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An Integrated Response to Complexity National Eating Disorders Framework 2012

National Eating Disorders Collaboration



The National Eating Disorders Collaboration is funded by the Commonwealth Department of Health and Ageing March 2012

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Foreword

Eating disorders are serious mental illnesses that cause significant physical impairment. They are far more prevalent than many are aware, and they are too often fatal. As with all mental illnesses, the need for early identification and early intervention is paramount.

The urgent need to address the prevention and management of eating disorders must be included in the broader need for national mental health reform. Mental health concerns must be addressed as an integral component of Australia's health program, particularly within the envelope of Australia's innovative youth mental health reform agenda. Both incremental and radical changes are required to adequately address eating disorders and integration within stigma free 21st century models of primary and specialist youth mental health reform is a crucial next step.

The formation and work of the National Eating Disorders Collaboration has enabled the eating disorders sector to be included in this agenda. The next step is redesign and new investment to ensure that integration within innovative service frameworks actually occurs.

The National Eating Disorders Collaboration is an initiative funded by the Department of Health and Ageing to bring together those with expertise and interest in the prevention and management of eating disorders to develop a nationally consistent evidence based approach for Australia. With over 320 members, the NEDC draws from a broad base in collaboratively developing this approach.

Our vision for the prevention and management of eating disorders is:

- 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 of an eating disorder has access to an effective continuum of eating disorders prevention, care and ongoing recovery support.

An Integrated Response to Complexity: National Eating Disorders Framework 2012 is the first national schema for eating disorders in Australia. Drawing on the evidence basis for these illnesses, it details the core principles for an integrated approach with a person centred, recovery focus. In addition to 7 principles for the prevention and management of eating disorders, there are 4 principles for implementation of the approach. These principles are aligned to the Mental Health Standards. Implementation of these principles for eating disorders will contribute to achievement of the mental health standards.

Its counterpart, *Clarity in Complexity: Strategic Communication to Support the Prevention and Early Identification of Eating Disorders* provides the evidence based approach for communicating about eating disorders, engagement in prevention programs and encouragement of help seeking. The reports have been subjected to intensive scrutiny and review. They represent the collective view of those from across Australia who live with and fight eating disorders. As such, they represent a unique collaborative view.

I therefore strongly commend these reports to anyone who is seeking not only to increase their understanding of eating disorders, but how to address their prevention and management at a practical and effective level.

I would like to take this opportunity of thanking all those who have contributed to this framework including our Steering Committee, staff and members of the collaboration. Their ongoing input, feedback, enthusiasm and support have been essential ingredients for this project.

Professor Pat McGorry AO Chair National Eating Disorders Collaboration

Acknowledgements

The development of this National Framework has been a collaborative effort involving many people from diverse sectors and organisations across Australia. The National Eating Disorders Collaboration (NEDC) gratefully acknowledges the time, effort and passion that people have brought to this process.

An iterative process of repeated cycles of evidence review, data collection, and review by the members and stakeholders of the NEDC has led to the development of a National Framework that as far as is possible reflects a consensus view of the principles on which effective prevention and management of eating disorders may be founded.

Particular thanks must go to the members of the Steering Committee who have made an extraordinary contribution through their leadership of the NEDC.

National Eating Disorders Collaboration Steering Committee

Prof Pat McGorry AO, Chair

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Summary

Eating disorders are serious mental illnesses resulting in significant physical complications and impairment together with an increased risk of mortality.

The rate of eating disorders in the Australian population is increasing¹. Eating disorders are estimated to affect approximately 9% of the total population (males and females of all ages)². In Australia, with a current population of 22,823,615, more than two million people are experiencing a form of eating disorder. For women, the risk is even higher with an estimated 15% of Australian women experiencing an eating disorder requiring clinical intervention during their lifetime³. 1 in 4 individuals know someone who has an eating disorder.

These are conservative estimates. At least two studies have indicated that only about one tenth of the cases of bulimia in the community are detected. The true incidence has been estimated to be as high as 1 in 5 amongst students and women in Australia. Prevalence in specific populations is even higher. Adolescents with diabetes, for example, may have a 2.4-fold higher risk of developing an eating disorder⁴.

Eating disorders occur in both males and females; in children, adolescents, adults and older adults; across all socio-economic groups; and from all cultural backgrounds. They are commonly perceived as being a disorder affecting adolescent girls but this belief masks the fact that they have a significant impact on boys and men⁵ and are increasing in both younger⁶ and older⁷ age groups.

Studies are showing an increase in the prevalence for risk behaviours for eating disorders in both women and men in Australia⁸. Research shows that it is possible to reduce the risk factors for eating disorders and enhance protective factors⁹. There is also evidence that full recovery from an eating disorder is possible¹⁰.

Early identification and prompt intervention, based on appropriate, multi disciplinary approaches, are required to reduce the severity, duration and impact of the illness. The best outcomes are achieved by people who receive person centred treatment early in illness and early in episode¹¹. This has been described as the 'ideal standard of care"¹².

⁵ Hudson et al, 2007; Weltzin et al, 2005

¹ Hay, Mond, Buttner & Darby, 2008

² Weltzin et al, 2005

³ Wade et al., 2006

⁴ Pereira & Alvarenga, 2007

⁶ Nicholls, Lynn & Viner, 2011

⁷ Fursland et al, 2010; Mclean et al, 2009

⁸ Hay et al., 2008

⁹ Fingeret et al, 2006

¹⁰ Bardone-Cone et al, 2010

¹¹ NICE, Clinical Guidelines 9, 2004

¹² AED, 2011

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The only safe way to respond to eating disorders is to address all of the aspects of the illness, including both physical and mental illness, and the environmental context in which the illness occurs¹³.

People with eating disorders require specific interventions designed to address the complexity of eating disorders, delivered by health professionals with an appropriate level of skill and knowledge of the disorders. Where the eating disorder co-occurs with another disorder, it is essential that the eating disorder is specifically addressed with the treatment for both disorders implemented collaboratively.

An Integrated Response

Eating disorders present challenges to the traditional organisation of prevention and treatment but these are challenges that can be addressed through the implementation of the national standards for prevention, early intervention and treatment presented in this national framework.

For effective treatment, integration and collaboration is required between:

- Physical and mental health services
- Public and private health services
- Professional disciplines
- Treatment approaches for comorbid conditions
- Families and clinicians as essential members of the treatment team

For effective prevention and early identification, integration and collaboration is required between the eating disorders sector and:

- Education, physical activity instruction, community services and frontline health professionals.
- Health promotion initiatives addressing weight and appearance related issues
- Professional training institutions

An Eating Disorders Continuum of Care

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 with variable frequency of access, with 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

¹³ AED, 2011; NICE, Clinical Guidelines 9, 2004

- 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 co-morbidity

Essential Practice Principles

The following practice principles are described in the National Framework for Eating Disorders, 2012.

- **Person and family centred care that addresses the needs of individuals** tailored to meet individual and family needs as they develop over the course of the illness; and
- **Prioritization of prevention, early identification and early intervention** to reduce the severity, duration and impact of the illness. People have access to 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; and
- Safety and flexibility in treatment options addressing all of the aspects of illness: physical, behavioural and psychological. Flexible and appropriately supported entry, exit and transition between services supports individually tailored care planning; and
- **Partnering to deliver multi disciplinary treatment in a continuum of care** Treatment is provided by a multi disciplinary team, working in partnership with the person, their family and other health and support providers, to implement individual care plans; and
 - Equity of access and entry ensure that 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; and
 - **Tertiary consultation is accessible at all levels of treatment** from early intervention to recovery support for consultation, supervision, guidance, training and referral if required; and
 - **Support for families and carers as integral members of the team** enable them to support the person with an eating disorder and to maintain personal good health.

Implementation Principles

To implement each of the practice principles, action will be required in four domains:

• Evidence informed and evidence-generating approaches are integral to the design and delivery of health promotion, prevention, early intervention, and treatment approaches for eating disorders, combining research evidence with expertise from people with personal experience of eating disorders; and

- A skilled workforce in which all health and frontline 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; and
- **Communication to ensure an informed and responsive community** that is aware of eating disorders as serious mental and physical illnesses. Eating disorder prevention integrates with wider physical and mental health promotion strategies to provide consistent health information that promotes wellbeing; and
- Systems support integration, collaboration and on-going development between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and community services and between professional disciplines. People with personal experience of eating disorders are involved at all levels of policy development, planning, and systems development.

This National Framework provides a detailed description of the continuum of care and each principle. Implemented together, these standards have the potential to guide the development of an effective national approach to the prevention and management of eating disorders. The standards align with the National Mental Health Standards (2001).

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Introduction

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The National Eating Disorders Collaboration

The National Eating Disorder 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 help develop a nationally consistent approach to the prevention and management of Eating Disorders.

The specifications for project include the following objectives:

- Provide or facilitate access to helpful, evidence based information to 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 Disorders prevention, care and ongoing recovery support.

Purpose and Scope of the National Eating Disorders Framework

The effective prevention and treatment of eating disorders require a 'whole of community' and 'whole of Government' approach.

The purpose of the National Eating Disorders Framework is to provide guidance that will assist decision making about the development and delivery of eating disorders services including prevention, treatment and support that will be nationally consistent and achieve or contribute to evidence based standards.

The National Framework promotes shared understanding of the issues in eating disorders prevention and treatment and integrated, systematic solutions to these issues. Shared understanding is an essential foundation for effective collaboration, both within the eating disorders sector and between the eating disorders sector and other sectors to facilitate the development of a nationally consistent response to eating disorders in Australia. In developing this framework, 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.

The immediate objective for the National Eating Disorders Collaboration is the adoption of the consistent national standards, represented in the National Framework, by all governments in Australia as the necessary foundation to reduce the incidence and impact of eating disorders in Australia.

The National Framework is the key document and cohesive source of support for a suite of proposed NEDC publications and resources:

- Communications Strategy Report (publication 2011)
- Prevention and Early Intervention Report (publication 2012)
- Gap Analysis Report (publication 2012)
- Professional development resources
- Website and online clearinghouse (launch 2012)

These publications will consider specific issues in greater depth than can be represented in the National Framework.

The National Framework is intended to establish broad standards applicable in a variety of contexts while subsequent publications will elaborate on these standards.



Eating Disorders in Context

Eating disorders are serious mental illnesses resulting in significant physical complications and impairment together with an increased risk of mortality (NEDC, 2010).

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, in early intervention and in 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 the course of illness. 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.

An illness with high risks

People with eating disorders can become seriously physically unwell and many will require access to hospital treatment. Common reasons for hospitalisation include medical complications such as cardiac abnormalities, electrolyte disturbance, bradycardia, hypotension, and suicidal behaviour. New South Wales data have suggested that 11% are admitted with a life-threatening complication, up to 61% if child inpatients are considered only (NEDC, 2010).

The medical and physical consequences of eating disorders include gastrointestinal disorders, menstrual and fertility problems, high blood pressure, kidney failure, osteoporosis and Type II diabetes. Children and adolescents with anorexia nervosa can experience additional physical consequences, such as arrested growth and development, and even after resolution of the eating disorder will, as adults, experience significantly higher levels of anxiety disorders, cardiovascular disease, chronic fatigue, depressive disorders, neurological symptoms, and suicide attempts (NEDC, 2010).

Eating disorders have an overall mortality rate of up to 20%. This increased risk of premature death exists for all types of eating disorders (Arcelus, Mitchell, Wales, & Nielsen, 2011).

The risk of premature death for women with anorexia nervosa is well documented, with estimates of risk at 6-12 times higher (AED, 2011) than the general population and "much higher" than other psychiatric disorders (Arcelus, et al., 2011). For females with anorexia nervosa and diabetes, there is a

15.7-fold increase in mortality rates when compared with females with diabetes alone (Pereira & Alvarenga, 2007).

The risk of premature death relates in part to medical complications associated with the disorder; however suicide has also been identified as a major cause of death (Pompili, Girardi, Tatarelli, Ruberto, & Tatarelli, 2006). Arcelus and colleagues (2011) found that 1 in 5 individuals with anorexia nervosa who died prematurely had completed suicide. Research data on suicide in bulimia nervosa and EDNOS is scarce but suicide attempts, which are a risk factor for completed suicide, are readily identified in people with bulimia nervosa, and people experiencing obesity with mental health issues (Pompili, et al., 2006).

