1997).

Both prevention and early intervention require a skilled frontline workforce with knowledge of eating disorders and skill to recognise warning signs, screen those presenting with problems and assess for risk and implement appropriate evidence-based prevention programs. The frontline workforce includes professionals from health and other sectors, including general practitioners,

nurse practitioners, school counsellors, teachers, youth workers, social workers and people engaged in physical activity instruction.

The frontline workforce reflects the attitudes and beliefs of the wider community. A greater level of community education is required to raise the level and accuracy of knowledge and beliefs about eating disorders in order to support prevention, early identification and help seeking (Hart et al., 2009).

Mental Health Literacy

Members of the community are generally able to recognise the behavioural characteristics of anorexia nervosa, however there appear to be misconceptions about the nature of the illness, with some people regarding it as a manifestation of low self-esteem, rather than a serious mental illness (Darby, Hay, Mond & Quirk, 2010).

In a survey conducted by the NEDC, clinicians indicated that they were able to identify the behaviours of anorexia nervosa and bulimia nervosa and, to a lesser extent, behaviours related to binge eating disorder and other eating disorders not otherwise defined. However, few were able to identify factors that would put their clients at risk of an eating disorder.

Training in Mental Health First Aid has been shown to be effective in increasing mental health literacy and supportive behaviours in the social networks of individuals with mental health problems.

Training in Mental Health First Aid is identified as a suitable intervention for increasing community knowledge and support for people with eating disorders to seek appropriate help (Hart, Jorm & Paxton, 2012).

Mental Health First Aid training has been successfully adapted for high school teachers, demonstrating positive effects on teachers' mental health knowledge, attitudes and confidence (Jorm, Kitchener et al., 2010).

Providing access to training is only the first step in ensuring that people are equipped to recognise and respond to eating disorders. It is also essential that primary health care providers are trained and resourced to screen, diagnose, refer and support people with eating disorders.

Training and Professional Development

Ensuring that all adults who intersect with high risk groups have access to training at an appropriate level for their role is crucial. For parents, teachers, youth workers and others who influence young people, this would include access to Mental Health First Aid training. For health professionals with responsibility for the diagnosis and referral of people with early symptoms of eating disorders, this would include access to training that achieves the core competencies for eating disorder treatment as outlined in the NEDC report: A Nationally Consistent Approach to Eating Disorders.

The Role of General Practitioners

The role of GPs in prevention has been recognised by the Council of Australian Governments (COAG, 2007). GPs are consistently identified in eating disorder research as the primary source of initial diagnosis and assistance.

Research suggests that the most common first point of professional contact is GPs (Sim et al., 2010). GPs themselves also acknowledge that they have an important role in the detection and management of mental illness (RACGP, 2012).

The general community identifies GPs as the most appropriate first point of contact for treatment of eating disorders. Most people who receive treatment for an eating disorder have been identified by their GP (Darby, Hay, Mond & Quirk, 2010). However, recognition and confidence among GPs in the treatment of eating disorders is often poor (Hay, De Angelis, Millar & Mond, 2006).

Improving eating disorder mental health literacy and eating disorder screening and assessment skills in GPs is vital to support early intervention. Improving eating disorders mental health literacy is equally important for paediatricians (Rosen, 2010), dietitians and counsellors. While the general community recognises the potential roles of dietitians and counsellors in the treatment of eating disorders, evidence suggests that eating disorder literacy among these groups and their confidence to treat is limited (Hay, Darby & Mond, 2007).

Although people with eating disorders may not volunteer information about specific eating problems in health care appointments many would welcome questions from health care providers about eating behaviours (Gilbert, Arcelus et al., 2012).

Screening for eating disorders involves asking individuals a small number of evidence-based screening questions on an opportunistic basis when the patient presents for other reasons. This would include patients who:

- Are identified as having a high risk of eating disorders or for whom an eating disorder would potentially exacerbate risks associated with other health conditions; e.g. adolescents, young adults, women, people with a personal or family history of eating disorders
- Present for the treatment of potential symptoms of eating disorder including weight related concerns, depression or anxiety
- Present for prevention advice on youth mental health, nutrition or exercise

While the screening questions for eating disorders have been developed and tested in the specific context of this group of illnesses, they are equally appropriate for people with other health conditions that involve investigation of the patient's nutritional, exercise or mental health status. Asking about eating habits and a person's relationship with food and exercise fits well with the current recommendations to GPs for general preventive screening (RACGP, 2012):

- *Preventive activities in children and young people*
Guidelines recommend the use of frequent contact with the GP during childhood to screen for a range of health conditions and promote health e.g.
 - All age groups to be screened for nutrition and physical activity

- Patients aged 6-19 years to be screened for healthy family functioning, social and emotional wellbeing and standard weight and height compliance
- Patients aged 14-19 years to be screened for major depressive disorder
- *Prevention of chronic disease*
SNAP risk factors include physical activity and dietary change. As a first step, GP screening processes include asking the patient in a systematic way about their nutrition, alcohol consumption and physical activity. Preventive screening for risk factors for chronic disease include:
 - BMI and waist circumference
 - Asking about fruit and vegetable consumption
 - Asking about alcohol and other substance consumption
- *Advice for women preconception*
Preventive practice with women preconception includes discussion of weight management, nutrition (including assessment of nutritional deficiencies and dietary practices) and periodontal disease. All of these assessments are compatible with screening for eating disorders.
- *Psychosocial*
Guidelines identify that GPs have an important role in the detection and management of mental illness. Screening focuses on depression and anxiety, both of which co-occur in people with eating disorders. At this stage, the guidelines do not mention eating disorders.

Opportunistic screening for eating disorders is a simple, safe and inexpensive approach that has the potential to enhance general health in patients who are screened, as well as identify people who have or are at high risk of developing an eating disorder.

Evidence-based resources exist to support screening including the simple five question SCOFF and in Eating Disorders Screen for Primary Care (ESP) tools. The questionnaires do not diagnose eating disorders but identify the possible presence of an eating disorder and prompt a more detailed assessment. Routine screening of adolescents is recommended as part of regular health examinations. An investigation of the use of SCOFF screening questions with adolescent school students found that 81% of the students who self-reported eating disorder symptoms in response to the SCOFF questions would have remained undetected if the questions had not been used (Hautala, Junnila et al., 2009).

6.3 Examples of Current Resources for Prevention and Early Identification

Early Identification

Evidence-Based Interventions for School Aged Children and Young People

The following list highlights a selection of programs that are supported by research evidence:

- **Media Smart**

A universal program for girls and boys in early high school (grades 7 and 8), Media Smart is an 8 session program and addresses media and peer issues in interactive classroom activities.

- **Happy Being Me**

Happy Being Me is an interactive school-based program specifically for grade 7 girls unselected for risk factors. This 3 session program addresses both media and peer issues.

- **The Body Project**

The Body Project is a two-part group intervention program for adolescent girls and young women at risk of developing eating disorders and which uses a cognitive dissonance approach. For older female students in upper high school and tertiary education, Student Bodies can be provided as an online psycho-educational intervention program. Delivered as a web based program, this has also been identified as a successful approach for the education of primary school teachers.

Promising programs that have an impact on body dissatisfaction include:

- **Free to BE** – A resource for students in grades 3 to 12 that aims to address the various factors that influence body image. This resource was developed by the Butterfly Foundation as a part of the Australian Government’s National Body Image Strategy.
- **Y’s Girl** – An affordable curriculum resource for girls in primary school, designed to be delivered by teachers. This program has demonstrated promising results in improving body dissatisfaction, thin ideal internalisation, self-esteem and disordered eating (Ross, Rodgers & Paxton).

6.4 Recommendations for Prevention and Early Intervention Initiatives

Integrated approaches to prevention are identified as a priority area for national action: we need to take an integrated, cross-sector approach to address the complex and interrelated problems of eating disorders, body dissatisfaction and obesity.

Changing risk behaviours and patterns of help seeking will require:

- A trained and resourced professional workforce, including health professionals and professionals in gatekeeper roles, such as teachers, school counsellors and physical activity instructors, who will be able to identify and respond to people at risk
- Consistent and widespread implementation of evidence-based prevention programs
- Extensive community education to develop mental health literacy about eating disorders
- Preventative screening in primary care for people in high risk groups:
 - Adolescents and young adults (ages 12-25)
 - Females
 - Athletes engaging in competitive sport, fitness or dance
 - People seeking weight loss treatment
 - People with a personal or family history of eating disorders
 - People with additional health risks, e.g. pregnant women, people with diabetes, Indigenous communities
- Facilitated access to early intervention or treatment for people who are identified as being at very high risk

Based on the standards for evidence-based practice and building on the promising approaches identified above, the following table details key strategic opportunities for addressing the gaps identified in current prevention and early intervention practice.

Immediate Opportunities	Integrate body image prevention with eating disorder prevention at a policy level
<i>Information and resources are already available to support these actions</i>	Implement the NEDC guidelines on safe, weight related messages as an interim strategy, while more detailed Australian guidelines are developed
	Implement existing evidence-based prevention and early intervention programs on a consistent basis, using existing mental health promotion initiatives as a platform for dissemination
	Provide training in the delivery of evidence-based prevention programs for teachers, sports coaches and other professionals working with young people
	Integrate eating disorder prevention resources with existing general mental and nutritional health strategies (e.g. add resources to MindMatters, Mindframe, KidsMatter)
Medium Term	Provide online access to professionally facilitated, self-guided early intervention

Planning

programs under the auspice of one or more existing eating disorder service providers

Further development of information and resources is required to support these actions

Cross-sector research and evaluation, including the development of an independent task force representing expertise in obesity, eating disorders and body image to investigate and report on the evidence-based health benefits and risks of dieting and the impact of popular interpretations of dieting (including an assessment of weight loss industry practices) on the current health status of Australians

Develop information packs for parents and schools that integrate information and advice for mental health, physical health (obesity prevention) and eating disorder prevention

Develop and assertively promote information packs on eating disorder screening, assessment and referral to health professionals who intersect with people at high risk, including GPs, paediatricians, obstetricians, diabetes educators, dietitians, physiotherapists, dentists, and emergency department personnel

Develop regulations and support systems for the commercial weight loss sector to ensure that: (a) eating advice and service conform to safe standards and (b) that people are medically screened for risk of eating disorders

Collaborate with sport, fitness and dance sectors to review, update and assertively promote information on eating disorder prevention and early identification that is relevant to the specific physical and nutritional requirements for each sector

Collaborate with health promotion campaigns to develop safe and effective approaches to weight management, with an emphasis on weight management strategies for children and young people and developing community awareness of the dangers of dieting

Collaborate with the media to develop guidelines on reporting on weight, body image and eating disorders

Investigate the information, prevention and early intervention needs of specific, vulnerable communities, including Indigenous communities

Optimal Model

All school children and young people have consistent access to evidence-based eating disorder prevention programs aimed appropriately at their developmental stage

All parents and professionals who intersect with high risk groups are trained in Mental Health First Aid or an equivalent

Individuals and families have access to information and resources, including self-help early intervention resources.