People with eating disorders experience higher rates of other mental disorders with reports of up to 97% of people with eating disorders having a comorbid condition. Mood and anxiety disorders occur commonly in people with all types of eating disorders. People with anorexia nervosa also experience higher rates of obsessive compulsive disorders (Blinder, et al., 2006). The use of pharmacological methods of weight control (e.g. laxatives, diet pills, diuretics) is associated with an increased risk of abuse of substances such as stimulants (Corte & Stein, 2000). People with comorbid bulimia nervosa and substance abuse are at increased risk of attempted suicide (Fisher & Grange, 2007).

Comorbid conditions increase the severity and chronicity of the eating disorder (Blinder, et al., 2006).

The consequences of an eating disorder are not limited to acute episodes of illness but may also be long term. The prospects for recovery for a young person with anorexia nervosa have been described as "often poor". Steinhausen (in Arcelus, et al., 2011) found that only 46% of patients fully recovered from anorexia nervosa while 20% remained chronically ill for the long term. Research into Binge Eating Disorder has identified that this disorder is more common than anorexia nervosa or bulimia nervosa and is at least as chronic and stable as these disorders (Hudson, Hiripi, Pope, & Kessler, 2007).

For the individual, the impact may include psychiatric and behavioural effects, medical complications, social isolation and disability. Eating disorders impose significant developmental constraints on adolescents in both physical and psychosocial domains, with anorexia nervosa rendering the most severe liabilities (Loeb & Le Grange, 2009). 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).

For families, the impact may include caregiver stress, loss of family income, disruption to family relationships and a high suicide risk (NEDC, 2010).

The cost of care 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).

A sense of urgency

The rate of eating disorders in the Australian population is increasing (Hay, Mond, Buttner, & Darby, 2008). Eating disorders are estimated to affect approximately 9% of the total population (males and females of all ages) (Weltzin, et al., 2005). It is estimated that approximately 15% of Australian women experience an eating disorder requiring clinical intervention during their lifetime (Wade, Bergin, Tiggemann, Bulik, & Fairburn, 2006). For young females, eating disorders represent the third most common chronic illness (Yeo & Hughes, 2011) and the second leading cause of mental disorder disability (Mathews, Hall, Vos, Patton, & Degenhardt, 2011). Prevalence in specific populations may be higher. Adolescents with diabetes, for example, may have a 2.4-fold higher risk of developing an eating disorder (Pereira & Alvarenga, 2007).

A study measuring the changes in community prevalence of eating disorder behaviours in South Australia over a ten year period found a two-fold increase in current regular use of three significant eating disorder behaviours in both women and men - binge eating, purging, and strict dieting or fasting (Hay, et al., 2008).

Eating disorders occur in both males and females; in children, adolescents, adults and older adults; across all socio-economic groups; and from all cultural backgrounds. They are commonly perceived as being a disorder affecting adolescent girls but this belief masks the fact that they have a significant impact on boys and men. Studies have shown that males may make up approximately 25% of people with anorexia nervosa or bulimia nervosa and 40% of people with binge eating disorder (Hudson, et al., 2007; Weltzin, et al., 2005).

Eating disorders are also increasingly being diagnosed in older women, with incidence and severity similar to that in female adolescents and young adults (Fursland, Allen, Watson, & Byrne, 2010; Mclean, Paxton, & Wertheim, 2010) and in younger children (Nicholls, Lynn, & Viner, 2011). Specific groups in the community may be at increased risk, including people with diabetes (Pereira & Alvarenga, 2007), people who are obese (Darby, et al., 2009), migrants (Bhurga & Jones, 2001), and people who participate in competitive sports and fitness activities (Weltzin, et al., 2005).

Research shows that prevention of eating disorders- specifically, reducing risk and enhancing protective factors - is possible and achievable. Two independent meta-analysis studies have found prevention initiatives to be effective in influencing eating disorder related knowledge, attitudes and behaviours. Small net effects have been identified across a range of different prevention strategies (Fingeret, Warren, Cepeda-Benito, & Greaves, 2006). These effects may be increased and become more sustainable when prevention is delivered in a context of environmental and social support and early access to treatment where required.

Integrated Responses to Complexity

Research provides evidence that full recovery from an eating disorder is possible, including the development of normal attitudes toward food and the body (Bardone-Cone, et al., 2010). The best outcomes are achieved by people who receive person centred treatment early in illness and early in episode (NICE, Clinical Guidelines 9, 2004).

Eating disorders are not self-limiting illnesses and early identification and prompt intervention, based on appropriate, multi disciplinary approaches, are required to reduce the severity, duration and impact of the illness. This has been described as the 'ideal standard of care" (AED, 2011). For early intervention to occur strategies are required to enable people to recognise when an illness is developing, access and engage with treatment and support, at the earliest point in illness or episode and whenever needed for the duration of the illness.

The only safe way to respond to eating disorders is to address all of the aspects of the illness and the environmental context in which the illness occurs. Prevention and treatment of eating disorders require integration of treatment from multiple disciplines addressing both physical and psychological health (AED, 2011; NICE, Clinical Guidelines 9, 2004).

People with eating disorders require specific interventions designed to address the complexity of eating disorders, delivered by health professionals with an appropriate level of skill and knowledge of the disorders. Many people with eating disorders receive treatment for comorbid conditions without receiving treatment for their eating disorder (Hudson, et al., 2007). It is essential that eating disorders are specifically addressed. Where the eating disorder co-occurs with another disorder, the treatment for both disorders should be implemented collaboratively.

For effective treatment, integration and collaboration is required between:

- Physical and mental health services
- Public and private health services
- Professional disciplines
- Treatment approaches for comorbid conditions
- Families and clinicians as essential members of the treatment team

For effective prevention and early identification, integration and collaboration is required between the eating disorders sector and:

- Education, physical activity instruction, community services and frontline health professionals.
- Health promotion initiatives addressing weight and appearance related issues
- Professional training institutions

An essential foundation for this level of integration will be the provision of basic professional training for health service providers, developing a consistent baseline of knowledge and skill in identification, diagnosis, early intervention, and case coordination to support the implementation of a nationally consistent approach to eating disorders. Equally essential, communication will be required to support shared understanding and collaboration which promotes awareness of eating disorders and awareness of the resources to support a nationally consistent approach: professional development, prevention programs, tertiary consultation pathways, information and professional networks.

Eating disorders present challenges to the traditional organisation of prevention and treatment but these are challenges that can be addressed through the implementation of the national standards for prevention, early intervention and treatment presented in this national framework.

Introduction to the National Standards Schema

This National Standards Schema details the integrated approach to eating disorders that is necessary to ensure everyone who has, or is at risk of developing an eating disorder, and those who care for them, has access to a network of skilled practitioners, evidence based treatment and support at all stages of prevention, illness and recovery.

A schema is a plan or outline that identifies the essential factors required to achieve an objective. The National Standards Schema for Eating Disorders is made up of a summary of the essential principles for service delivery for the prevention and management of eating disorders and a continuum of care outlining the essential levels of intervention required to provide a complete and integrated approach.

The prevention and treatment of eating disorders requires a clearly identifiable continuum of care which includes flexible care options to meet the physical and mental health needs of people presenting with varying levels of risk, severity, complexity and acuity.

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 with variable frequency of access, with 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 co-morbidity

These principles and continuum of care are discussed in detail in the National Framework which follows the schema.

Objectives

Early access to treatment and support reduces the severity, duration and impact of the eating disorders. The objectives of the national standards schema are:

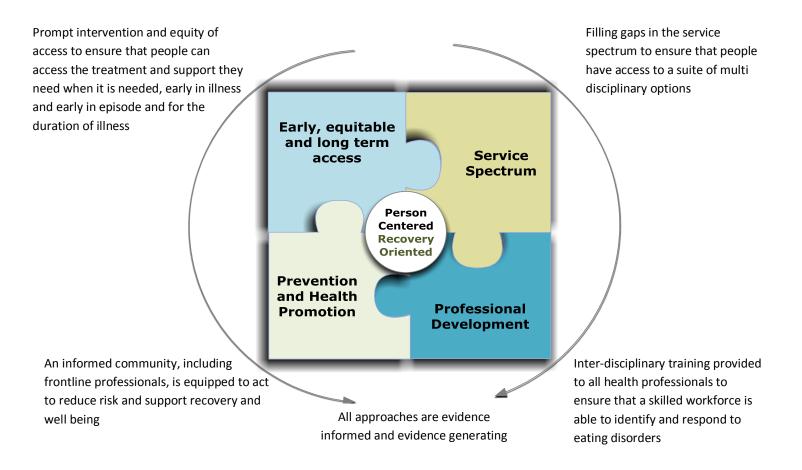
To ensure that everyone has access to information, support and prevention when required.

To ensure people with eating disorders actively seek and engage with the right treatment and support which meets their individual needs at the earliest possible point from the onset of illness or the onset of an episode of illness.

There are four key areas that must be addressed to meet this objective:

- 1. Early and equitable access to prevention and treatment options
- 2. Ensuring the service spectrum includes all the components of the continuum of care
- 3. Ensuring an informed community that will support early identification and intervention
- 4. Providing a skilled workforce

The principles and action domains outlined below need to be addressed in each of these four key areas.



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 to 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-focussed approach, supporting long-term recovery, tailored to meet individual decision making capacity and needs as they develop over the course of the illness; and

• Prioritization 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; and

• 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; and

• Partnering to deliver multi disciplinary treatment in a continuum of care

Treatment is provided by a multi disciplinary team who work in partnership with the person,

their family and other health and support providers, including treatment of co-morbid issues. The multi disciplinary 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; and

• 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; and

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; and

• 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; and

• 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; and

• Systems support integration, collaboration and on-going 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. On-going 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 which 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*)
 - o 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

Illustrating the National Standards Schema

The diagram on the following page integrates the principles and continuum of care demonstrating the relationship between the principles and services elements.

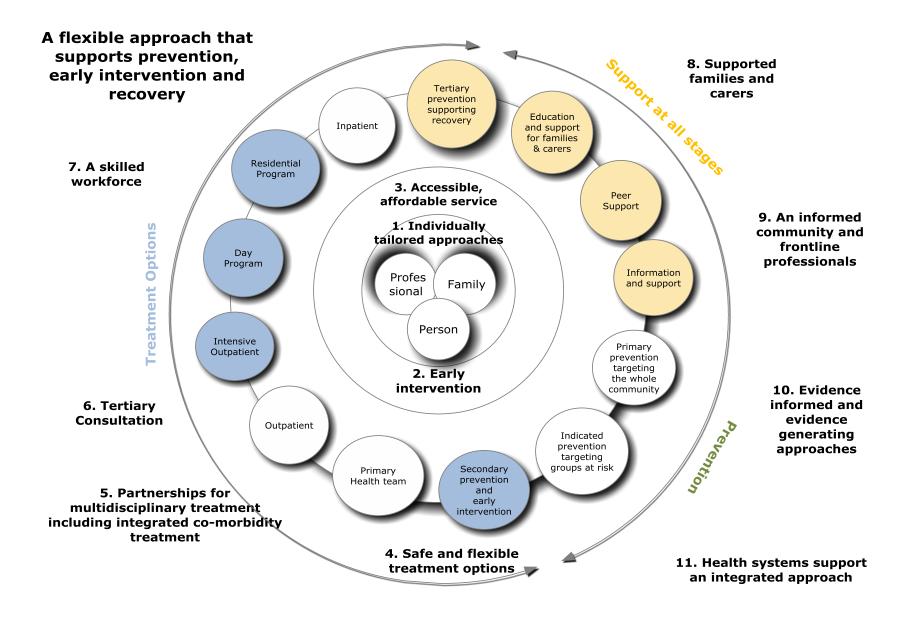
The diagram starts at the centre with a collaborative relationship between the person with, or at risk of developing, an eating disorder, their family or carers, and their primary health service provider or case worker. This is the point at which a person's immediate needs are identified and addressed. This could be at any point in the development of an eating disorder from recognition of risk factors, diagnosis of illness through to support for recovery. Depending on the person's needs and circumstances, services may be selected from any point in the suite of service elements.

The principle applied at this point is (1) individually tailored approaches that meet the needs of the person and their family. The principle of individually tailored approaches may also refer to approaches tailored to meet the needs of identified target groups for population health initiatives.

For simplifying the process of applying prevention interventions to a population, the following broad population groups can be used (soon to be released Promotion and Prevention Framework for NSW):

- 1. The whole community or groups in the community
- 2. Groups in the community known to be at higher risk of developing an eating disorder
- 3. Groups or individuals at high risk and / or who are showing early signs of an eating disorder
- 4. Individuals currently experiencing an episode of an eating disorder
- 5. Individuals recovering from an eating disorder.

The suite of service elements appears around the person and their family with no defined linear pathways between services emphasising the principle of flexible access to multi disciplinary options. This flexible approach requires clear transition protocols and a collaborative and coordinated approach to service provision.





National Framework March 2012

Principle: 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-focussed approach, supporting long-term recovery, tailored to meet individual decision making capacity and needs as they develop over the course of the illness.

The experience of an eating disorder is specific to the individual and their family and this must be reflected in treatment approaches. A person centred, recovery oriented approach for eating disorders is one which is a sustained, long term approach that attends to all of the dimensions of the illness: physical, psychological, behavioural, social and practical. This approach must be maintained both during treatment and in the recovery process.

Person Centred Approaches

It is imperative that all treatment approaches are tailored to meet the specific presentation of the illness in the person. That presentation will be influenced by the genetic makeup and personality of the person, their age and gender, their family and social constructs, and the culture in which they live.

It will also be shaped by the nature of the eating disorder itself – whether it is Anorexia Nervosa restricting; Anorexia Nervosa binging / purging; Bulimia Nervosa; Binge Eating Disorder or a variant of any of these disorders (EDNOS). Patients with a diagnosis of EDNOS eating disorder constitute the majority of patients seen at eating disorders facilities across Australia (Hay, et al., 2010). These disorders are considered to be as clinically severe as anorexia nervosa and bulimia nervosa.

The term 'person centred' encompasses respect for the individual person and a holistic perspective that is contextually congruent with the person in their environment, including the family environment (Law, Baptiste, & Mills, 1995). 'Person centred approaches' put the needs of the person at the core of all decision making about treatment and support. Eating disorders can affect a person's insight and capacity to make informed decisions for their own health safety. 'Person centred' in the context of eating disorders refers to treatment decisions which are made in the best interests of the individual, taking the whole person into consideration including their current decision making capacity.

For children and young people, a holistic approach must take into account the level of physical, social, emotional, and intellectual development of the child. Treatment provided in a group environment (e.g. inpatient) should take into consideration the child's need for healthy relationships with their age peers.

The active involvement of family is essential for the provision of age appropriate treatment.

Effective person centred treatment approaches for young people under 18 years of age recognise the importance of the role of the family and involve the family in treatment (NICE, 2004). These approaches must be family sensitive, ensuring that there is an appropriate partnership between the parents and health services providers to support the young person towards recovery. This is discussed in more detail in the context of the principles of safety and flexibility in treatment options (principle 1.3).

Person centred approaches for adults over 18 years of age can include appropriate family sensitive treatment options if that is in the best interest of the patient, and health service providers work collaboratively with the patient, their family and other health professionals (Lutz & Bowers, 2000).

Eating disorders present in all ethnic and cultural groups, and in Indigenous people, across males and females of all ages. The cultural and family context of the person is an

Person centred approaches require:

- Respectful, trusting relationships between treatment providers, people with eating disorders and their family or supporters
- Understanding of the whole person in the context of their culture, values, interests, environment and experiences
- 3. Flexible access to services and to health professionals
- 4. A partnership approach, sharing power and responsibility
- 5. Individually planned and coordinated treatment and support

(Law, et al., 1995)

important influence on the choice of treatment and support. Cultural influences in terms of food, eating behaviours, family structures and hierarchies, and ways of recognising and addressing stress are the context in which the person with an eating disorder must address and overcome their illness.

For adults, the recovery process starts when the person with the illness takes control of the illness and commits to actions and behaviours that will enable them to work with their clinical and support teams to distance themselves from the illness and then to manage it.

Consultation with people with personal experience of eating disorders (NEDC, 2011) identified a 'personal strengths' approach which recognises and works with the individual's strengths to support recovery as the preferred approach. Working with the person – their goals, their self knowledge and their strengths – to achieve a recovery that is meaningful to the person, rather than working with the treatment modality to achieve a standard outcome.

Recovery from Eating Disorders

Full recovery from eating disorders is possible (Bardone-Cone, et al., 2010). As such, recovery should always be the goal of treatment, defined in ways that are meaningful to both the person and their treatment team. Recovery is a process that may take an extended period of time, both during and after participation in treatment.

In the context of eating disorders, recovery is understood as both clinical and personal. Clinical recovery comprises restoration of physical, behavioural and psychological health. Bardone-Cone and colleagues (2010) proposed a definition of recovery which takes into consideration both physical and psychological aspects of eating disorders and is applicable to all eating disorders:

Personal recovery is a process of changing attitudes, values, thoughts, feelings, goals, skills and/or roles (National Mental Health Policy, 2008). Personal recovery encompasses a range of factors that influence quality of life, including internal personal conditions and external conditions that facilitate recovery (Jacobson & Greenley, 2001). These may include:

- Finding and nurturing hope; a sense of meaning and overall purpose
- Appropriate access to the practical necessities of life such as housing and income
- Supportive relationships; interpersonal acceptance and a sense of social belonging
- Empowerment and self-determination
- Development of personal coping strategies and behaviours (including self-management or selfhelp)

Criteria for Recovery

- Diagnosis no longer meeting diagnostic criteria
- 2. Behaviour no longer engaging in eating disorder behaviours
- Physical health weight within healthy BMI range
- Psychological positive attitudes to one's self, food, the body, expression of emotions and social interaction
- Practical quality of life including capacity for engagement in work or education, and leisure

(Bardone-Cone, et al., 2010)

From the perspective of people who have experienced an

eating disorder, research has identified five factors that are important manifestations of recovery: having self-acceptance, accepting one's body, having a relaxed attitude to food, having a functioning social life, and being in contact with and having the courage to express emotions (BjöRk & Ahlström, 2008).

Strengths Focused

A strengths approach works with the individual to identify and articulate their own strengths, those factors within them which will enable them to overcome the eating disorder. A person with an eating disorder often has a very low self esteem and can struggle to recognise personal strengths. Sacker (2007) describes eating disorders as masking the true identity of the person. Working with the patient to identify their personality, separate from but alongside treatment of their eating behaviours, is essential.

Recovery, for people with eating disorders has a unique characteristic when compared with other mental illnesses. When people who have had an eating disorder regard themselves as recovered, they no longer acknowledge eating disorders as a part of their identity (BjöRk & Ahlström, 2008).

The experience of an eating disorder distorts thinking, undermining the understanding that people have of themselves, disrupting personal relationships, and limiting the capacity for learning. During episodes of illness, the person tends to isolate themself, focusing on their eating behaviour to the exclusion of almost everything else (Sacker, 2007). Seemingly irrational fears or compulsions and a preoccupation with food dominate the person's life (BjöRk & Ahlström, 2008).

People with eating disorders describe an unrelenting internal dialogue that is the cause of much of the suffering associated with eating disorders.

NEDC members with personal experience of eating disorders, or experience as carers, describe the experience as:

"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."

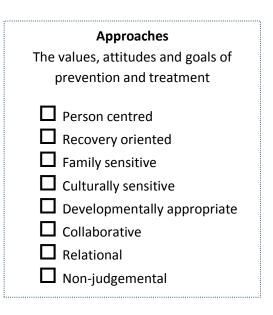
"Sufferers describe having a tyrant yelling abuse, threats and instructions in their head 24 hours a day. This tyrant began as a friend, helping protect the sufferer from a world that, for many reasons, is perceived as threatening." (NEDC, 2011)

It is this dialogue which must be addressed, in addition to eating disorder behaviours, in order to achieve full recovery, focusing on strengthening the individual's interests, values, hopes and aspirations. The presence of on-going eating disorder attitudes is of concern for the long term sustainability of recovery. Elevated anorexic attitudes and residual concerns about weight and shape, for example, are predictors for relapse (Bardone-Cone, et al., 2010).

Implementing National Standards

Person-centred and recovery oriented approaches are promoted and incorporated in policy as the best practice standard for all mental health services.

Ensuring that these approaches are implemented in the prevention and treatment of eating disorders will require adoption of the standard of individually tailored approaches for all service users with eating disorders. This will have implications for the range of services that are provided or networked together. Individually tailored approaches presume access to more than one treatment option and access to the full suite of disciplines identified as essential for the treatment of eating disorders. These implementation issues are discussed in principle 1.3 and 1.4.



Principle: 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 illness, early in help seeking and early in recurrent episodes of illness, with immediate access to treatment and support.

Eating disorders are severe illnesses that do not self-limit and prevention, early identification and prompt intervention are required to reduce the severity, duration and impact of the illness (Currin & Schmidt, 2005). This has been described as the 'ideal standard of care" (AED, 2011).

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).

Prevention and Health Promotion

Prevention interventions work by focusing on reducing risk factors and enhancing protective factors associated with mental ill health. The risk and protective factors for eating disorders occur within the context of everyday life – perinatal influences, family relationships, interpersonal relationships, the home environment, schools, workplaces, recreational and sport activities, media and social influences, the health of the individual and the health of the community. The complex interplay of biological, psychological, social, environmental, cultural, economic and political factors support the use of population health approaches to eating disorders prevention.

When a large population is exposed to a risk factor, preventing exposure to the risk factor can result in valuable reductions in the burden of associated disease (Commonwealth Department Health and Aged Care, 2000). Small net effects have been identified in eating disorder behaviours and attitudes across a range of different prevention strategies. Two independent meta-analysis studies, found prevention initiatives to be effective in influencing eating disorder related knowledge, attitudes and behaviours (Fingeret, et al., 2006). These effects may be increased and become more sustainable when prevention is delivered in a context of environmental and social support.

Primary prevention – Universal, Selective & Indicated	 Initiatives and strategies to prevent the onset or development of mental ill-health, which may be: Universal – target the whole community <i>e.g.</i> a media advertising program or curriculum for the whole school Selective – target groups known to be at higher risk <i>e.g.</i> a body image program for all girls in a grade 7 class; or Indicated* – target individuals at very high risk who may be showing early signs of mental ill-health <i>e.g.</i> grade 7 girls with high levels of body image concerns
Secondary prevention – Early Intervention	Initiatives and strategies to lower the severity and duration of an illness through <i>early intervention</i> , including early detection and early treatment. These interventions can occur at any stage of life, from childhood to older age. The distinguishing feature is that intervention occurs early in the pathway to mental ill-health. *There is considerable overlap between <i>indicated prevention</i> and <i>secondary prevention</i> . The difference relates to the degree of demonstratable risk
Tertiary prevention:	Interventions and strategies to reduce the impact of mental ill-health on a person's life through approaches such as rehabilitation and relapse prevention. It also includes actions to ensure people have access to supports within the community, such as housing, employment and social interactions.

Eating disorder prevention programs with the most favourable outcomes are those which focus on reducing modifiable risk factors for eating disorders (Jacobi, Hayward, de Zwaan, Kraemer, & Agras, 2004). Prevention approaches include targeting those most at risk of developing an eating disorder, including school aged children and young adults, together with the people who can positively influence them including families, educators, youth services, fitness and sports instructors and the media.

To develop an environment in which it is possible to effectively act to reduce the risk factors for eating disorders, prevent their onset and intervene with early treatment where prevention is not possible, there is a need to build the capacity of families and frontline professionals to enable them to understand eating disorders as being serious mental illnesses, the potential for them to affect anyone, the early indicators of risk, and the actions they can take in response.

Effective prevention approaches need to be assertively disseminated over an extended time period to schools, service providers and community groups, accompanied by appropriate training and support in order to maximise reach and effectiveness.