7. Evidence-Informed National Standards

7.1 Standards For a Nationally Coordinated Response to Eating Disorders

The goal of the NEDC is to develop a nationally consistent approach to the prevention and management of eating disorders in Australia. Achieving a nationally consistent approach across different state and territory health systems will require the implementation of agreed national standards and practice guidelines supported at a national level.

Implementation of consistent, evidence-based standards will support confidence to treat and improve access to evidence-based eating disorder treatments and reduce unwanted variation in treatment standards.

It is imperative that any standards that are adopted are informed by evidence. This will require an ongoing process of review of emerging evidence and translation of evidence into practice and capacity in order to commission data collection and research that will address significant gaps in the current knowledge base.

Two principles in the National Standards Schema specifically apply to the issue of evidence-based national standards:

- **Systems support integration, collaboration and ongoing development**
Policy and systems support collaboration between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and community services and between professional disciplines. Ongoing processes of review and shared learning support the consistent implementation of evidence-based approaches. People with personal experience of eating disorders are involved at all levels of policy development, planning, and systems development.
- **Evidence-informed and evidence-generating approaches**
Research and evaluation are integral to the design and delivery of health promotion, prevention, early intervention and treatment approaches. Basing approaches on evidence ensures that people have access to the most effective approaches, all approaches develop in response to emerging evidence and new approaches that contribute to emerging, practice-informed evidence are encouraged. People with personal experience of eating disorders are involved at all levels of service development and evaluation.

To achieve a nationally consistent, best-practice approach to eating disorder treatment in Australia, national coordination will be required to ensure:

- Policy and systems support collaboration between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and

community services and between professional disciplines

- Ongoing processes of review and shared learning support the consistent implementation of evidence-based approaches
- People with personal experience of eating disorders are involved at all levels of policy development, planning, and systems development
- Eating disorders are recognised in health policy and practice as a separate group of serious and complex psychiatric disorders requiring evidence-based prevention, treatment and support
- Persistent and enduring eating disorders have the status of a chronic disease
- Health services and health fund policies specify long term treatment for eating disorders at a sufficient evidence-based dosage
- Health services and health fund policies cover all aspects of treatment and support including:
 - Early intervention and timely access to services
 - Multidisciplinary treatment
 - Family support and education
 - Long term access to recovery support
 - Case coordination
 - Long term medical monitoring
- Data is collected nationally on the prevalence of eating disorders, access to prevention, treatment interventions and outcomes of intervention
- The ongoing development and evaluation of eating disorder initiatives is guided by expertise in eating disorders, representing research, clinical experience and lived experience
- National standards and evidence-informed protocols are disseminated to support a nationally consistent approach
- Research and evaluation are integral to the design and delivery of health promotion, prevention, early intervention and treatment approaches

7.1.1 National Standards for Eating Disorders

Because of the seriousness and prevalence of eating disorders, it is important to disseminate evidence-based protocols for eating disorder treatment in a manner that is easily accessible to a broad range of clinicians (Fursland, Byrne et al., 2012).

A nationally consistent approach to eating disorders requires the adoption of common standards and practice principles across state and territory health services.

The National Standards Schema, published by the NEDC in 2012, details the integrated approach to eating disorders that is necessary to ensure everyone who has or is at risk of developing an eating disorder, as well as their carers, has access to a network of skilled practitioners, evidence-based treatment and support at all stages of prevention, illness and recovery.

The National Standards Schema is made up of a summary of the essential principles for service delivery for the prevention and management of eating disorders, as well as a continuum of care outlining the essential levels of intervention required to provide a complete and integrated approach.

Seven core principles and four implementation principles have been identified that, if implemented together, will provide the foundation for an effective and nationally consistent system to address eating disorder management.

The principles of prevention and treatment focus on access to comprehensive, coordinated approaches that provide individually tailored pathways that can be consistently implemented. The principles are predicated on the need to be informed by evidence from research and the lived experience.

Standards of care must apply to those:

- At risk of developing an eating disorder, where the goal is prevention
- With early symptoms of an eating disorder, where the goal is early intervention
- With acute illness, where the goals of treatment are recovery and relapse prevention
- With a severe or enduring disorder, where goals of care may be modified to encompass improvements in quality of life

These principles are consistent with national policy and with the requirements for the delivery of mental health services in Australia as outlined in the National Mental Health Service Standards (2010).

The implementation of shared clinical guidelines, decision support tools, clinical routines and protocols will build system-based competence for the multidisciplinary, and potentially multi-agency treatment of eating disorders.

A collaborative approach to systems leadership is required to support this level of collaborative practice involving all governments and departments concerned with the provision of prevention and care.

7.1.2 Standards for Research and Evidence-Based Solutions

Priority area 4 of the Fourth Mental Health Plan requires the development of, “explicit avenues of support ... to implement evidence-based and innovative models of care, to foster research and dissemination of findings.”

While this is identified as a priority area, there are no mechanisms currently in place to ensure that eating disorder research is translated into policy and practice. While the NEDC has a role in ensuring that existing evidence-based information is readily accessible, there are no resources to support the generation of new evidence. While individual services and clinicians are diligent in their application of existing research and participation in new research, there is no consistent approach relevant to all service areas.

The first National Framework identified priority areas for the development of research infrastructure as:

- Establishment of a National Research Agenda focused on the gaps in knowledge and the areas where evidence-based treatments are still needed
- Collection of consistent national data to monitor the incidence and progression of eating disorders and ensure that this is included in service planning and evaluation
- Identification and implementation of diverse evaluation strategies for all eating disorder activities
- Definition of an efficient pathway from existing evidence to pilots to practice experience and to RCTs
- A collaborative national research community – a research institute ‘without walls’ – to encourage interdisciplinary and cross-discipline research that will target and address the complexity of eating disorder illnesses and accelerate the identification of causes and treatment options

Australian National Research Priorities

A research agenda for eating disorders must align with Australia’s national research priorities (listed below), with particular reference to the priority of ‘promoting and maintaining good health’. The NEDC supports the recommendation to amend this priority, with the addition of mental health to preventative health care and Indigenous health as priority issues.

Promoting and Maintaining Good Health

A healthy start to life

Counteracting the impact of genetic, social and environmental factors that predispose infants and children to ill health and reduce their wellbeing and life potential.

Preventive health care

New ethical, evidence-based strategies to promote physical and mental health and prevent disease through the adoption of healthier lifestyles and diet, along with the development of health-promoting products.

Strengthening Australia's social and economic fabric

Understanding and strengthening key elements of Australia's social and economic fabric to help families and individuals live healthy, productive and fulfilling lives.

Indigenous health

Understanding and improving the health of Indigenous Australians.

Finding cures for disease

Developing new medical technologies to improve health outcomes

(National Research Priorities, Commonwealth of Australia 2012)

7.2 Current Practice in Evidence-Based Standards

Underpinning all of these issues are gaps in health service systems at policy, leadership, professional development and service provider levels. Systems are required to support the integration of services provided at different levels of care, in different settings, from community services to tertiary services, and potentially in different health regions or even different states. This level of formal integration is essential to address gaps in workforce capacity and specialist service provision.

Reference to eating disorders is largely absent from health policies and funding arrangements. Reliance on an understanding of other mental illnesses as the basis for policy development has led to initiatives that do not address the complexity and duration of eating disorders.

Eating disorder services have often developed on an opportunistic basis in isolation from one other and from other health sectors; they have been driven by individual expertise, perceived local need and funding opportunity. A key gap is the development of a systematic approach that embeds eating disorder treatment into mainstream health systems and ensures that the majority of people with eating disorders have access to excellent care.

It would be beneficial to have one set of clear guidelines on eating disorder treatment that are informed by the evidence. This will support confidence to treat, improve access to evidence-based treatment and reduce unwanted variation in treatment standards.

7.2.1 Service Standards

There is a lack of consistency in treatment models and variations in the scope of services, including eating disorder specialist services and a lack of published evaluation of services. While a diversity of treatment options is essential for eating disorders, all treatment approaches should have the capacity to deliver safe, flexible, multidisciplinary treatment tailored to meet individual needs.

"It is important to note that unless more effective treatment becomes more accessible and affordable, these sufferers will lean on the health system, often for a lifetime. Whilst our daughter is

only 23, she maintains her anorexia, manages it, survives, but the side effects may only increase and become apparent as she gets older"

7.2.2 Policy and Protocols

There is a lack of articulation of eating disorder treatment requirements in policies and protocols at all levels, including specification of the core competencies required to provide eating disorder diagnosis, assessment and treatment.

"Recognition by health authorities and governments that eating disorders are a serious condition requiring a holistic treatment framework, such as those that exist for cancer, diabetes, heart disease etc, is essential"

For general mental health initiatives, eating disorders are typically grouped (although not named) with mild to moderate levels of anxiety and depression and general youth mental health (e.g. Better Access, ATAPS, Headspace, ReachOut). This contributes to a pattern of treatment made up of unconnected short term episodes of treatment with limited or no support between those episodes or after recovery is achieved.

7.2.3 Current Practice in the Implementation of Clinical Guidelines and Standards

NEDC consultation with clinicians has identified a need for clinical guidelines, decision support tools and exemplar protocols that are specific and relevant to the different professions and service contexts in which eating disorders are treated.

"It would be really helpful to have one set of clear guidelines on treatment that are informed by evidence"

The implementation of shared clinical guidelines, decision support tools, clinical routines and protocols will build system-based competence for the multidisciplinary, and potentially multi-agency treatment of eating disorders.

There are already mechanisms in place to drive the development of national standards, e.g. COAG Mental Health Standing Committee and the National Health and Medical Research Council. Expertise in eating disorders, representing research, clinical experience and lived experience, is required to inform these bodies on the most appropriate content. The NEDC provides a possible source of such expertise. At present, the NEDC is the only national body of eating disorders expertise representing all areas of eating disorders expertise.

7.2.4 Eating Disorder Data Collection

Current data collection on mental health in Australia does not prioritise (and in many instances, does not even include) eating disorders. The Australian Bureau of Statistics (ABS) does not appear to have ever collected data on eating disorders.

The last official estimate by the Australian Institute for Health and Welfare (AIHW) was published in 2003 and was based not on Australian data, but on a small survey of Swiss schoolgirls conducted in the mid-1990s. No males were included in the estimate and no estimates were made for EDNOS.

This lack of data has a direct impact on the effectiveness of mental health policy and service planning. For example, recent changes to the BAMHS were based on data that did not specifically investigate the diagnosis of eating disorders due to lack of data (ANZAED, 2011).

There is an urgent need to collect better information about all diagnoses of eating disorders, particularly in relation to tracking prevalence, mortality and health system costs.

7.2.5 Published Research

Between January and September 2012, 319 new journal articles on the topic of eating disorders were added to the NEDC Clearinghouse.

The primary areas investigated included risk and protective factors (23%) and treatment types (28%). The primary focus of this research was on anorexia nervosa (34%) and for various issues (such as risk and protective factors) on all eating disorders (33%). Only 8% of articles focused on binge eating disorder and 4% focused on EDNOS.

The treatment setting was frequently not identified (27%) and the research involved those not currently in treatment (34%); hence, the research did not significantly contribute to an understanding of the treatment setting as an influence in outcomes. The majority of the articles reported on cross-sectional studies (51%) that will have influenced the selection of people from varied treatment/non-treatment settings.

4% of research articles in 2012 focused on prevention and 6% on recovery and tertiary prevention. There is a need for a greater focus on evaluating the outcomes of prevention, preferably integrated with other health issues. There is also limited evidence on prevention and treatment that integrates approaches to obesity with approaches to eating disorders.

Treatment trials need to move beyond targeting core eating disorder pathology (primarily weight restoration) and examine efficacy and effectiveness in minimising harm and reducing personal and social costs of chronic illness (Hay, Touyz & Sud, 2012).

Type of Eating Disorder

AN	BN	BED	EDNOS	All EDs	Not Classified
110	53	24	12	105	15
% of papers					

34%	17%	8%	4%	33%	4%
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Focus of Research

Diagnosis & Assessment	P+EI	Prevalence	Risk Factors	Genetics	Treatment Type	Burden of Disease	Recovery Experience
46	14	11	73	2	90	5	18
% of papers							
14	4	3	23	1	28	2	6

Treatment Setting

Hospital	Primary Care	Residential	Specialist	Outpatient	Not specified	Not in Treatment
13	4	4	35	11	85	107
% of papers						
4	1	1	11	3	27	34

42% of the research papers published in 2012 make recommendations that have implications for clinical practice. There are currently no systematic mechanisms to translate these research recommendations into useable practice resources and this absence has implications for the quality and effectiveness of treatment provided.

There is currently no significant research into the experience of eating disorders in Indigenous communities. Only 2% of research papers published in 2012 investigated eating disorders in culturally diverse communities.

7.2.6 Innovation and Evaluation

While evaluation of services forms part of the National Mental Health Service Standards, there is currently no nationally consistent standard for evaluating the practices and outcomes of eating disorder treatment and prevention services. Few eating disorder services are evaluated on a consistent basis with consumer participation in the evaluation process. A standard for service evaluation with agreed definitions could address these gaps.

A flexible range of evidence-based interventions are required to meet the needs of people with eating disorders. Some services and clinicians are addressing the need for innovative variations in treatment in their practice, however, there is limited evidence to support these emerging prevention and treatment initiatives. Investigation of alternative prevention and treatment approaches is important in order to meet the needs of the large percentage of people who do not respond to current treatment.

7.2.7 Gaps in Knowledge

The following priority 'gaps' or needs in research were identified in the NEDC Evidence Review and the first National Framework:

Prevention and Early Identification

- *Prospective and repeated follow-up* over months and years is required to determine whether the benefits of prevention programs are durable and cost-effective
- *Identification of clear, consistent and integrated health-promoting messaging for the eating disorder and obesity fields* is an important priority for future research
- *The effectiveness of interventions to improve eating disorder mental health literacy*, aimed at the general community, at-risk individuals and/or treatment providers, is required
- *Pure and guided self-help programs* are likely to be effective among individuals showing eating disorder early warning signs, yet this has not been specifically evaluated
- *Early warning signs of eating disorders* can vary as a function of population type and more research is required to understand the course of eating disorders in order to better identify and assist those in the prodromal state

Treatment

- *More research is needed on treatments*, particularly for Anorexia Nervosa in adults and eating disorders in youth
- *Research into eating disorders and disordered eating amongst Indigenous Australians to date is limited*
- *The comparative benefit of treatment settings has not been adequately evaluated*. There is very little evidence to discriminate between the effectiveness of inpatient, day patient, outpatient, and residential settings
- *Active psychological treatments require comparison in RCTs*, particularly among the populations of youth with anorexia nervosa, adults with anorexia nervosa and individuals who do not respond to first-line treatment for bulimia nervosa and binge eating disorder

7.3 Examples of Current Resources to Build On

7.3.1 A National Research Agenda for Eating Disorders

The NEDC has developed draft guidelines for a national research agenda to establish national priorities, focus and direction for eating disorder related research in Australia. The purpose of such an agenda would be to focus resources on research that will:

- Improve the lives and outcomes for people who have or are at high risk of developing an eating disorder

- Address important gaps in the evidence base to inform policy and practice
- Promote partnerships and collaboration within the eating disorder research sector and with other research sectors

The draft research agenda provides a starting place for the development of strategies to address gaps in the evidence base for eating disorder prevention and treatment.

National Research Agenda for Eating Disorders

Strategies to Enable Australian Research

The priority areas for the development of research infrastructure for the eating disorder sector include:

- Collection of consistent national data to monitor the incidence and progression of eating disorders and ensure that this is included in service planning and evaluation
- Prioritisation of eating disorder issues within mainstream Australian research funding and activities
- Identification and implementation of diverse evaluation strategies for all eating disorder activities
- Definition of an efficient pathway from existing evidence to pilots to practice experience and to RCTs
- A collaborative national research community to encourage interdisciplinary and cross-discipline research that will target and address the complexity of the illnesses and accelerate the identification of causes and treatment options
- Effective participation strategies for people with experience of eating disorders, their families and carers

Research Principles

Priority will be given to research that:

- Addresses priority gaps in knowledge
- Focuses on outcomes that will influence practice
- Is collaborative and cross-disciplinary
- Is inclusive of people with experience of eating disorders in the design and conduct of research and in the interpretation of results
- Targets issues relevant to high risk groups and people with lived experience

- Builds on existing evidence where possible
- Incorporates explicit strategies for dissemination of results

Research Priorities

1. Prevention and Health Promotion

Research Direction: Identification and evaluation of effective strategies that integrate eating disorder prevention with other prevention and health promotion initiatives in different settings in the Australian social context

Identified areas of inquiry:

- Adaptation of evidence-based prevention approaches for consistent use in different settings, including the use of online technology, group and individual approaches and implementation in sport, recreation and employment settings
- Prospective and repeated long term follow-up to determine whether the benefits of prevention programs are durable and cost-effective
- Identification of shared risk factors, prevention and health promotion strategies for the eating disorder, obesity, youth mental health and substance abuse sectors
- Evaluation of integrated, health-promoting messaging for eating disorders and other sectors, including evaluation of the effectiveness of interventions to improve eating disorder mental health literacy

2. Early Intervention

Research Direction: Identification and evaluation of cost-effective approaches to identify people with eating disorders early in the course of illness and reduce the duration and impact of illness

Identified areas of inquiry:

- Investigation of the naturalistic course of eating disorders to identify early warning signs and stages and better assist those in the prodromal state
- Evaluation of pure and guided self-help programs for early intervention

3. Effective Treatment

Research Direction: Identification and evaluation of effective therapies for all presentations of eating disorders.

Identified areas of inquiry:

- Investigation of approaches to match treatments to individual needs

- Investigation of treatment approaches for all types of eating disorders and eating disorders with comorbid conditions in children, youth and adults
- Investigation of the comparative outcomes and cost-effectiveness of different treatment settings, including primary care, community-based and specialist settings
- Comparison of psychological treatments in RCTs, particularly among the populations of youth with anorexia nervosa, adults with anorexia nervosa and individuals who do not respond to first-line treatment for bulimia nervosa and binge eating disorder

4. Profile and Prevalence Data

Research Direction: Developing an accurate profile of the incidence and impact of eating disorders in Australia, including the incidence and impact in specific populations

Identified areas of inquiry:

- Australian eating disorder demographic profile and trend information, developed in collaboration with national health surveys, contributing to the targeting of services where they are most needed
- Research on the prevalence, profile, experiences and issues affecting diverse groups of people with eating disorders, such as:
 - Aboriginal and Torres Strait Islander communities
 - People from culturally and linguistically diverse backgrounds
 - People in regional, rural and remote areas
 - People seeking treatment or support for weight loss

5. Sector Development and Sustainability

Research Direction: Analysis of the factors that support sector development and sustainability for nationally consistent and long term solutions to eating disorders in Australia

Identified areas of inquiry:

- Evaluations, reviews and research to contribute to the evidence base to improve service delivery and support options and to contribute to quality assurance and continuous improvement
- Research into the training, professional development and supervision of health professionals who work with people with eating disorders and their families and carers
- Investigation of strategies, policies and procedures to best inform person-centred planning, inclusion of families and simplified access to specialist eating disorder services

- Develop meaningful inclusion, collaboration and participation models involving people with eating disorders, their families and their representative organisation in research and evaluations
- Develop strong relationships and information sharing with other researchers, research organisations and various eating disorder stakeholders through partnerships and networking opportunities
- Engage with other research communities and establish co-research programs and partnerships

7.4 Recommendations for Evidence-Based Standards

Nationally consistent approaches to eating disorders in Australia can only be achieved with the consistent implementation of shared standards.