Prevention/Early Intervention
Actions to promote mental health and wellbeing; actions to prevent the
onset of eating disorders
School or community based programs for groups
 Self-directed programs for individuals under supervision of health professional
• Media literacy e.g. <i>Media smart</i> Cognitive-behavioural therapy e.g. <i>Student Bodies</i>
Cognitive Dissonance e.g. Stice's version
 Self-esteem enhancement e.g. Everybody's Different
Mental health literacy e.g. First Aid for Eating Disorders
Multicomponent e.g. Food, Mood and Attitude
One Shot e.g. Stice's Healthy Weight Intervention
• Psychoeducation e.g. The Student Body: Promoting Health at Any Size

Early Identification and Intervention

Early intervention comprises interventions that are appropriate for, and specifically target, people displaying the early signs and symptoms of mental ill-health. By definition, early intervention is a form of prevention activity and overlaps both primary and secondary prevention. Interventions can be:

- 1. Prevention focussed targeting individuals beginning to show the early signs and symptoms of a problem (*indicated primary prevention*); and
- 2. Treatment focussed targeting individuals experiencing a first episode of mental illness (*secondary prevention*). Treatment focussed early intervention requires an intensive, multi disciplinary treatment approach supported by expertise in eating disorders treatment.

There are significant barriers to early identification and intervention and these must be recognised and strategies developed to address and overcome them.

- Ambivalence and denial of illness by the person concerned (and their family) which can be a characteristic of eating disorders
- Hidden nature of eating disorder behaviours, often masked by the socially accepted desire to be thin and misconceptions about healthy eating and exercise
- Social stigma associated with mental illness in general and with eating disorders in particular
- Lack of awareness or understanding of eating disorders, including:
 - Lack of awareness of warning signs
 - o Lack of awareness of the achievability of recovery and the effectiveness of treatments
 - o Lack of awareness of the range of people who may be affected by an eating disorder
 - o Lack of awareness of types of and entry points for eating disorder specific treatment

- Lack of understanding about how to provide support to someone developing an eating disorder and how to effectively facilitate engagement with appropriate mental health and health services
- Lack of coordinated primary prevention approaches for eating disorders
- Lack of knowledge about, and availability of, early intervention programs
- Systemic barriers such as the need to meet diagnostic criteria before referral to eating disorders treatment and the high cost of receiving services from multiple service providers over a long time period

A key problem for effective early intervention in eating disorders is identification. Since first investigated in the 1980s, all studies, including 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).

While someone with a deeply entrenched eating disorder will exhibit behaviours that can clearly be recognised as belonging to the illness, for those who are in the early stages or who are actively seeking to hide the behaviours, it is not so easy to discern.

Most people in Western society are exposed to a culture of dieting, poor nutrition and unrealistic body ideals providing an environment conducive to the development of eating disorders, disordered eating and body dissatisfaction (Durkin, Paxton, & Wertheim, 2005). Dieting and body dissatisfaction are now so common, particularly in adolescence, that identifying people who have disordered eating or an eating disorder can be very challenging (Yeo & Hughes, 2011).

A favourable regard for weight loss, and poor eating disorder mental health literacy of both people living with an eating disorder and health care providers are important reasons for low identification and inappropriate or low help seeking (Mond & Hay, 2008; Hay, Darby, & Mond, 2007).

Help seeking and Early Intervention

The ability to engage with appropriate help at an early stage in illness is widely regarded as a protective factor for mental health. People with eating disorders often do not seek help, or only seek help after a long period of illness (Kelly, Jorm, & Wright, 2007; NEDC, 2010). A national survey of eating disorders in the USA found that, despite the fact that the majority of people identified as having an eating disorder experienced severe symptoms that were disruptive to normal life, only 45% sought help from any form of health care provider (Hudson, et al., 2007). In Australia, it has been noted that there is typically a long delay between onset and time of first treatment, with some individuals spending months or years living with the illness before receiving a correct diagnosis (NEDC, 2010).

Analysis of the duration of treatment delay has identified a median of 10 years delay for those with bulimia nervosa and 15 years for those meeting criteria for anorexia nervosa (Oakley, Browne, Wells, & McGee, 2006, cited Hart, Jorm, Paxton, Kelly, & Kitchener, 2009). Hart and colleagues conclude that "if symptom severity, associated disability and economic burden are to be reduced, the very poor health service utilization of those experiencing eating disorder behaviours must be addressed" (Hart, et al., 2009).

Factors which inhibit help seeking for people with eating disorders include:

• Stigma associated with mental illness

Stigma is frequently raised as an issue that inhibits help seeking (Queensland Alliance, 2010) and reluctance to seek help has been identified as a general issue for people with various mental health problems. Young people, who are identified as a population with the greatest need for mental health interventions, are the least likely group to actually seek help. This situation is exacerbated for young people from Aboriginal, Torres Strait Islander or cultural and linguistic minority communities. Males of all ages are less likely to seek help than females (Rickwood, Deane, & Wilson, 2007).

• Stigma associated with eating disorders

People with eating disorders experience the stigma related to specific misconceptions or lack of awareness of eating disorders in the community. Stigma may be an external experience, in the form of teasing, bullying, criticism or exclusion from social groups all of which are identified as risk factors for the development of eating disorders. Stigma may also be an internal experience in which the person adopts the dominant ideas of their culture and these ideas combine with other personal risk factors for eating disorders, such as low self-esteem or perfectionism, to create a fear of rejection by others. Self-stigma has been identified as harmful to self identity. Eating disorders are often associated with feelings of shame (Newton & Chizawsky, 2006).

Mental health literacy

Knowledge of the signs of an eating disorder, where to seek help, what effective treatments are available and when it is best to seek them, are all aspects of mental health literacy that can facilitate help seeking. A lack of mental health literacy can contribute to low rates of help seeking.

• Denial of illness

A characteristic of eating disorders is that they are ego-syntonic (Newton & Chizawsky, 2006) which is often expressed as denial of illness or concealment of behaviours (Tury, Gulec, & Kohls, 2010; Vandereycken & Van Humbeeck, 2008). Hepworth and Paxton (2007, cited Hart, et al., 2009) identify the person's ability to recognise that their behaviour is a problem is an important precursor to help seeking. Vandereycken and Van Humbeeck (2008) found that people with eating disorders were aware of eating disorders as an illness but did not apply the concept to their own experience.

• Socio-economic factors

Other factors which reduce help seeking include rural location, lower education levels and lack of sufficient financial resources.

Raising awareness of eating disorders in people who have or are at risk of developing an eating disorder is important but may not be sufficient to improve patterns of help seeking or contribute to early intervention. Communication must also target people who are in influential roles, including family, partners, peer groups, health professionals and other frontline professionals who are positioned to act as gatekeepers.

First Point of Contact

When people do seek help it is often for other problems and from health care professionals outside the eating disorders field. The most common first points of contact are GPs and for younger people also school counsellors (Sim, et al., 2010).

One of the most common presentations in primary care is with weight concern and request for help to lose weight, no matter if the person is under, normal or over weight. This is of concern as the prevalence of people in Australia with both an eating and weight disorder is increasing (Darby et al., 2009). Another common presentation is for infertility treatment for both women and men (Ogg, Millar, Edit, Pusztai, & Thom, 1997).

For specific at-risk groups, specialist health services 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); for people seeking treatment for diabetes or obesity, an endocrinologist or a diabetes educator may be the first point of contact (Pereira & Alvarenga, 2007). 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 and access help through a dentist.

At first point of contact, people may frequently seek help for an emotional problem rather than directly identify that they have symptoms of eating disorder. Hudson and colleagues (2007) found that the majority of people who responded to their survey who had bulimia nervosa or binge eating disorder had received treatment at some point in their lives for emotional problems, although less than half of respondents had sought treatment for their eating disorder. For those who do seek help, it may be necessary to see several doctors before receiving a correct diagnosis and each delay is likely to further influence duration of the illness and outcomes of treatment (NEDC, 2010).

Training and supervision of generalist inpatient and outpatient mental health services in the assessment and treatment of people for eating disorders is an essential foundation for early intervention.

Timely Access to Services

National Framework March 2012

For early identification and intervention to occur strategies are required to enable people to access and engage with treatment and support, at the earliest point in illness or episode and whenever needed for the duration of the illness. Taking into consideration the barriers to early intervention noted above, it is imperative that early identification and intervention strategies address the key points in the development of both the disorder and help seeking:

- Early in development where behaviours are recognised as being risk factors for an eating disorder. Recognition and response to early signs and symptoms that are fewer than, or less intense than, those required for a diagnosis is a requirement for early intervention. For early access to treatment and support, there is a need to broaden the definition of eating disorders beyond the existing diagnostic criteria. Replacement of diagnostic criteria as the point of access to services with evidence based proximal risk factors is desirable to ensure that people receive treatment early in the development of the disorder.
- Early in help seeking where the person is identifying that they have an eating disorder and have made the decision to seek help. A prompt response and access to treatment early in help seeking may assist the person to engage with and pursue treatment. Given the reluctance to seek help experienced by most people with eating disorders, a request for help may be the only 'window of opportunity' to intervene early. There is evidence that people who are required to wait for treatment by being placed on a waiting list are more likely to drop out of treatment at a later stage (Byrne, Fursland, Allen, & Watson, 2011). People who seek help early should be validated with a prompt response.
- Early in subsequent presentation where the person has previously received treatment and has experienced relapse or recurrence. Recovery is a challenging experience in which relapse should be an anticipated occurrence. Prevention and early intervention are as important during relapse or recurrence as at other stages of illness, potentially reducing the risk of chronicity.

An NEDC *Evidence from Experience* focus group explored the issue of enabling people to engage with and access treatment and support at the earliest point in illness and whenever it is needed. The focus group identified four approaches that help a person take the step from being aware of an eating disorder, or a relapse after treatment, to taking appropriate action:

- Having someone to talk to informed and supportive people in first contact roles who are able to engage people in a non-judgemental, empathic way. Having someone to talk to who could listen, provide information and help the person navigate the treatment options was described as "the single thing that makes the biggest difference".
- 2. **Information** and referral tailored to meet individual needs at any given point, providing an opportunity to explore options and plan individually appropriate referral pathways. Credible information was described as information in everyday language, supported by research information that validates treatment approaches

- 3. **Opportunities to hear from people who have recovered** from an eating disorder. Speaking to someone who has recovered was identified as very helpful in motivating people to start or continue to engage with treatment.
- 4. **Soft entry points** recognisable (i.e. accredited or credentialed) agency in community settings, in which people with eating disorders at any stage in their illness and carers –personal and professional and families can feel comfortable making contact, asking questions and sharing their story

Implementing National Standards

Communication

Community education about eating disorder warning signs and improved community attitudes towards help seeking and treatment for eating disorders together with clearly identified 'soft entry' access points located in the community are required to overcome barriers to help seeking and facilitate early access to treatment and support. These issues are discussed in detail in the NEDC report *Clarity in Complexity: Strategic Communication to Support the Prevention and Early Intervention of Eating Disorders* (2011).

Equity of Access and Entry

Criteria for access to services should support early intervention. Treatment referral and health fund requirements must recognise early symptoms as sufficient criteria for access to early intervention and to more intensive treatment where required in order to reduce the impact and severity of the illness and the ongoing need for treatment. This issue is discussed in principle 1.5.

A skilled workforce

Both prevention and early intervention require a skilled frontline workforce with knowledge of eating disorders, and skill to recognise warning signs, screen and assess for risk, and implement appropriate evidence based prevention programs. The frontline workforce include 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 need for a skilled workforce is discussed in principle 2.2.

A continuum of care

Prevention and early intervention are essential components of the continuum of care. They interact and overlap with each other and with treatment and recovery support. Communication and prevention activities provide an environment in which early intervention is achievable.

Prevention and early intervention strategies will be discussed in detail in the NEDC report *Prevention and Early Intervention* to be published in 2012.

Principle: Safety and flexibility in treatment options

Safe treatment for eating disorders addresses all of the aspects of illness: physical, behavioural and psychological. People have to have 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.

Eating disorders are amongst the most difficult psychopathologies to treat and a mono-therapeutic "one size fits all" approach to treatment is unlikely to be safe or effective. The differences between disorders, the interaction with comorbid conditions and individual personality, environment and experience all contribute to the complexity of the disorders and therefore the complexity of treatment. There is a need to develop a suite of safe treatment options that can be delivered in a flexible approach with scope for individual choice. The provision of a range of treatment options is expected to increase both engagement with treatment and the effectiveness of treatment.

Eating disorders are not static illnesses; there is a dynamic interplay between physical, behavioural and psychological aspects of illness with the potential for illness to manifest in different ways at different times in the course of illness. If treatment is biased towards one aspect, such as distorted eating behaviours, then these behaviours may be improved but the eating disorder may manifest in alternative ways. Weight gain, loss or stabilization alone is not a cure for eating disorders.