Implementation of consistent national standards is identified as a priority area for action to ensure a nationally consistent approach to eating disorders. It will be vital to build on the impetus and expertise of the NEDC project to drive the development and implementation of national standards, clinical guidelines and decision support tools.

National standards must be based on quality research and data. National data collection is identified as an essential first step towards a nationally consistent approach. The inclusion of all diagnoses of eating disorders in health and welfare data collection should be a first step towards developing a detailed profile of eating disorders in Australia.

Recommendations made by Deloitte Access Economics in their 2012 report, 'Paying the Price', are supported by the NEDC investigation of data collection. These recommendations build on existing data collection strategies in Australia:

- Include eating disorder questions in the Australian Health Survey. This provides a relatively simple and inexpensive approach to data collection that is consistent with approaches in New Zealand and the United States.
- Implement a national Australian epidemiological study to better understand eating disorders and their impact nation-wide
- Reassess mortality data. The AIHW (2012) notes that most people have three causes of death and as many people have five causes of death (20%) as those who have only one cause of death. Eating disorders are frequently not included as a reason for admission to hospital or as a cause of death. Better recording of the presence of eating disorders generally, whether identified as a cause of death or not, would improve understanding of the impact of eating disorders in Australia

- Include binge eating disorder as a condition in the International Classification of Primary Care. At present, the ICPC 2 Plus contains categories for anorexia nervosa and bulimia nervosa, but not for binge eating disorder or eating disorders not otherwise specified (EDNOS); which are currently the most frequently diagnosed eating disorders in Australia. The inclusion of binge eating disorder in the DSM-5 emphasises the importance of this change and brings Australian classification into line with international approaches
- Include eating disorders in welfare data. At present, there is no information on eating disorders as a cause for unemployment benefits, sickness benefits or disability support pension. Given the high prevalence of eating disorders, this should be revisited (Deloitte Access Economics, 2012)

Based on the standards and evidence for national coordination in eating disorders, the following table details key strategic opportunities for development of a nationally consistent approach.

Immediate Opportunities	In consultation with community health regions, facilitate networking between primary and secondary health services and existing eating disorder specialist services
<i>Information and resources are already available to support these actions</i>	<p>Maintain the NEDC as a national source of tertiary expertise to inform the development of eating disorder initiatives to:</p> <ul style="list-style-type: none"> • Work with state and territory governments, private health providers and professional peak bodies to identify opportunities to implement strategic options for eating disorder services • Provide expert consultation to support the implementation and evaluation of eating disorder initiatives <p>Assertively disseminate the principles and standards from the National Framework and Gap Analysis (short form) to all health services working with people at high risk of developing an eating disorder</p> <p>Include all diagnoses of eating disorders as distinct categories in national data collection activities</p>
Medium Term Planning	Implement a national epidemiological study into eating disorders and their impacts
<i>Further development of information and resources is required to</i>	<p>Systematically collect consumer and carer information through existing consumer and carer support organisations</p> <p>Implement intensive outpatient services, including day and residential programs, in areas which are currently underserved</p>

support these actions

Implement community-based entry points, family and consumer education and support programs in areas which are currently underserved

Develop online/videolink approaches to improve tertiary consultation access for rural and regional areas

Review and re-develop or endorse clinical guidelines, taking into consideration the new diagnostic criteria in the DSM-V

Develop good practice indicators mapped to the National Standards Schema and adoption of national standards for the prevention and treatment of eating disorders

Resource a national epidemiological study into eating disorders and their impacts

Develop evaluation criteria to support National Standards Schema and adoption of national standards for the prevention and treatment of eating disorders

Include eating disorders as a national research priority and support a national research agenda for the eating disorder sector to address gaps in knowledge

Optimal Model

Every health region has formal connections with a tertiary service that is resourced to provide training, supervision and shared care

Every health region has access to a full continuum of care

A single national point of access to expertise in eating disorders, representing research, clinical experience and lived experience, informs the development and maintenance of a nationally consistent approach

A nationally consistent approach to eating disorders is supported by national performance standards and clinical guidelines across all health professions

Access to a full continuum of services, including intensive outpatient, day and residential programs

One consistent introductory training program on eating disorders for all health professionals

National data collection strategies

Part B:

**Models for a
Nationally Consistent
Approach to Eating
Disorders**

A Hub and Spoke Model of Service Delivery for Eating Disorders

A goal of the Fourth National Mental Health Plan (2009) is to, “better target services and address service gaps through cooperative and innovative service models for the delivery of primary mental health care.”

The challenges in developing a systematic response to eating disorders in the Australian context are shared with many other health sectors. They include:

- Promoting early intervention and recovery in a social context of stigma and misunderstanding about eating disorders specifically and mental health generally
- Providing expert care to relatively small populations
- Providing care outside metropolitan centres
- Integrating both physical and mental health services
- Integrating health and non-health (e.g. education, community support) services as part of a whole treatment pathway

The National Eating Disorders Framework and this Gap Analysis identify that eating disorders can be treated in any health care setting provided that there is access to skilled staff to deliver treatment in that setting and that the mechanisms exist to facilitate access to more intensive levels of specialist treatment in response to a patient’s changing needs. Tertiary consultation is the recommended mechanism to ensure that all health professionals have access when they need it to an appropriate level of specialist expertise.

A ‘hub’ is a relatively small centre of expertise with the capacity to resource and support service delivery through primary and secondary care services. The provision of tertiary consultation support from a hub enables people to access eating disorder treatment, at least in the first instance and during recovery support, within their local community.

A ‘hub and spoke’ approach was suggested in the National Eating Disorders Framework (2012) to promote integrated, coordinated treatment options across health regions. Fragmentation of services across primary, community and secondary care and the challenges of providing health care in rural and remote areas has led to the adoption of hub and spoke approaches in most states. The concept of an eating disorder hub and spoke model fits well with these existing approaches.

Tertiary Consultation: Regional Service Hubs

At a state or regional level, a service hub has two key roles to play:

- Provision of tertiary intensive outpatient and inpatient treatment for eating disorders for people with complex and severe eating disorders and for those who have not responded to treatment within their local services

- Provision of tertiary consultation support, joint assessment, supervision and training for community-based services provided by public and private health services and non-government organisations

The scope of treatment provided in an eating disorder-specific program is discussed in Chapter 1 of this report. In addition to delivering this range of services, an eating disorder hub would require the capacity to provide:

- Consultation, resources and expert advice to primary and secondary care clinicians to allow them to support patients in their own communities
- Assessment and advice on referrals when a higher level of treatment is required
- Participation in case review discussions
- Regular telephone and email contact with spoke services
- Training and supervision to selected staff in spoke services

The hub service may be accessed by primary care providers and other community agencies, as well as secondary health services providing inpatient and outpatient treatment for people with eating disorders where there is no eating disorder specialist service available in the community.

An eating disorder tertiary consultation hub must have specialist knowledge, expertise and experience in the management and treatment of eating disorders and be able to contribute to and draw on research to inform practice.

Creating Virtual Hubs

Comprehensive eating disorder programs that integrate the full scope of treatment and tertiary support in one centre are efficient. However, the lack of a comprehensive service should not be a barrier to the provision of expert support to 'spoke' services.

Where no single centre of eating disorder expertise exists with the potential to act as a hub, it may be possible to link a number of smaller services with expertise in different aspects of eating disorder treatment into a virtual hub using a partnership model. The development of formal alliances between eating disorder specialist services within hospitals, community-based outpatient and recovery support programs and organisations with the capacity to provide training may be a first step towards a hub and spoke model for some regions.

Similarly, smaller scale clusters may be developed in regional areas, linking primary and secondary care service providers into networked treatment teams in order to strengthen the capacity of spoke services to deliver safe, multidisciplinary treatment at the local service level.

Building Capacity Through Outreach and Putpost Services

Both child and adolescent and adult mental health services in regional and rural locations experience difficulties maintaining staff teams that are skilled in the treatment of eating disorders. The relatively

small number of patients with eating disorders requiring treatment at any one time does not support the development of extensive clinical expertise in every health service.

The following approaches address this issue by providing visiting expertise or by embedding expertise in the regional health team.

Outreach Approaches

An outreach approach enables trained eating disorder clinicians working from a central hub location to visit and work directly with treatment teams in regional locations.

An outreach approach contributes to:

- Direct provision of patient assessment and treatment planning
- Ensuring quality standards of treatment provided through all hospital and community level treatment services
- Building workforce capacity through mentoring and experiential learning
- Facilitation of referrals and transitions to other services as required

Outpost Approaches

An outpost approach also enables health professionals trained in eating disorders to work with local treatment teams. In an outpost approach staff are embedded in local services on a long term basis and provide a direct service to patients and local clinicians.

Opportunities exist to embed outpost services within Medicare Local Health regions to support the development of local responses to eating disorders, coordinate multidisciplinary care for individuals, support transitions between services, and provide a local point of contact for eating disorder information.

Embedding specifically trained health professionals in local regions will build capacity into the local workforce and provide for:

- Coordination between service providers
- Skilled initial assessment and triage
- Coordination of individual treatment plans in collaboration with service providers and families
- Facilitation of individual case coordination and the development of multidisciplinary teams in primary care
- Development of local system capacity through the development of outpatient service models where eating disorder services do not already exist within the community
- A point of contact for clinicians, people with eating disorders and their families
- Provision of education to individuals and groups
- Transition and recovery support
- Delivery or facilitation of basic professional development sessions for primary care and other professionals

This model addresses several of the key gaps identified by this Gap Analysis:

- Delivery of eating disorder-specific care in local regions
- Enhancing referral pathways and ease of access
- Workforce development; providing skilled eating disorder professionals to augment and support existing primary and secondary health services
- Individual care planning
- Coordination of safe, multidisciplinary responses
- Triage and rapid referral for people requiring more intensive intervention

The outpost model places the emphasis on early intervention, recovery support and tertiary prevention. This model presumes a deficit in local eating disorder service provision and intentionally adds capacity to the workforce. The model is specifically intended for health regions that are not already well served by eating disorder services.

Whether employed by the local region or by the eating disorder hub, outpost staff should be trained, supported and supervised by the tertiary hub in order to ensure appropriate links between the hub and spokes and maintain consistent practice standards.

The Eating Disorders Outreach Service (EDOS) in Queensland provides a practical example of the outreach approach.

The Role of Service Spokes

‘Spokes’ may provide a range of services for people with eating disorders depending on the scope of their usual professional role. The scope of eating disorder services to be provided in the community includes:

- Provision of information
- Promotion of prevention resources
- Initial diagnoses and assessment
- Provision of targeted prevention and early intervention for people at high risk
- Treatment of mild to moderate eating disorders in outpatient programs and through ‘virtual’ and local multidisciplinary teams
- Ongoing medical monitoring as part of a shared care arrangement
- Transition support, follow-up and recovery support for people who have received treatment elsewhere
- Family education and support
- Patient education, social and peer support

The key to successful service delivery through a ‘spoke’ service is the commitment of that service to work collaboratively with the hub and with other service providers in their region. Partnership agreements, protocols and nominated roles to promote coordination are required to ensure that the hub and spokes work effectively together.

Example of a Youth Mental Health ‘Spoke’

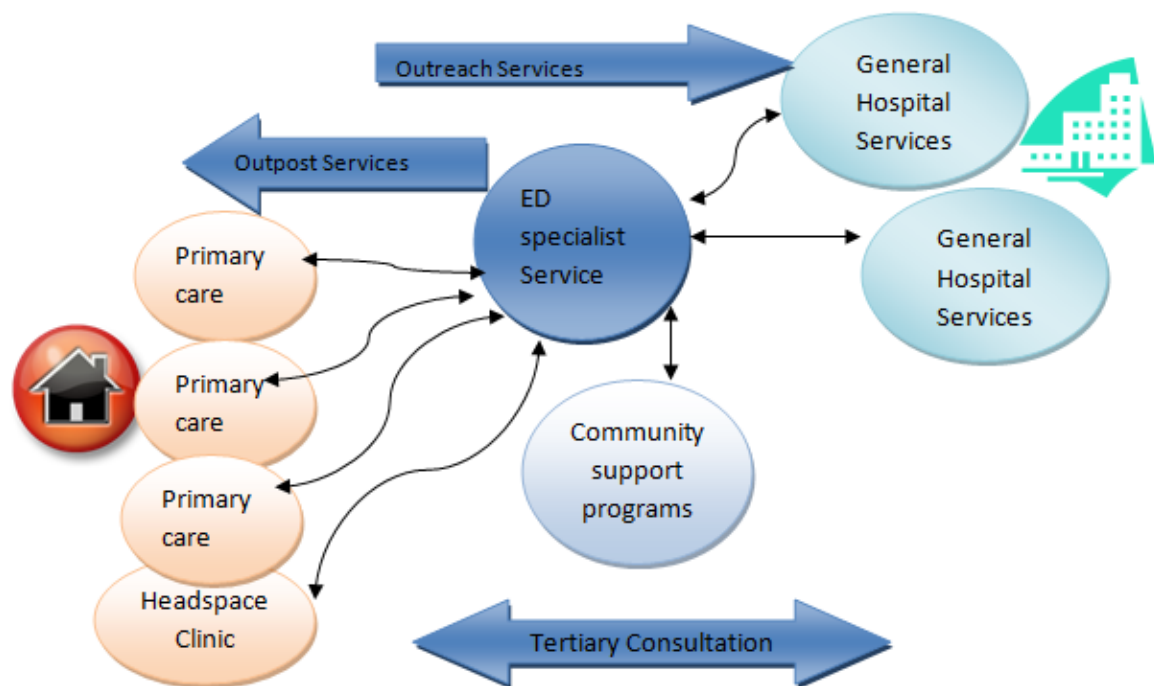
Existing early intervention health services in the community may provide appropriate ‘spokes’ for the hub and spoke approach. An example would be the Headspace centres providing a prevention and early intervention service to promote youth health. Each Headspace centre is different, reflecting the needs of the local community. All Headspace centres have the potential to disseminate prevention information about eating disorders and to act as an entry point for further help. As part of skills development for the frontline workforce, Headspace staff could be equipped with the skills to identify eating disorders, make appropriate referrals and support the person in seeking help. For Headspace centres providing a full frontline medical service, tertiary support for Headspace staff would enable the skilled provision of early intervention for eating disorders. The addition of dietitians to the Headspace team would support this provision of treatment.

Service Delivery: Minimum Requirements for Eating Disorder Treatment Services

A service providing treatment specifically for eating disorders should be able to demonstrate that:

- All staff delivering treatment to people with eating disorders are trained in the delivery of that treatment
- Patients collaborate in the development of individual treatment and recovery plans
- Assessment and decisions about the type and level of treatment are based on the patient’s physical condition, psychology, eating disorder behaviours and social circumstances
- Treatment is motivational and non-coercive in approach
- Treatment specifically addresses physical, psychological and nutritional needs and is delivered by a multidisciplinary team
- Treatment duration and dosage is evidence-based and sufficient to address the complexity of the disorder
- Family members are actively engaged and supported as integral members of the treatment team, unless contraindicated
- There are formal links and coordination between inpatient, outpatient and primary care services with effective transition strategies to ensure coordinated, long term care
- Treatment and support strategies are evidence-informed and/or evidence generating, including systematic evaluation of patient outcomes and satisfaction

An Eating Disorders Hub and Spoke Service Model



Note: the links between hub and spokes in this model represent flows of information and not direct supervision. Services operating as spokes in this model operate independently of the hub. Formal partnerships and protocols may be developed to enable communication, collaborative decision making, shared case management, shared training and mutual engagement in research.

Elements of Regional Hub and Spoke Approach to Eating Disorders

1. **Hub:** Tertiary ED Specialist Service providing:
 - a. Inpatient treatment
 - b. Intensive outpatient/day or residential programs
 - c. Outpatient treatment
 - d. Patient and family education and support
 - e. Tertiary consultation
 - f. Outreach support
 - g. Training and development
 - h. Research and evaluation
2. **Spoke:** Secondary, non-specialist eating disorder service provided through general hospitals and mental health services
3. **Spoke:** Primary care coordinated community treatment provided by interdisciplinary teams supported by outreach and tertiary consultation
4. **Spoke:** Eating disorder support services – soft entry points for targeted prevention and early intervention, referral, education and support and recovery support programs
5. **Case Coordination:** May be delivered as part of a local eating disorder support service or managed from the eating disorders hub
 - a. linking virtual teams at local level through skilled case coordination
 - b. linking primary, secondary and tertiary
 - c. supporting transition

Integration and Coordination

The National Mental Health Services Standards emphasise the importance of collaboration and integration for effective delivery of mental health services (Standards 8, 9 and 10.6, 2010). Improved coordination between primary care and specialist care is a goal of the Fourth National Mental Health Plan (Priority area 3, 2009).

The hub and spoke model is compatible with the provision of long term eating disorder treatment and support and provides for a continuity of care between levels of service and episodes of treatment. There is a need for a strong relationship between the specialist hub and local services to allow transfer of knowledge and continuity of care.

The point of difference between an eating disorder specialist service and a hub is the development of mechanisms to connect the hub with other service providers and the development of capacity within the hub to provide tertiary consultation.

Achieving a collaborative, multidisciplinary team approach will require the implementation of mechanisms to support professional networking across traditional treatment and professional boundaries. The multidisciplinary team must work across both physical and mental health, between public and private health services, across specialist disciplines and between health, education and social services.

A collaborative approach to systems leadership is required to support collaborative practice at all levels of service provision. Representation from all of the professions and service providers engaged in a multidisciplinary team approach to eating disorders and the departments involved in the provision of care will contribute to the effective implementation of safe, flexible, person-centred and multidisciplinary treatment approaches.

The development of connections with other service providers requires action on the part of both hub and spokes to ensure development and implementation of mutually appropriate protocols. Collaborative approaches are required in policy, protocols and governance, as well as in service delivery.

Connection between hub and spokes would require:

- Partnership agreements and protocols for the integration of tertiary services into existing service approaches
- Development of communication strategies between hub and spokes
- Assertive engagement of and liaison with health professionals in communities, providing information about eating disorder treatment and the tertiary consultation support available
- Agreement to the provision of training for health professionals
- Development of telecommunications capacity to support telephone contact, videolinks and online consultation

An effective hub and spoke model would be fully integrated at the policy, regional planning and direct service delivery levels. Evidence shows that integration at policy and service levels supports effective service delivery.