Safe treatment for eating disorders therefore addresses all of the aspects of illness: physical, behavioural and psychological. It is unsafe to treat one dimension without the others. This has implications for the organisation of eating disorders services, with a need for the provision of collaborative care on an ongoing basis. All treatment options for children and young people should be family sensitive, supporting and working with the family as important members of the treatment and support team.

In part as a result of the complexity of eating disorders, evidence supporting the efficacy of treatments is limited (Fairburn, 2005). Safe treatment options should be evidence based, founded on the best available evidence from the established research evidence base and the consensus of expert opinion published in clinical practice guidelines. It should also take into consideration emerging promising practices from current treatment research and the lived experience.

Safe Treatment Options

Safe treatment is characterized by:

1. Evidence

Safe treatment is founded on the best available evidence from research, clinical consensus and lived experience. The selection of treatment options should take in to consideration:

- The date of publication of evidence, with preference given to the most recent research or review, and relevant current treatment research
- The characteristics of patients referred to in evidence and the relevance of the treatment modality for the group or individual person requiring treatment. Factors to be considered include:
 - patient age and developmental stage
 - o stage of illness
 - o treatment setting
 - o social and family context
 - o level of expertise required to deliver treatment

2. Multi disciplinary approaches

Safe treatment addresses all aspects of illness and is optimally delivered by a multi disciplinary team.

Risk Assessment

Patients must be screened for physical health risks and risk of suicide. Medical stabilization, where required, must be provided before or simultaneously with other interventions. Eating disorders can impair a person's insight and ability to make informed decisions. Decisions regarding treatment must always take into consideration the person's capacity to make decisions for their own safety.

• Physical Health Assessment and Treatment

General medical health care is essential with regular assessment of physical health risks. There is a need to actively promote normal physical growth in children and adolescents as a priority of care. Specialist interventions may be required by some patients to prevent or treat a wide range of physical health conditions including gastrointestinal disorders, malnutrition, osteoporosis, damage to teeth, infection, cardiac complications, kidney failure, menstrual problems and treatment of comorbid conditions such as diabetes. Physical assessment and treatment can also be useful in the identification and management of compulsive exercise and improvement of body awareness and body responsiveness.

Psychological: Mental Health Interventions

The best available evidence to date supports the use of psychotherapies for adults.

Anorexia Nervosa

Family based treatment (FBT) for adolescents with anorexia nervosa is currently the bestestablished treatment for adolescents with anorexia nervosa demonstrating efficacy (Smith & Cook-Cottone, 2011). On the basis of current evidence, FBT should be made available for adolescents with anorexia nervosa, in line with the recommendations of key eating disorder guidelines (American Psychiatric Association, 2006; NICE, 2004). (See Appendix 1 for further information on mental health interventions)

Specialist supportive clinical management (SSCM) provides an integrated, non-specialized therapy for anorexia nervosa which has demonstrated efficacy with adults in research trials (McIntosh, et al., 2006).

Grade C evidence (NICE, 2004) indicates that cognitive analytical therapy and focal psychodynamic therapy should be considered as treatment options for adults with anorexia nervosa. Promising results have been demonstrated in preliminary evidence on a number of other psychotherapies and emerging evidence should be taken into consideration when selecting psychotherapies.

Bulimia Nervosa and Binge Eating Disorder

Manual based cognitive behavioural therapy (CBT) has the most empirical support for the treatment of bulimia nervosa and binge eating disorder (Wilson, 2005). CBT-E, designed to treat all types of eating disorders, is showing promise as a trans-diagnostic treatment, however further research is required to compare CBT-E against other alternatives.

Interpersonal Psychotherapy (IPT) is recognized by the NICE guidelines (2004) as an appropriate treatment for adults with bulimia nervosa and binge eating

Nutritional Interventions

Dietary advice has been shown to improve outcomes for people with anorexia nervosa (RANZCP, 2011) and may enhance nutrition for people with bulimia nervosa and binge eating disorder. A nutritionally balanced intake may restore body weight within a healthy range, restore body composition and biochemistry and improve medical status (RANZCP, 2011). Nutritional interventions should include monitoring of food consumption, binge eating and purging behaviour, support for culturally appropriate eating behaviour, and education about the medical, physical and psychological consequences of bingeing or weight loss behaviours (Hart et al, 2009).

• Social: Family Education

Family and carers require education and support to enable them to support treatment and maintain their own health. In addition to this essential general level of family education and

support as an adjunct to treatment, skill based training for parents or carers has been effectively used as a primary treatment mode (Zucker, Marcus, & Bulik, 2006). Education for families should be integrated with other aspects of treatment.

• Other Interventions

Individuals may also require physical activity interventions, such as physiotherapy or exercise to assist in the management of mood and physical conditions such as osteoporosis, and occupational therapy or education support. Physiotherapists can collaborate with mental health professionals to assist individuals with assessment and management of compulsive exercise.

A Flexible Suite of Treatment Options

A continuum of services is required along a spectrum from low to high intensity including primary care, secondary and tertiary levels of care with increasing levels of support through outpatient (both general and specialized), day and residential programs and intensive inpatient care.

A person's progression through an eating disorder is not linear. There is no single consistent pathway that may be used to determine the level of intensity of treatment and support that all patients will require. Individual assessment of several dimensions of need is required to determine the level of intensity of treatment including:

- **Diagnosis**, stage of illness and stage of treatment including previous treatment experience
- Severity of psychological and medical illness including suicide risk, severity of symptoms (e.g., purging) and BMI
- **Motivation to change:** the ability of the person to actively engage with treatment and work towards recovery, albeit with the fears and ambivalence prevalent in this population
- Access to treatment and support: the person's ability to access treatment and support services within their community, taking into consideration the available range of services, location, cost and entry criteria
- **Range of multi disciplinary support**: The areas of life in which the person requires support and the number of professional disciplines required to address these needs (e.g. physical health, mental health, nutrition, social, occupational etc)
- Impact of co-morbidities: The extent to which other physical and mental illnesses (e.g. anxiety, Personality Disorders or diabetes) impact on the person's recovery and treatment needs
- **Transition issues**: The level of difficulty experienced in generalizing new behaviours in different settings (e.g., meal planning and preparation). The frequency and type of support required to sustain healthy behaviours, from occasional contact to daily or full time contact
- Level of family or community support: The level and appropriateness of support available from family and friends, including their availability to engage in treatment, and the appropriateness

of the home environment to support recovery, taking into consideration variations over time (e.g., carer stress, changed family circumstances or living arrangements)

To meet the differing individual levels of need for intensity of treatment, with the capacity to step down or step up intensity as required, there are five core components that must be included in the continuum of care:

- General outpatient support provided in both hospital and community settings with flexible access to a range of services delivered with variable frequency of access, with particular emphasis on relapse prevention / early intervention. As described here, outpatient services includes clinical outpatient services, community support and recovery oriented programs.
- 2. Intensive outpatient support for people living with their family or other support structures who require intensive clinical support
- 3. Day programs, providing a more structured program than outpatient treatment, including group therapy, psycho-education and behavioural support
- 4. 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
- 5. Inpatient services for medical intervention and stabilisation

All of these components are essential to provide access to effective care at each stage in the development of and recovery from an eating disorder. They must be delivered with a step up, step down, step in, step out flexibility.

Relapse prevention

Relapse prevention refers to strategies to reduce the risk of relapse after treatment and interventions, and responses to early signs of recurring illness for people who have already experienced an eating disorder.

Some experience of relapse (or 'lapse') is common during and immediately post treatment and with timely intervention and support contributes to the learning and self-discovery process of recovery.

In the longer term, a fairly high level of relapse has been identified in people with both anorexia nervosa and bulimia nervosa. In a study by Keel and colleagues (2005) relapse occurred in 36% of women with anorexia nervosa and 35% of women with bulimia nervosa. Women with intake diagnoses of anorexia nervosa, restricting subtype, tended to develop bulimic symptoms during relapse, whereas women with intake diagnoses of anorexia nervosa, binge-purge subtype, or bulimia nervosa tended to return to bulimic patterns during relapse. Greater body image disturbance contributed to a risk of relapse in both eating disorders (Keel, Dorer, Franko, Jackson, & Herzog, 2005).

While recovery from an eating disorder is certainly possible it does not always eventuate. At present, fewer than 50% of adults suffering from anorexia nervosa will recover. For anyone who has suffered

from any type of eating disorder, there is a real possibility of a recurrence. Factors which may contribute to relapse and recurrence include:

- Duration of illness
- High levels of body image disturbance
- Co morbidities
- Personality traits
- Entrenched belief systems
- Stressful life events (e.g. divorce, unemployment, pregnancy, menopause)
- Lack of access to transition services to support generalization of new behaviours and beliefs

The vulnerability to illness continues long after weight restoration and potentially throughout life. There is therefore a need for treatment that is available for the long term, delivered through services that are sensitive to adults seeking support.

Treatment options must recognise and address these aspects of the illness. For those who do not recover, long term care is required where the focus is on improving the quality of the person's life rather than recovery from the illness. However, it must be stressed that recovery can occur at any stage of the illness and hope for recovery should never be abandoned. For those who have entered recovery, it is imperative that they have accessibility to support and treatment if they identify at any time they are at risk of relapse or, indeed, find themselves in the actuality of relapse.

Stepped Care Approaches

The most appropriate treatment approach for eating disorders is a flexible stepped model with options to step treatment up or down throughout the continuum of care and to exit and enter treatment at any level on the continuum on an individual basis, in response to the development of the illness.

This is a more complex and variable approach than the traditional linear stepped-care model which typically always starts treatment at the lowest level of intensity and then progressively increases intensity (Bower & Gilbody, 2005). A focus on low-intensity treatment can be counterproductive for eating disorders where an inadequate level of treatment may lead to adverse consequences including disengagement from treatment or increased risk of suicide, or may result in persistent eating disorders cognition which is a known factor for relapse.

The use of the lowest intensity intervention is appropriate for people in the early stages of bulimia nervosa or binge eating disorder. The use of low intensity approaches as a starting point for treatment may not be appropriate for people who meet the full diagnostic criteria for anorexia nervosa or for people with any eating disorder with complex comorbid conditions. These conditions are best managed through intensive multidisciplinary models of care.

Service Models

Outpatient Service Models

Most people with eating disorders should be managed in an outpatient setting (NICE, 2004). Hospitalisation can be essential where physical impairment is significant. However, it is not the optimum environment for sustained change in eating behaviours. Wherever possible, services other than inpatient care should be provided in community locations with flexible entry and exit processes to allow for individual variation in access to treatment. Community based treatment is the preferred option, taking into consideration the potentially long term nature of the illness and treatment, the importance of family and social relationships during treatment and the need to generalize new behaviours to everyday living situations.

The scope of outpatient treatment includes but is not limited to services provided by:

- Private practitioners
- Services provided in youth, women's and men's health clinics, as well as clinics meeting the needs of migrants, Aboriginal and Torres Strait Islander communities
- Outpatient and outreach programs associated with hospitals
- Specialist eating disorder clinics and services provided independently or as outreach programs from hospitals
- University clinics
- Intensive outpatient programs including home visiting

Outpatient service models may include self help programs and groups, individual counselling, individual psychotherapy, therapeutic groups, , and recovery oriented community based programs.

As for all service models, safe treatment delivered through outpatient services should address all aspects of illness including physical, psychological, nutritional and social. Depending on individual need outpatient treatment may therefore include the provision of services by a range of health care providers including general practitioners, paediatricians, dietitians, physiotherapists and social workers. A general practitioner is frequently the first point of contact and is an important member of the multi disciplinary team. Community case management models may be required to coordinate multi disciplinary outpatient services.

Day and Residential Programs

Both day and residential programs offer alternative settings for treatment that provide interim levels of intensity between outpatient and community based support and inpatient services.

Residential and day programs provide a step down from the intensity of inpatient treatment, with an opportunity for consolidation of the gains made during inpatient treatment in a more normalized

environment. They may also provide a step up from outpatient treatment, and offer more structure and a level of intensity appropriate for people who require intensive psychological support but do not require medical stabilization. Day programs may also reduce the demands on families and carers providing opportunities for carer respite. Both types of programs have the potential to integrate the delivery of treatment and support, including psychological, nutritional, medical, psychiatric, and complementary therapies, in a safe, supportive, and homelike environment.