Shared Protocols

Coordination of care within a hub and spoke network of services will be enhanced with the collaborative development of shared protocols that are implemented by all services and professions providing treatment. To support the development of an eating disorders hub and spoke model, there will be a need to develop shared:

- Care assessment protocol
- Referral protocols that include agreed referral pathways, criteria for referral, mechanisms for referral and minimum information required for referral completion
- Shared care and multidisciplinary team meeting protocols
- Information provision protocols to ensure consistent information and communication to patients and between health care providers
- Treatment protocols
- Documentation on the care coordination components of health care providers' roles to support a team approach for achieving continuity of care for all patients
- Protocols for the appointment of case managers for patients with complex needs
- Discharge documentation protocols to facilitate transition between health care providers
- Protocols for inclusion of key contacts in discharge planning to contribute to continuity of care, ensuring links between past, current and future episodes of care (Haggerty, JL et al.. 2003)

Networking

- Developing awareness and relationships between service providers at all levels to facilitate referral and sharing of information
- Development of multidisciplinary teams in primary and secondary care services who are able to work together as the need arises
- Establishing local, collaborative networks or groups for professional development and peer support
- Increasing use of technology for networking and to assist in shared, real time case management

Governance

- Strengthening governance and management structures to enable the examination of barriers and challenges around process requirements and support for care coordination initiatives
- Developing and implementing initiatives that support the inclusion of the patient and carer experience to inform planning, development and implementation of initiatives

Professional Development

- Improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice
- Education, engagement and consultation with key stakeholders in service planning and development activities

National Coordination

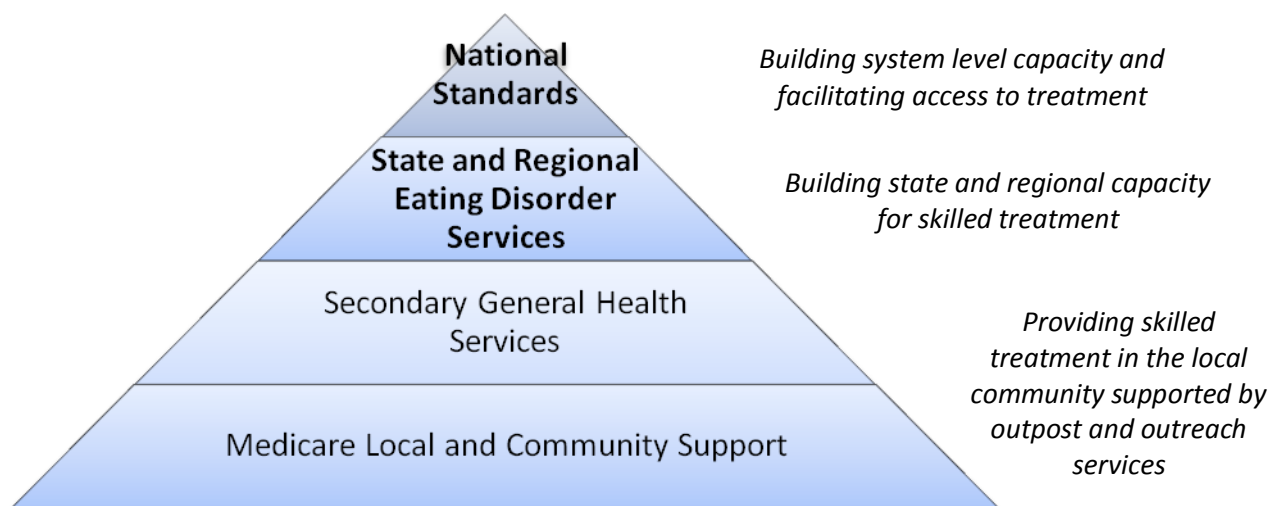
With the adoption of strong national standards for eating disorder treatment and prevention, part of the tertiary consultation role for eating disorders – the dissemination of evidence-based standards – may be most effectively addressed at a national, rather than a regional, level. Australia has the strategic option to develop a national, tiered approach to eating disorder prevention and treatment with clearly identified hubs and spokes at all levels:

Tier 1 – Medicare Local and community support services: primary care services providing eating disorder outpatient treatment; non-government support services providing prevention, service access, education and recovery support in consultation with Tier 3 & 4 eating disorder specialist hub(s)

Tier 2 – Existing generic mental and physical health services providing inpatient and outpatient treatment in consultation with Tier 3 eating disorder specialist hub(s)

Tier 3 – Specialist eating disorder teams providing inpatient, outpatient, outreach and community outpost services with tertiary consultation capacity to support Tiers 1 & 2

Tier 4 – National Coordination hub providing a nationally consistent point for dissemination of national standards, clinical guidelines, service implementation advice and supporting prevention and early intervention through a national information and individual support teleweb service.



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National Eating Disorders Collaboration Publications

2012

National Framework: An Integrated Response to Complexity 2012

Communication Strategy Report: Clarity in Complexity 2012

Appendix: Eating Disorders - A Current Affair

Appendix: Healthy Weight related Messages

Appendix: Evidence from Experience Report

Appendix References

2010

Evaluating the Risk of Harm of Weight related Public Messages

Eating Disorders: The Way Forward – An Australian National Framework

Eating Disorders Prevention, Treatment and Management – An Evidence Review

Eating Disorders Information and Support for Australians – Resource Review

Eating Disorders: The Way Forward – A Strategic Communication Framework

Appendix 1

National Eating Disorders Collaboration

Interdisciplinary Advisory Group Members

Australian and New Zealand Obesity Society - Leah Brennan

Australian College of Mental Health Nurses - Kim Ryan, Advisory Group Chair

Australian College of Nurse Practitioners - Alyson Wheelhouse

Australian Dental Association - Sharon Liberali

Australian Psychological Society - Natasha Hepworth

Dietitians Association of Australia - Susan Hart

Occupational Therapy Australia Ltd - Genevieve Pepin

Royal Australian College of General Practitioners - Sue Page

Royal College of Nursing Australia - Mary Bronson

The Royal Australasian College of Physicians - Simon Clarke,

The Royal Australian New Zealand College of Psychiatrists - Mark Oakley Browne

Appendix 2

Service providers who contributed to the NEDC Gap Analysis

The following services contributed information to the NEDC Gap Analysis, through completion of the online survey and/or provision of relevant service material. This list includes public and private services and non-government organisations. In some cases, multiple sources of information were obtained from within larger organisations, for example, government health departments.

A number of individual private practitioners also provided feedback for the Gap Analysis; however, their details have not been listed here.

Services are listed in alphabetical order.

Eating Disorder Services

ACEDA (incorporating panic & anxiety, obsessive compulsive and eating disorders associations) (SA)

Acorn support group (VIC)

ACT Eating Disorders Program (ACT)

Adolescent Medical Unit, Monash Medical Centre (VIC)

Adolescent Unit, John Hunter Hospital (NSW)

Albert Road Clinic (VIC)

Alma St Centre (VIC)

ARAFMI (TAS)

BETRS, Austin Hospital Psychiatric Unit (VIC)

BodyMatters, Australasia (NSW)

Bridges Eating Disorder Association for Western Australia (WA)

Central Coast Eating Disorders Early Intervention Outpatient Service (NSW)

Centre for Clinical Intervention (WA)

Centre for Eating and Diet Disorders & Missenden Psychiatric Unit, Royal Prince Alfred Hospital (NSW)

Centre for Psychotherapy (NSW)

Child & Adolescent ED Program, Austin Hospital (VIC)

Child and Adolescent Health Service - Princess Margaret Hospital, Eating disorders Program (WA)

Child and Family Therapy Unit, Royal Children's Hospital (QLD)

Darling Downs Hospital and Health Service (QLD)

Diabetes Resource Centre (QLD)

Eating Disorder Clinic, Royal Children's Hospital (VIC)

Eating Disorders Association (QLD)

Eating Disorders Foundation of Victoria (VIC)

Eating Disorders Outreach Service (QLD)

Eating Disorders Service, Barwon Health (VIC)

Eating Disorders Service, Loddon-Campaspe-Southern Mallee Region (VIC)

Eating Disorders Unit, Melbourne Hospital (VIC)

ED Service, Alfred Child & Adolescent Mental Health Service (VIC)

Flinders Medical Centre Weight Disorders Unit (SA)

Flinders University Services for Eating Disorders (SA)

Geelong Clinic (VIC)

Hollywood Private Hospital (WA)

Illawarra Eating Disorders Service (NSW)

Latrobe Regional Hospital Mental Health Program (VIC)

Lismore & District Women's Health Centre (NSW)

LRH- Sale Community Mental Health Service (VIC)

Macarthur Eating Disorders Service (NSW)

Mandometer (VIC)

Melbourne Centre for ISTDP (VIC)

Melbourne Dialectical Behavioural Therapy (DBT) Centre (VIC)

Mindful Moderate Eating Group - Binge Eating (VIC)

New Farm Clinic (QLD)

Northern Rivers Eating Disorders Service (NSW)

Northside Greenwich Clinic (NSW)

Pathways (VIC)

Peel Child and Adolescent Mental Health (WA)

Pilbara Health Network; Community Dietetic Service (VIC)

Princess Margaret Hospital for Children, Eating Disorders Program (WA)

Queen Victoria Women's Centre (VIC)

Queensland Health - Gold Coast Health services - Robina Hospital (QLD)

Recovery is Possible (RIPE) (VIC)

Royal Brisbane & Women's Hospital, ED Outreach Service (QLD)

Royal Children's Hospital, ED Clinic (QLD)
Royal Hobart Hospital Paediatric Eating Disorders Clinic (TAS)
Shoalhaven Eating Behaviour Service (NSW)
Southern Health Butterfly Eating Disorders Day Program (VIC)
Southern Health Wellness and Recovery Centre (VIC)
St John of God Health Care (WA)
Stanthorpe Community Mental Health (VIC)
Sutherland Shire Child, Youth & Family Eating Disorders Service (NSW)
Sydney Western Area Health Service ED Day Program (NSW)
Tasmania Recovery from Eating Disorders (TAS)
The Body Esteem Program (WA)
The Butterfly Foundation (Australia Wide)
The Children's Hospital at Westmead, Eating Disorder Clinic (NSW)
The Eating Disorders Outreach Service Queensland Health (QLD)
The Eating Issues Centre (QLD)
The Hills Clinic (NSW)
The Hobart Clinic (TAS)
The Hobart Clinic Eating Disorders Assessment and Day Program (TAS)
The Melbourne Clinic (VIC)
The Prince Charles Hospital (QLD)
The READ Clinic (NSW)
The Redleaf Practice (NSW)
The Sunshine Coast Private Hospital (QLD)
Total Health Care (NSW)
Victorian Centre for Excellence in Eating Disorders (VIC)
Wesley Private Hospital, Peter Beumont Centre for Eating Disorders (NSW)
Women's Centre for Health Matters (ACT)
Womens and Children's Hospital, Dept Psychological Medicine (SA)
Women's Health (SA)
Youth Reach South (WA)