A recent Australian study has reported very promising results, showing that the gains achieved during day program care are retained at a 3 months follow up (Willinge, Touyz, & Thornton, 2010).

Models of residential and day programs vary considerably and at this time there is no agreed model for the delivery of these programs. Frisch, Herzog and Franko's (2006) study of residential treatment for eating disorders in the United States found that there is no standard definition of the services provided in residential treatment, with centres using a wide variety of treatment methods in different combinations. Fairburn (2005) points out, "it is not clear whether such day programs are cheaper alternatives to in-patient care, constitute more intensive out-patient treatment or are in fact are a distinct treatment with their own strengths and weaknesses".

There is a need for research to quantify treatment program effectiveness in the residential treatment setting.

The treatment components in an effective day or residential program should address all aspects of illness through a multi disciplinary team approach.

All treatment models, including day and residential programs, must be delivered as essential parts of an integrated continuum of care. The specific model chosen for day and residential programs should integrate with and fill identified gaps in the accessible continuum of care available within a region.

Used appropriately, residential and day programs have the capacity to reduce distress and stress for individuals, ensure that new behaviours are generalizable to everyday living and prevent relapse requiring hospital admission.

Hospital at Home

Hospital-at-home is defined by a Cochrane review as "a service that provides active treatment . . . in the patient's home of a condition that otherwise would require acute hospital in-patient care" (Shepperd, 2001). Use of hospital-at-home for the treatment of patients with eating disorders requires the selection of appropriate patients, assessment of the home environment and family or carer capacity to provide support, and the capacity to provide expert supervision at an appropriately intense level. There are high risks associated with the use of hospital-at-home without appropriate assessment and expert supervision. In appropriate cases, hospital-at-home may provide an effective, safe and cost efficient approach to treatment.

Inpatient Services

While most people with an eating disorder can be treated effectively as outpatients, there is a continued need for specialist inpatient services for people with severe illness. Available beds are required for children and young people and for adults in both mental health and medical facilities.

Inpatient treatment is most appropriate for people who:

- Need a life saving step due to being acutely medically or psychiatrically compromised e.g.,
 - o Require medical stabilization
 - o Require naso-gastric feeding or require supervision at every meal
 - Have an active plan for suicide
- Require more intensive treatment than that provided in outpatient, day or residential services
- Experience continuous preoccupation with eating disorder thoughts or require modification of extreme behaviours, after lower level of care has not helped
- Have another psychiatric disorder requiring hospitalization
- Are only able to cooperate in a highly structured treatment environment e.g., are unable to cease excessive purging or excessive exercising
- Have significant family or social problems or
- Cannot access the level of care they require in their own community

The inpatient ward environment is very important to a successful outcome. Patients (and their families) may suffer psychological trauma when treated in inappropriate settings. There are well recognized problems and risks with:

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

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

• Management by professionals unfamiliar with current management and/or the potential for adverse effects of excessively punitive and coercive approaches (ANZAED, 2007)

Inpatient accommodation for children and young people must be separate from adult accommodation in order to minimise the risk of harm and ensure that the medical and psychosocial needs specific to children and young people are appropriately met. This approach is consistent with the World Health Organisation standards for treatment services for children and young people and aligns with the proposed consensus standards for the care of children and adolescents in Australian health services (Hill, Pawsey, Cutler, Holt & Goldfield, 2011).

Transitioning between treatment services

Coordination and collaboration are particularly significant when people are discharged from inpatient treatment or transition between types or levels of service. It is essential that continuity of care is maintained between levels of treatment.

Smooth transitioning and handover between treatment teams has been identified as imperative to ensure the sustainability of treatment outcomes. *"Seamless would indicate that the support guidelines for everyone involved were set out from the beginning to be clear and concise and direct, so that the person suffering from the eating disorder could have some stability in the knowledge of how the support team would work together to help them, with clear boundaries, actions and indicators of what would happen in the event that things went downhill....." (NEDC, 2011).*

Follow up protocols are required for service providers to ensure that follow-up is planned and does occur. People with eating disorders and their carer(s) also need to know the indicators concerning when it is necessary to get back in touch with a treatment provider.

NEDC members with experience of eating disorders (NEDC, 2011) identified the following key themes for seamless and collaborative transition:

- Clear communication and handover meetings between teams
- Listening and open communication
- Involvement of parents/carers /family in meetings with healthcare professionals where family is available
- Transition criteria for people who are not supported by family to ensure that they have adequate support in the community
- Clear, well managed plans (discharge plans) and good record-keeping that 'travel with' the person from one treatment service to the next
- Continuity of care with the same inpatient/ outpatient team or with an assigned case-worker to act as a consistent point of contact in transitioning between treatment teams
- Training and support services for carers
- Transitional step-down facilities between inpatient and outpatient options
- Education for people with an eating disorder to acknowledge and normalise relapse as part of the recovery process
- Consistent levels of treatment for adults as well as children with appropriate transition strategies for people as they move between child and adult treatment providers to ensure that there is no loss of continuity in treatment.

To promote safety, risk of suicide must be included as one aspect of psychological assessment when determining fitness for discharge or transition.

An Informed Choice of Treatment

For all forms of treatment, it is essential that the person and their family understand the risks and benefits associated with the treatment in order to provide informed consent. Information provided should include an indication of the strength of the evidence base for the particular treatment and should raise awareness that no single treatment is effective for all patients. A choice of treatments should always be provided.

For people with eating disorders, their families and carers, the concept of choice encompasses:

- A choice of programs/interventions available in all areas/locations, with an emphasis on community based services at all levels except inpatient care
- A choice of medical professionals/multi disciplinary teams with training in the provision of integrated eating disorders treatment
- Access to affordable choices regardless of economic status
- Flexibility to revisit and make new choices as their needs change (NEDC, 2011)

Clinical Guidelines

New guidelines are required to support a nationally consistent approach to eating disorders in Australia.

In the absence of these guidelines, there are a number of established treatment guidelines, which may be helpful including: NICE, AMA and RANZCP. Evidence on effective and safe treatment approaches continues to emerge and these guidelines should be implemented in the context of this emerging evidence. When determining which guidelines to utilise, the date of publication should be taken into consideration and the guidelines should be interpreted in the context of the clinical environment, the individual patient and the national standards for eating disorders treatment.

Implementing National Standards

Safe treatment approaches for eating disorders must address both physical and psychological aspects of the illness. It is unsafe to treat one dimension without the other. This has implications for the organisation of eating disorders services, with the joint provision of care between health disciplines and services on a long term basis.

Factors which may contribute to improvements in the delivery of consistently safe treatment options include:

- Adoption of national standards
- Development of a continuum of services providing flexible access to a range of service options for both adults and young people
- Skilled professionals with experience in working with eating disorders available to deliver treatment options to best meet the needs of individuals
- Development of Australian Clinical Guidelines for all eating disorders
- Evidence generating approaches to treatment that will add to the understanding of the effectiveness of existing and alternative therapeutic approaches, particularly for the treatment of individuals with comorbid conditions or chronic illness.

Principle: Partnering to deliver multi disciplinary treatment in a continuum of care

Treatment is provided by a multi disciplinary team who work in partnership with the person, their family and other health and support providers, including treatment of co-morbid issues. The multi disciplinary team will be able to meet physical, mental, nutritional, occupational and social needs. Individuals with an eating disorder require individual care plans and have access to a designated case coordinator.

A person centred approach requires collaboration between patients, their families or supporters, and health professionals (Lutz & Bowers, 2000).

The majority of eating disorder patients require long-term multi disciplinary care, potentially provided across different levels of care and different service agencies.

Common features of a person centred approach identified from the literature include (Law, et al., 1995).

- Sharing of power and responsibility in a partnership relationship, each person contributing to the partnership from their knowledge and skills; and each person taking responsibility for decisions and actions
- Accessibility and flexibility of services and the health professionals providing service
- Co-ordination and integration of actions, taking into consideration the interaction between treatment approaches and the whole experience from the point of view of the patient

The Multi Disciplinary Team

The eating disorders treatment team requires a multi disciplinary approach to address the physical components of the illness, the eating behaviours, the psychological thought processes, and the social and work needs of the person. A 'complete' team might include a general practitioner or paediatrician (depending on age and severity of illness), a psychiatrist, a dietitian, a psychologist, a nurse, a family therapist, possibly a social worker, and often an occupational therapist and/or physiotherapist. Outside the health sector, additional components of the team may include community support organisations, teachers and school counsellors (for young people at school needing support), and therapists with a focus on stress identification and reduction.

Members of the multidisciplinary team will vary depending on the needs of the patient. A minimum team for safe interventions will include both physical and psychological disciplines.

This treatment team needs to partner with other health service providers if and when they are involved. The majority of those suffering from an eating disorder will have a co-morbid condition and, as such, a broader medical team may be involved.

The way in which treatment teams work together will to some extent be determined by service location and resources. Teams do not have to be made up of professionals who work together in the same service or the same location. Team members may need to connect across private, public and non government organisational boundaries and between geographic locations. The use of technology, such as videoconferencing may support the development of a team approach.

Person Centred Approaches to Team Treatment

The process of treatment and recovery needs to be owned by the person with the eating disorder. In a person centred approach, the person with the eating

A 'Complete' Treatment Team

A team could include:

- General Practitioner or paediatrician
- Psychiatrist
- Dietitian
- Psychologist
- Psychiatric Nurse
- Nurse Practitioner
- Family therapist
- Specialists working with co-morbid conditions
- Social worker
- Occupational therapist
- Physiotherapist
- Educator
- Community support organisation
- School counsellor

The actual members of a team will vary depending on the needs of the person at any given time.

disorder needs to feel safe, understood, not judged and involved in decision making as the key member of the partnership.

Key people in the person's support network must also be key members of the treatment team. In the same way that a diverse range of professionals need to work collaboratively together, the professional team needs to work effectively with the family or other support network. Treatment interventions require a supportive environment in which people can develop new patterns of thinking and behaviour. For most children and many adults, the supportive environment is created by family, defined in the inclusive sense of people in relationships such as parents, siblings, partners, carers, extended family and close friends. For people who do not have access to this strong network of social support, consideration must be given to providing treatment within a more formally constructed social environment such as residential care.

The concept of the whole family or support network at the centre of treatment, rather than a single individual is recognised within some treatment models, such as FBT. For young people and adults, there are tensions between current policy approaches to confidentiality and the necessary inclusion of key support people in treatment planning and implementation. It is not uncommon for a person over 16 years to both want and not want the involvement of their carer and family. The right to privacy is absolutely inherent to the patient. At the same time, failure to provide people who are actively involved in the provision of support with sufficient information to act appropriately, places the person receiving

treatment at risk. Negotiation of the balance between inclusive partnership and confidentiality is an additional responsibility of the multi disciplinary team.

The adoption of a 'team approach' to treatment, with agreed protocols for the sharing of information with team members may provide a solution to this difficulty. In a person centred approach, the person with an eating disorder would be at the centre of decision making about who is included in the team and the scope of information to be shared. This would then create a base for a charter or service contract.

Individual Care Plans

The use of individual care plans supports a person-centred, recovery oriented approach. An individual care plan is a working summary of goals and strategies, including strategies to prevent relapse, put together by the person with an eating disorder and their treatment team.

The care plan must be individualised and appropriate to the age, needs and family circumstances of the person. The role of the person's support structure (usually the family) must be incorporated into treatment and, in turn, the needs of the family and carers including information, education and support, must also be addressed as an integral part of the plan.

An individual care plan is appropriate for people when multiple service providers are involved in the delivery of treatment and support.

Case Coordination

To achieve a collaborative multi disciplinary team approach will require the implementation of mechanisms to support professional networking across traditional treatment boundaries. The multi disciplinary team must work across both physical and mental health; between public and private health services; across specialist disciplines and between health and social services.

A key theme from the NEDC consultation with people with experience of eating disorders was the need for collaboration between members of the treatment team and between the treatment team and the person with an eating disorder and their family or carers. The multi disciplinary team requires proactive coordination to enable each profession to work collaboratively with the others to provide consistent treatment.

Case coordination is one approach to supporting the development of a collaborative team. Appointing one person to coordinate the individual care plan and act as principle point of contact, coordinating shared information, and facilitating collaboration may be helpful to support the implementation of complex care plans.