General services engaging with eating disorders consumers and carers

Armadale Health Service (NSW)

Ballarat Youth Mental Health Services (VIC)
Bentley Child and Adolescent Mental Health Service (WA)
Calvary Hospital (ACT)
Carers WA (WA)
Child & Adolescent Mental Health Services (NSW)
Child and Adolescent Mental Health Services (VIC)
Child and Youth Mental Health (QLD)
Community Nutrition Unit (TAS)
Department of Health (NT)
Adult Community Health (QLD)
Frankston Hospital (VIC)
Headspace (Australia-wide)
Logan Hospital – Dietetics (QLD)
Mental Illness Fellowship North Queensland (QLD)
Mind Potential (NSW)
New Horizons Enterprises (NSW)
NOURISH Nutrition.Health.Fitness (WA)
Queensland Health (QLD)
Reachout (Australia-wide)
Royal Brisbane and Women's Hospital - Department of Nutrition and Dietetics (QLD)
Sane Australia (Australia-wide)
Tamworth Base Hospital, Nutrition and Dietetics Department (NSW)
The Townsville Hospital (QLD)
Top End Mental Health Services (NT)

Appendix 3

National Standards Schema

Practice Principles

Seven core principles and four implementation principles have been identified, which, if implemented together, will provide the foundation for an effective and nationally consistent system to address eating disorders.

The principles of prevention and treatment focus on access to comprehensive, coordinated approaches that provide individually tailored pathways that can be consistently implemented. The principles are predicated on the need to be informed by evidence from research and the lived experience.

Standards of care must apply to those at risk of developing an eating disorder where the goal is prevention, those with early symptoms of an eating disorder where the goal is early intervention, those with acute illness, where the goals of treatment are recovery and relapse prevention, and those with a severe or enduring disorder, where goals of care may be modified to encompass improvements in quality of life.

- **Person and family-centred care that addresses the needs of individuals**

Individual treatment plans are developed within a person-centred, family and culture sensitive and recovery-oriented framework. Services are delivered with a strengths-focused approach, supporting long term recovery, tailored to meet individual decision making capacity and needs as they develop over the course of the illness.

- **Prioritisation of prevention, early identification and early intervention**

Prevention, early identification and prompt intervention are necessary to reduce the severity, duration and impact of the illness. Early intervention for eating disorders includes strategies that enable people to access services as soon as they are needed: early in the development of the illness, early in help seeking and early in recurrent episodes of illness, with immediate access to treatment and support.

- **Safety and flexibility in treatment options**

Safe treatment for eating disorders addresses all of the aspects of illness: physical, behavioural and psychological. People have access to a range of safe treatment options, which meet different needs at each stage of risk, illness and recovery. Flexible and appropriately supported entry, exit and transition between services supports individually tailored care planning. When transitioning from child and adolescent services to adult services appropriate support is provided to the individual and their family.

- **Partnering to deliver multidisciplinary treatment in a continuum of care**

Treatment is provided by a multidisciplinary team who work in partnership with the person,

their family and other health and support providers, including treatment of comorbid issues. The multidisciplinary team will assist clients to meet physical, mental, nutritional, occupational and social needs. Individuals with an eating disorder require individual care plans and access to a designated case coordinator.

- **Equity of access and entry**

People have access to treatment and support services when and where they are needed, early in the illness and early in each episode of illness. The requirements of regional and rural areas are recognised and technological solutions to providing accessibility are included. The entry requirements and the costs, subsidies or fee rebates for treatment take into consideration the long term and complex nature of eating disorders and the need to ensure they are accessible and affordable to all. Clearly identified entry points, ideally located in the community, assist people to make informed decisions about treatment options and enable them to engage with accessible and affordable services.

- **Tertiary consultation accessible at all levels of treatment**

Access to expert consultation is required at the earliest possible point to ensure appropriate and early intervention. Wherever treatment occurs in the continuum of care, from early intervention to recovery support, there must be access to tertiary-level expertise for consultation, supervision, guidance and referral, if required.

- **Support for families and carers as integral members of the team**

Families and carers, where available, are recognised as integral members of the treatment and support team and receive support, skills and strategies, education and information to enable them to support the person with an eating disorder and to maintain personal good health. Where such support of a family or carer is not available, this gap in the team and support structure is taken into account and addressed by the service providers.

Implementation Principles

To implement each of the practice principles, action will be required in four domains:

- **Evidence-informed and evidence-generating approaches**

Research and evaluation are integral to the design and delivery of health promotion, prevention, early intervention and treatment approaches. Basing approaches on evidence ensures that people have access to the most effective approaches, all approaches develop in response to emerging evidence and new approaches that contribute to emerging, practice informed evidence are encouraged. People with personal experience of eating disorders are involved at all levels of service development and evaluation.

- **A skilled workforce**

An effective system is founded on a skilled and supported workforce. All health professionals receive training in eating disorders to raise their awareness of the serious nature of eating

disorders and to enable them to identify, assess and contribute to the treatment of eating disorders. Training includes the development of attitudes and practices that support early identification and intervention and a person-centred and recovery-oriented approach. General Practitioners are recognised as being the first point of contact in many instances and are educated on how to interview the patient and their family to facilitate an early diagnosis. Training includes attitudes and practices that support early identification, intervention, recognition of the ambivalence and fear that is prevalent in this population and a recovery-oriented approach.

- **Communication to ensure an informed and responsive community**

Consistent and appropriate messages are provided to make sure that the community is aware of eating disorders as serious mental and physical illnesses. Such messages also educate the community to reduce the stigma that hampers help seeking. Eating disorder prevention integrates with wider physical and mental health promotion strategies to provide consistent health information that promotes wellbeing. Frontline professionals and adults with a duty of care and who influence young people (e.g. parents, school counsellors, teachers and youth workers) are trained to recognise and respond appropriately to eating disorders.

- **Systems support integration, collaboration and ongoing development**

Policy and systems support collaboration between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and community services and between professional disciplines. Ongoing processes of review and shared learning support the consistent implementation of evidence-based approaches. People with personal experience of eating disorders are involved at all levels of policy development, planning and systems development.

World Charter for Eating Disorders

In addition to the core principles of prevention and treatment, the World Charter for Eating Disorders is recognised as the international benchmark for the rights of those experiencing or impacted by an eating disorder. The World Charter promotes five key rights:

- Communication/partnership with health professionals
- Comprehensive assessment and treatment planning
- Accessible, high quality, fully funded specialised care
- Respectful, fully informed, age appropriate, safe levels of care
- Accessible, appropriate support education and resources for carers

A continuum of care

The essential service elements of a continuum of care that has the capacity to address both prevention and treatment, taking into consideration the high degree of variation in individual and family needs, are identified as:

Prevention

- Primary prevention strategies targeting:
 - The whole community (*universal*)
 - Groups known to be at higher risk (*selected*) or
 - Individuals at very high risk who may be showing early signs of mental ill health (*indicated*)
- Secondary prevention strategies to lower the severity and duration of an illness through *early intervention*, including early detection and early treatment
- Tertiary prevention intervention strategies to reduce the impact of mental ill-health on a person's life, through approaches such as rehabilitation and relapse prevention

Treatment

- Primary health care
- Community-based clinical outpatient treatment
- Intensive outpatient treatment
- Day programs
- Residential programs
- Inpatient treatment
- Recovery-oriented, community-based support programs

Support Services:

- Continuum elements of relevance at all stages from prevention to recovery
- Education and support for families and carers
- Non-clinical counselling
- Peer support
- Information and referral support

Appendix 4

Gap Analysis Consultation Questions: Individual Clinicians

The National Eating Disorders Collaboration (NEDC) brings together experts in the eating disorder field, a range of health care and research areas and people with a lived experience of an eating disorder to form a nationally consistent, evidence-based 'voice'.

One of the key activities of the NEDC this year is a 'Gap Analysis'. This report will profile current services, practice approaches and information available and identify any priority gaps or opportunities for further development of the eating disorder sector in Australia.

We would like to invite you to complete this brief survey to assist us in identifying what is available to support clinicians in professionally responding to eating disorders and related issues of health and wellbeing. The information you provide will help inform the federal government and eating disorder services' approach to professional development and support to prepare clinicians and other health professionals to address these issues with their clients.

Your responses will not be individually identifiable. The information acquired from the surveys will be kept confidential and only the principal researchers working on the survey will have direct access to them.

If you would prefer to complete the survey online or would like further information about eating disorders, please go to the NEDC website: www.nedc.com.au.

1. What is your professional role (tick all that apply)?

- | | | |
|--|---|---|
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> General Practitioner |
| <input type="checkbox"/> Paediatrician | <input type="checkbox"/> Nurse | <input type="checkbox"/> Dietician |
| <input type="checkbox"/> Physiotherapist | <input type="checkbox"/> Social Worker, | <input type="checkbox"/> Dentist |
| <input type="checkbox"/> Other (please give details) _____ | | |

2. How long have you worked in this role?

- 0-2 years 2 –5 years 5 – 15 years over 15 years.