Case coordination may be advantageous for transition management, ensuring continuity of support and seamless transitioning between types and levels of treatment, and integration of health services with community support.

The coordinator may be the doctor (GP), a nurse practitioner, a mental health professional, dietitian or any other member of the treatment and support team. Appointment of a person who is able to provide face to face contact within the person's local community and who has a relationship of trust with the person and their family will facilitate collaboration.

At present, the role of case coordination often falls to a member of the family or, for some adults, to the person with an eating disorder acting on their own behalf. This places increased stress on the person and their family and does not exert sufficient influence on health service systems to enable a team-treatment approach.

People with experience of eating disorders (NEDC, 2011) describe a professional role that can support people to engage with treatment. The characteristics of this role are essentially the same as those described for the first point of contact.

"One professional who can help the person to connect with the services they need, assessed on the basis of presenting needs, individual personality and circumstance, and changes in needs and circumstances over time". A 'case coordinator' who is accessible, knows the local and eating disorders health systems, and is able to facilitate access to multi disciplinary care at different levels.

The focus group noted that collaboration and communication between service providers helps to make the best of the services that are already in place.

An effective treatment system would support different professions working together; breaking down the professional barriers through training and case coordination. Coordinated, collaborative care would involve case conferencing and shared referral pathways ensuring access to services.

Shared clinical guidelines across health professions and on-going processes of review and shared learning will support the consistent implementation of multi disciplinary evidence based approaches.

Implementing National Standards

Treatment for eating disorders can require coordinated and collaborative input from many different professionals, always including access to tertiary consultation as required, as well as from the person with the eating disorder and their family or support network.

Multi disciplinary teams provide support for the professionals participating in the team reducing the risk of burn out for individual professionals. A team approach provides the critical mass of professionals with a common interest required to support the provision of education and professional development and the implementation of research and evaluation strategies.

A particular benefit of multi disciplinary teams is the mutual support that team members provide. This is necessary in managing the most complex of patients where staff would otherwise be at risk of burnout.

The provision of education and professional development opportunities, and the implementation of research or evaluation strategies are both enhanced by the critical mass of multi disciplinary teams. National Framework March 2012

Systems and protocols are required to support this integrated and intensive approach to treatment. Strategies which may facilitate a multi disciplinary partnership approach include:

- Shared clinical guidelines across health professions
- Shared training in eating disorders treatment across health professions
- Protocols to support a 'team approach' to treatment
- Adoption of individual care plans and case coordination to support implementation of complex, multi-provider care plan
- Health fund recognition of multi disciplinary teams and case coordination as essential parts of the treatment approach for eating disorders

Principle: 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.

Person centred approaches (Law, et al., 1995) promote accessibility and flexibility: equitable service provision that is provided in a timely and accessible manner to meet the needs of the client.

The first national framework for eating disorders (The Way Forward, p39) noted that: "Improved access to services for people in all locations in Australia is a high priority for consumers, carers and families. Increased access to services will involve reduction of the current barriers to access which stem, in part, from a lack of access to information and skills on how to identify eating disorders at the early stages when diagnostic criteria are too limited a tool. Increasing access will require action in the following areas:

- Geographic access to services
- Clear signposting of referral /care pathways
- Removing diagnostic criteria as a point of access to services and adopting more lenient criteria for referral that do not exclude any Eating Disorder diagnosis
- Utilising technology in the delivery of care including video conference, email, telephone, online services, DVD/telephone counselling formats, whilst retaining the opportunity for face to face services

Timely Access to Services

The timing of access to eating disorders treatment is a critical factor in reducing the duration, severity and impact of illness. Intervention at the earliest possible point in recognition of symptoms is required, both before the illness fully develops, and subsequently at the earliest presentation of symptoms during episodes of illness.

Criteria for access and entry to treatment services must support:

• Intervention early in the development of illness – broad definitions of eating disorders are required, that take into consideration early signs and symptoms that are fewer than, or less intense than, those required for a diagnosis. Replacement of diagnostic criteria as the point of

access to services with evidence based proximal risk factors is required to ensure that people receive treatment early in the development of the disorder.

- **Prompt intervention, early in help seeking** people who seek help for an eating disorder should be validated with a prompt response. Active engagement by the person with an eating disorder is essential for recovery. Prompt access to treatment early in help seeking may assist the person to successfully engage with and pursue treatment. People who have been on waiting lists for treatment are more likely to drop out of treatment before achieving their treatment goals, requiring subsequent re-engagement with treatment (Byrne, et al., 2011).
- Intervention early in each episode of illness for people who have previously received treatment, prevention and early intervention are as important during relapse or recurrence as at other stages of illness, potentially reducing the risk of chronicity.

Access to a Suite of Services

The national standards stress the necessity for access to a suite of services, regardless of a person's geographic location, age, or economic circumstances.

- Services provided by multiple disciplines: The most effective treatment for eating disorders addresses all aspects of the illness through a multi disciplinary team.
- A suite of services: a range of treatment and support options is required to enable the provision of individually tailored interventions that are congruent with the person's circumstances and experience.
- A stepped model of service: varying levels of intensity of service are required to meet the differing needs of individuals at each stage of illness, to effectively support transition from intensive treatment, and to reduce the need for hospital admission
- Services for adults and children: the vulnerability to illness continues long after weight restoration and potentially throughout life. There is therefore a need for services that are sensitive to adults seeking support and for health services to provide treatment for adults as well as youth.

Geographic Access to Services

A relatively small number of people with eating disorders require hospitalisation and usually only for a relatively short duration, having regard to the overall length of time a person is in treatment. In addition to sufficient beds in the hospital system, treatment services therefore need to be found in outpatient and community settings.

The treatment of eating disorders in Australia must take into consideration the significant difficulties in providing care in rural and remote settings. Here mental health resources may be limited and the

multidisciplinary approach advocated as "best practice" may not be available due to distance and small population numbers.

To achieve access in all communities there is a need for:

- Recognition of early intervention and treatment of eating disorders as "core business" for all General Practitioners, dietitians, psychologists and other health service providers in positions as first point of contact
- Locally accessible clinical training
- Access to tertiary consultation support from specialist services.

There is evidence that video conferencing provides an effective vehicle for the provision of psychotherapy for people with eating disorders. A number of studies (e.g. Simpson, Knox, Mitchell, Ferguson, Brebner & Brebner, 2003; Mitchell, Myers, Swan-Kremeier, & Wonderlich, 2003; Mitchell, et al., 2004; Simpson, Bell, Britton, Mitchell, & Johnston, 2006;) have found video therapy (telepsychology) to be as effective as face-to-face therapy in terms of patient outcomes for people with bulimia nervosa. Video therapy has also been identified as a cost effective approach, particularly for people living in remote areas.

Visibility of Entry Points

With the complexities of multi disciplinary treatment options, one of the most difficult things for people seeking help is determining the entry point. Ideally, the entry point for eating disorders is flexible with access to treatment pathways through any of the people who act as first point of contact. For people who can acknowledge that they have an eating disorder, and for families and support people who are able to recognise the warning signs of eating disorders, this includes community organisations with a specific focus on eating disorders.

An argument was made by people with experience of eating disorders and carers (NEDC, 2011) for the promotion of 'soft entry points': professional information, referral and support services located in the community providing a clearly signposted entry point that is approachable and non-threatening. Organisations based in the community were described as playing a key role in facilitating access to services; for the person with an eating disorder, this could be explaining the journey that they could take; for the carer it could be the provision of information about eating disorders and treatment options and on how to support the person with the eating disorder.

Affordable Treatment

There is a wide individual range in the length and intensity of treatment required to achieve recovery. Premature withdrawal of treatment is counterproductive, increasing the risk of relapse or recurrence of illness. The median (mid range) of duration of treatment is 1 to 2 years for adults with Anorexia Nervosa and 6 months for adults with Bulimia Nervosa. This is the period of time from the point at which the patient is ready for change and able to actively cooperate in working towards recovery and the achievement of recovery. Individuals may require many years of treatment intervention before this period in order to stabilize health.

Criteria for funding treatment for eating disorders must therefore provide:

- Sufficient flexibility to respond to the varying needs of individuals
- Consistent availability without interruption for the long term
- Services delivered by a multi disciplinary team
- Varying levels of intensity

Treatment services for eating disorders are provided in both the public and private health sectors. With a shortage of eating disorder services in the public health sector, a very significant component of services are provided in the private health sector, with associated issues for economic access to services.

Treatment for an eating disorder is potentially lengthy. Even with rebates from private health funds, the cost to the individual and their family is high and such rebates are only available in specific circumstances, usually where there is hospitalisation for the illness. Under current Medicare arrangements there are issues associated with the range and type of eating disorder services that qualify for a rebate, and the amount, if any, of co-payment that can be charged and recovered by the practitioner.

A review of health fund practices is required to ensure that people with eating disorders have access to the range of treatments and the duration of treatment that they require at every stage in their illness and recovery. Specific issues in such a review would include:

- Criteria for access to treatment services criteria for access to services should support early intervention. Treatment referral and health fund requirements must recognise early symptoms as sufficient criteria for access to early intervention and to more intensive treatment where required in order to reduce the impact and severity of the illness and the ongoing need for treatment.
- Criteria for duration of treatment and number of sessions people who meet the criteria for a full diagnosis of eating disorder generally require long term treatment. Brief episodes of treatment which do not result in full recovery expose people to risk of relapse and recurrence and increase the probability of chronicity. Premature release from treatment before treatment goals are achieved in order to comply with funding criteria, will result in a longer duration of illness and a longer duration and complexity of overall treatment. Medicare funding and private health fund rebates need to match the course of eating disorders and the evidence based treatment models. Person centred, flexible approaches that respond to the individuality of the disorders requires a matching degree of flexibility in the number of sessions funded through

Medicare.

 Criteria for type of treatment – health fund support is required for the full continuum of eating disorders care, including hospital substitution services such as day and residential programs and prevention programs utilising early interventions strategies. These services reduce the frequency of readmission and therefore the costs associated with inpatient hospitalisations.

Support is also required for the simultaneous provision of services from multiple disciplines (see principles 1.3 and 1.4) including physical, psychological, nutritional and occupational services.

• **Criteria for review and data collection** – the provision of health fund support for long term treatment should be monitored with regular reviews ensuring that the treatment is effective, the patient is continuing to actively engage and there is evidence of on-going need. Data collected in this process could be used to enhance the evidence base on the treatment of eating disorders in Australia.

Implementing National Standards

In summary, equity of access and entry to services will require:

- A review of Medicare and health fund criteria for funding eating disorder treatment
- Professional development for frontline professionals, including training and access to tertiary support and supervision, to enable accessible community based service delivery
- Support for community based organisations as soft points of entry to treatment
- Review of the current range of services to ensure a full suite of services is accessible, taking into consideration issues associated with the geographic location, economic circumstances and individual treatment needs of people with eating disorders

Principle: Tertiary consultation 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 service providers have access to tertiary level expertise for education, consultation, supervision, guidance and referral if required.

It is important to ensure that appropriate expertise is available at every level of care and every incidence of care.

People with eating disorders require specific interventions designed to address the complexity of eating disorders, delivered by health professionals with an appropriate level of skill and knowledge of the disorders. People are best treated closest to home and family. Referral to tertiary services outside the local community or region should be a last option for most patients.

There are a limited number of eating disorders experts/specialists in Australia. Most people receive treatment at non-specialist primary and secondary levels of care. The only way of delivering services in many geographic areas, particularly in rural and regional areas, is by up-skilling current heath primary and secondary health practitioners. To assist them in treating people with eating disorders there is a need to provide them with access to additional expertise in eating disorders when this is required.

Tertiary consultation is the recommended mechanism to ensure that all health professionals, including General Practitioners and specialists in other health fields, have access when they need it to an appropriate level of specialist expertise. Tertiary consultation is intended to resource and empower local treatment providers. A key issue for non-specialist clinicians is knowing that information and support are available at an early stage in planning treatment. Tertiary consultation may be provided in person however it is most likely to be delivered by video or teleconferencing.

A Hub and Spoke Approach

A 'hub and spoke' approach is suggested to promote integrated, coordinated treatment options across health regions. The 'hubs' would be specialist eating disorder units providing excellence in care; the spokes would be primary and secondary health service providers and community based eating disorders programs.