3. Which state or territory do you reside in?

- | | | | | |
|--|--|-----------------------------------|-------------------------------------|---|
| <input type="checkbox"/> NSW | <input type="checkbox"/> Victoria | <input type="checkbox"/> ACT | <input type="checkbox"/> Queensland | <input type="checkbox"/> Northern Territory |
| <input type="checkbox"/> South Australia | <input type="checkbox"/> Western Australia | <input type="checkbox"/> Tasmania | | |
| <input type="checkbox"/> Outside Australia _____ | | | | |

4. How important is it for you to address healthy eating, body image and eating disorders in your practice?

- | | | |
|---|---|---|
| <input type="checkbox"/> very important | <input type="checkbox"/> somewhat important | <input type="checkbox"/> somewhat unimportant |
| <input type="checkbox"/> very unimportant | <input type="checkbox"/> unsure. | |

5. Do you think current practice in your profession has an adequate focus on early intervention for eating disorders?

- Yes it is adequate
 Yes, but could be improved
 No it does not address healthy eating or body image.

Give details; _____

6. What do you believe might place a client/patient at risk of an eating disorder?

7. Do you routinely screen clients/patients for eating disorders?

- Yes No Not applicable

Give details; _____

8. Do you use or are you aware of any prevention information or resources that would be suitable for your patients/clients?

- Yes No Not applicable / Unsure

Give details (If yes, what are you using? If no/unsure, what resources would be helpful for your practice?); _____

9. Do you or your service provide any of the following:

Clinical services to people with eating disorders?

- Yes No Not applicable

Specialist eating disorders intervention?

- Yes No Not applicable

Practice guidelines for staff working with eating disorders?

- Yes No Not applicable

Health information resources relevant to eating disorders?

- Yes No Not applicable

Comments _____

10. When would you refer a client / patient to an eating disorder?

11. Where would you refer a client/patient who has or is at high risk of developing an eating disorder?

12. Are the referral services available to you adequate to meet your client/patients' needs?

- Yes No Not applicable

13. What sort of services would you prefer to be able to refer your clients/patients to?

14. Have you ever experienced difficulty in seeking services for a client/patient who has or is at risk of an eating disorder?

Yes No Not applicable

Give details; _____

15. Did you receive training in eating disorders as part of your mandatory training for professional qualification?

Yes No Not applicable

Give details; _____

16. Have you received any professional development or support in relation to eating disorder since qualifying (tick all that apply)?

internal supervision external supervision peer support networks
 in-house training external training other (give details)

17. What were the most useful aspects of training in preparing you to identify and address eating disorders?

18. Do you feel confident to treat people with eating disorders?

Yes No Not Applicable

19. What would help you feel better prepared to address eating disorders in your role?

22. For your profession, what do you think is the core knowledge or skills in assisting you to address clients with negative body image or eating disorders?

21. Have you experienced any barriers to attending professional development opportunities?

Yes No Not applicable

Give details; _____

Gap Analysis Consultation Questions: Service Provider Review

a) Introduction

The National Eating Disorders Collaboration (NEDC) brings together experts in the eating disorder field, a range of health care and research areas and people with a lived experience of an eating disorder to form a nationally consistent, evidence-based 'voice'.

One of the key activities of the NEDC this year is a 'Gap Analysis'. This report will profile current services, practice approaches and information available and identify any priority gaps or opportunities for further development of the eating disorder sector in Australia.

We would like to invite you to complete this brief questionnaire to assist us in identifying what is currently available to support people with eating disorders, and their carers, in Australia.

The closing date for this service review is 30 September 2012.

b) Survey: National Eating Disorders Collaboration - Service Provision Review

1. What is the name of your service?
2. What state is your service located in?
3. Which of the following best describes your organisation or service?
4. What are the contact details of your service?
5. Does your service provide clinical mental health programs?
6. Do you routinely screen clients/patients for eating disorders?
7. Does your service have policies or guidelines in assessing and/or treating patients with eating disorders? If yes, please give details.
8. Do you provide clinical services specifically for clients/patients with eating disorders?
9. What diagnosed eating disorders does your service provide treatment and/or support for (tick all that apply)?

- Anorexia Nervosa
- Bulimia Nervosa
- Binge Eating Disorder
- Eating Disorder Not Otherwise Specified (EDNOS)
- Other (please specify)

10. Does your service provide inpatient treatment for eating disorders?
- 10a. How many places/beds are available in your inpatient service?
- 10b. What population do you provide inpatient treatment services to?

	Male	Female	Any gender	Not provided
Children (under 14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (14 - 16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (16 - 18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young Adults (18 - 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adults (over 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10c. Does your service have specific criteria for inpatient admission? If yes, please give details.

10d. Does your service have exclusion criteria for inpatient treatment? If yes, please give details.

10e. What input does your service offer during inpatient treatment (tick all that apply)?

- | | |
|---|--|
| <input type="checkbox"/> Medical stabilization | <input type="checkbox"/> Case Management |
| <input type="checkbox"/> Medical monitoring | <input type="checkbox"/> Cognitive-Behavioural Therapy |
| <input type="checkbox"/> Nutritional Rehabilitation | <input type="checkbox"/> Family Therapy |
| <input type="checkbox"/> Nutritional counselling | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Psychiatric care | <input type="checkbox"/> Social Work Services |
| <input type="checkbox"/> Psychological services | <input type="checkbox"/> Group Therapy |
| <input type="checkbox"/> Psychosocial Interventions | <input type="checkbox"/> Creative Therapies e.g. Art therapy |
| <input type="checkbox"/> Other (please specify) | |

10f. In general, how long do clients/patients have to wait to be admitted to your inpatient service?

- There is no waiting period as we usually have vacancy in our service
- There is no waiting period as we do not maintain a waiting list
- Our waiting list is approximately 0 - 3 months long
- Our waiting list is approximately 3 - 6 months long
- Our waiting list is approximately 6 - 12 months long
- Our waiting list is over 1 year long
- Other (please specify)

11. Does your service provide outpatient treatment for eating disorders?

11a. How many places are available in your outpatient service?

11b. What population do you provide outpatient treatment services to?

	Male	Female	Any gender	Not provided
Children (under 14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (14 - 16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (16 - 18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young Adults (18 - 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adults (over 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11c. Does your service have specific criteria for outpatient program admission? If yes, please give details.

11d. Does your service have exclusion criteria for outpatient treatment? If yes, please give details.

11e. What input does your service offer during outpatient treatment (tick all that apply)?

- Nutritional Rehabilitation
- Nutritional counselling
- Psychiatric care
- Psychological services
- Psychosocial Interventions
- Case Management
- Other (please specify)
- Cognitive-Behavioural Therapy
- Family Therapy
- Occupational Therapy
- Social Work Services
- Group Therapy
- Creative Therapies e.g. Art therapy

11f. In general, how long do clients/patients have to wait to be admitted to your outpatient service?

- There is no waiting period as we usually have vacancy in our service
- There is no waiting period as we do not maintain a waiting list
- Our waiting list is approximately 0 - 3 months long
- Our waiting list is approximately 3 - 6 months long
- Our waiting list is approximately 6 - 12 months long
- Our waiting list is over 1 year long
- Other (please specify)

12. Does your service provide day program treatment for eating disorders?

12a. How many places are available in your day program?

12b. What population do you provide day program services to?

	Male	Female	Any gender	Not provided
Children (under 14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (14 - 16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (16 - 18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young Adults (18 - 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adults (over 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12c. Does your service have specific criteria for day program admission? If yes, please give details.

12d. Does your service have exclusion criteria for day programs? If yes, please give details.

12e. What input does your service offer during day program treatment (tick all that apply)?

- Nutritional Rehabilitation
- Nutritional counselling
- Psychological services
- Psychosocial Interventions
- Case Management
- Cognitive-Behavioural Therapy
- Other (please specify)
- Family Therapy
- Occupational Therapy
- Social Work Services
- Group Therapy
- Creative Therapies e.g. Art therapy
- Education

12f. In general, how long do clients/patients have to wait to be admitted to your day program?

- There is no waiting period as we usually have vacancy in our service
- There is no waiting period as we do not maintain a waiting list
- Our waiting list is approximately 0 - 3 months long
- Our waiting list is approximately 3 - 6 months long
- Our waiting list is approximately 6 - 12 months long
- Our waiting list is over 1 year long
- Other (please specify)

13. Does your service provide community-based treatment for eating disorders?

13a. How many clients (approximately) does your community-based treatment service see in a 12 month period?

13b. What population do you provide community-based treatment services to?

	Male	Female	Any gender	Not provided
Children (under 14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (14 - 16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adolescents (16 - 18)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young Adults (18 - 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adults (over 25)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13c. Does your service have specific criteria for inclusion in community-based treatment? If yes, please give details.

13d. Does your service have exclusion criteria for community-based treatment programs? If yes, please give details.

13e. What input does your service offer as a community-based treatment (tick all that apply)?

- Nutritional Rehabilitation
- Occupational Therapy
- Nutritional counselling
- Social Work Services
- Psychological services
- Group Therapy
- Psychosocial interventions
- Creative Therapies e.g. Art therapy
- Case Management
- Education
- Cognitive-Behavioural Therapy
- Carer support
- Family Therapy
- Other (please specify)

13f. In general, how long do clients/patients have to wait to access your community-based services?

- There is no waiting period as we usually have vacancy in our service
- There is no waiting period as we do not maintain a waiting list
- Our waiting list is approximately 0 - 3 months long
- Our waiting list is approximately 3 - 6 months long
- Our waiting list is approximately 6 - 12 months long
- Our waiting list is over 1 year long
- Other (please specify)

14. Does your service provide any of the following to clients/patients with eating disorders (tick all that apply)?

Accident and emergency treatment

Group support programs

Carer support programs

Rehabilitation services

Other medical services

Other psychological services

None

Please provide details of these services _____

15. Does your service provide patients with eating disorders with information sheets or other resources? If yes, please give details.

16. Does your service provide carers/parents of patients with eating disorders with information sheets or other resources? If yes, please give details.

17. Do patients and/or carers have any opportunity to provide feedback on care in your service? If yes, what?

18. Do you have any further comments regarding the provision of services for patients with eating disorders?

C) Conclusion

Thank you for completing this questionnaire and participating in the NEDC service provision review.

If you would like further information on the work of the NEDC, please visit: www.nedc.com.au.