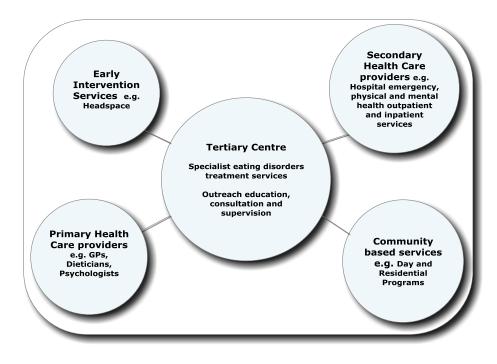
The 'hub' has two key roles to play, firstly as a source of tertiary treatment for eating disorders including residential beds, and secondly providing specialist clinical support, joint assessment, supervision and training, and mentoring for community based services provided by public and private health services and non government organisations.

Connection between these elements would require an outreach approach providing:

- Assertive engagement of health professionals in communities, providing information about eating disorders treatment and the tertiary consultation support available
- Provision of training for health professionals
- Consultation support through telephone contact, video links, online consultation, and site visits
- On-going supervision and support where required
- Brokerage and support of multi disciplinary teams for remote areas where required

Current centres of expertise in eating disorders which meet the proposed national standards and provide inpatient treatment through a multi disciplinary team, should be considered as potential hubs for tertiary consultation.

Tertiary consultation services must be able to address the needs of children, youth and adults. This may be achieved through separate youth and adult hubs or through integration in one single hub. Where no single centre 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 disorders treatment into a virtual hub using a partnership model.



Example

Existing early intervention health services in the community may provide appropriate 'spokes' for the 'hub and spoke' approach. An example would be 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 to further help. As part of skill development for the frontline workforce, Headspace staff could be equipped with the skills to identify eating disorders, make appropriate referrals and support the person to seek 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.

Implementing National Standards

A key to the provision of treatment for eating disorders is to make it 'core business' for all health professionals. This requires an appropriate level of expert support

The provision of tertiary consultation support enables people to have access to eating disorders treatment, at least in the first instance, within their local community.

Existing eating disorder services may require capacity building for the provision of education outreach and supervision.

Principle: 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.

In most instances it is preferable to manage eating disorders on an outpatient basis in a community location where the person can remain close to family and social relationships, continue engagement in work or education where possible, and generalize new behaviours into everyday situations.

Family, carers and support services play an important role in facilitating this approach to treatment which can be seen in three key areas:

- Supporting engagement with treatment: A characteristic of eating disorders is that the person will be reluctant to seek help, often denying illness or concealing behaviours (Tury, et al., 2010; Vandereycken & Van Humbeeck, 2008). People in close relationships to the person with an eating disorder play a vital role in influencing help seeking, raising awareness of problem behaviours, and supporting recognition of stages in recovery.
- **Supporting implementation of treatment:** The family or support network are integral members of the treatment team. To support complex multi disciplinary treatment in the context of a dynamic illness that manifests in different ways at different points in the course of illness, families require knowledge and skills.
- **Providing long term care and support:** Long term treatment requires an equally long term commitment from the person's support network with implications for the family or carer's economic, social, physical and mental wellbeing.

There is a close relationship between the adoption of the principle of collaborative care and the active engagement of families in treatment. Families require inclusion in treatment, support and guidance in their child's care, and positive relationships with health professionals (Honey, et al., 2008). Parent and carer skill building interventions may be both a primary form of treatment intervention and an adjunct to treatment approaches.

Research supports the view that illness and disability affects the lives of all family members (RANZCP, 2011). Caring for a person with an eating disorder can be a very stressful experience for all family members and high levels of anxiety and depression have been found amongst carers. In the context of the extensive demands that management of eating disorders place on families, there is a need for

effective intervention strategies that improve the effectiveness of families as moderators of treatment outcomes (Treasure, et al., 2007) and ease the stress on family members (Zucker et al, 2006).

In addition to treatment options it is important that people with eating disorders and their carers and families are provided with support, education and, where required, counselling services throughout the duration of the illness. These services are required by the main carer and by the family group, including mothers, fathers, partners, siblings and children.

Parent and carer support must be relevant to stage of illness, the developmental stage of the person with an eating disorder, and family and cultural considerations. Increased support may be required at acute stages of illness, when the person with an eating disorder is a younger child, or when the family is more socially isolated.

Assessing family strengths and needs

The family or carer should be included in the assessment and treatment planning process wherever possible. Assessment of family or carer needs and strengths should form an integral part of the assessment process. Interventions to support families, including siblings, should be planned at the time of diagnosis and support should continue for the duration of the illness.

Counselling at diagnosis should be an "opt-out" process not an "opt-in" one as many parents will be focussed on therapies for the child with disability and overlook their own needs and those of other family members (RANZCP, 2011).

Strategies for Family and Carer Support

Families have identified a need for general information about the physical and emotional aspects of eating disorders, information about treatments (Halverson, et al., 2007), support strategies such as nutrition and meal planning, information on the recovery process (Zucker, et al., 2006) post-discharge planning and follow up, and counselling and support options for parents (Honey, et al., 2008).

Research findings on parent education indicate that parents who participate improve knowledge, feel less excluded from their child's care, and are better equipped to take their child home after hospitalization (Carlton, et al., 2007).

Training or skill-building can include management of eating disorder behaviours, role modeling, development of healthy home environments, focus on family interpersonal processes and care giver attitudes and behaviours. A suite of family and carer education topics could include:

Information

- Understanding eating disorders and the specific diagnosis
- The role of parent/carer role in supporting the person with an eating disorder
- Understanding treatments accurate, evidence based information on treatment approaches and expected outcomes

- Understanding role of professionals, how to interact with professionals, be part of a team
- Information about services and supports available

Skill Development

- Practical guidance on management of eating disorder symptoms including meal support, overeating and purging, and co-morbidities
- Communication and interaction strategies including lowering expressed emotion and motivational approaches
- Emotional skills such as reflective functioning, emotional intelligence, stress management

Personal Care and Support

- Emotional impact of eating disorders guilt, blame, fear, anger and personal strategies to address these
- Information and assistance for parents to access their own help/support/therapy
- Problem solving strategies to assist families to maintain normal life patterns
- Supporting and protecting siblings
- Financial, legal support, respite, in home assistance

Education and Support for Children and Young People

Children and young people may be involved with someone who has an eating disorder in a number of different ways; as siblings, as the children of someone with an eating disorder, and in some cases as carers.

Children and young people living with or closely related to someone with an eating disorder represent a high risk group who should be considered for targeted prevention and early intervention programs. Identification and assessment of their needs, is critical in helping these children and young people obtain appropriate supports and services (RANZCP, 2011).

Access to age appropriate information and support is particularly important for children and young people to ensure their healthy development and ongoing wellbeing as well as that of the person with an eating disorder.

Information should include as a minimum:

- what the illness means for their family member
- how they can interact with their family member as a sibling or carer
- how to explain the situation to others
- how to express and manage their own emotions
- how to problem solve
- how to maintain their own physical and mental health (RANZCP, 2011)

Peer Support

The term peer support includes a variety of different approaches for the provision of support, by sharing information and experience with peers.

Peer support may be appropriate for people with eating disorders, for parents and carers, and for siblings. Provision is required for age appropriate peer groups and for gender and role appropriate groups, with specific provision for fathers groups and consideration of the different information needs of siblings and young carers.

There is evidence that for a person currently experiencing an eating disorder, having contact with someone who has had a similar experience in the past can provide beneficial support and offer hope for the future (Loth, Neumark-Sztainer, & Croll, 2009). People with eating disorders participating in NEDC consultations have identified peer forums as a vital source of support and understanding that help a person to engage, and stay engaged with treatment (NEDC, 2011)

A qualitative study (Jamieson & Joyce, 2008) explored the factors regarded as important in setting up a peer support "buddy" program for AN. The factors identified included a clear definition and description of the role of buddy, careful selection, training, protection and support for the buddy, supportive infrastructure, and evaluation of both process and outcomes.

A study by Rhodes and colleagues (2008) explored the use of parent to-parent consultations as an augmentation to clinical treatments. Parents indicated that the experience helped them to feel less alone, to feel empowered to progress, and to reflect on changes in family interactions.

Flexible approaches to family support

Support for families and carers must be provided in a variety of formats to meet different needs.

- **Mode of delivery**: support may be delivered in individual one-to-one sessions, in family sessions, in peer groups, and in multi family groups. Online forums and telephone interventions are also appropriate for people who have difficulty accessing centre based activities. Support may be provided independently from involving the child or adult with an eating disorder and therefore can occur without that person's consent if necessary where the person's confidentiality is maintained.
- Intensity of delivery: single and multiple session approaches may be acceptable with varying levels of intensity
- Location of delivery: family support may be embedded within clinical treatment or provided as a separate activity within the community. Delivered by the clinical treatment team as an integral aspect of treatment, family education and peer support may improve engagement with treatment and communication between professionals and family (Pasold, Boateng, & Portilla, 2010). However, for many people a non-clinical location for education and support

is more acceptable and has the capacity to provide support to people through a variety of treatment transitions.

Regardless of the source of family education and support, this should always be regarded as an essential and integral component of treatment.

Implementing National Standards

The inclusion of families and carers as integral members of the treatment team is an essential principle for the delivery of effective eating disorders treatment.

Treatment approaches should include, either within the treatment model or externally through community support services, education and skill development for families and support to sustain families through the treatment and recovery process.

Family and sibling issues are not well understood by health service providers (RANZCP, 2011). There is a need for more skills training for health and community service workers to enable them to assess and respond to the needs of the whole family when a child or adolescent in the family has an eating disorder.

Training and support services for carers are an essential component of eating disorders treatment and these services should be available to everyone who needs them for as long as required.



Part 2: Implementation

Principle: 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.

The safe, effective implementation of national standards and prevention and treatment approaches requires the continuous development of a strong evidence base informed by personal experience of eating disorders, clinical expertise and research.

The NEDC believes that effective health care is created through equal partnerships between provider, practitioner and patient (NEDC Project Charter, 2010). This approach is consistent with Sackett and colleagues (1996) definition of evidence based practice as the integration of the best available research evidence with clinical expertise and patient experience.

Evidence based practice is adopted to improve both the quality and efficiency of healthcare services (APA, 2005; Haynes & Haines, 1998). Implied within the term 'quality' is the expectation that services will be as safe and effective as possible for patients.

For eating disorders, evidence informed approaches means more than implementing known best practices. In part as a result of the complexity of eating disorders, evidence supporting the efficacy of treatments is limited (Fairburn, 2005). The NEDC Evidence Review (2010) confirmed that there are very significant gaps in the evidence base for eating disorders and addressing these gaps is a high priority for the development of the eating disorders sector. Fairburn (2005) suggests that even the models of treatment with the strongest available research "barely" constitute sufficient evidence. New forms of treatment and strategies for reducing barriers to engaging professional help are needed for all eating disorders, especially for adults.

'Evidence informed and evidence generating approaches' as a principle in the eating disorders national framework therefore refers to approaches which:

1. Promote the implementation of quality practices that are supported by existing valid and applicable research where this is available, clinical and patient experience, together with

 The active collection, interpretation and integration of newly emerging valid and applicable patient reported, clinician observed and research derived evidence (adapted from McKibbon & Walker, 1994).

The priorities for evidence generation include:

- The inclusion of research and evaluation strategies as an integral component of all eating disorders services and strategies. On-going monitoring and review are essential to ensure the safety and appropriateness of all prevention, treatment and support strategies. This is equally applicable to new initiatives and to existing services and strategies. Evaluation, both formative and summative, and research, is essential to capture emerging knowledge for integration into policy and practice.
- National data collection on the incidence and progression of eating disorders as an essential component of service planning and evaluation.

Data on the incidence and progression of eating disorders is essential for the evaluation of effective approaches to the prevention and treatment of eating disorders. At present there are no data collection strategies in Australia that capture the full national picture including the diagnosis of all eating disorders and information on people who receive treatment outside the hospital system.

• Development of a National Research Agenda to drive collaboration and focus research activity on gaps in the existing evidence base including validation of evidence based approaches in the Australian context. Continuing

Evidence informed and evidence generating approaches are:

- 1. Based on and referenced to the best available research
- Informed by the expertise of people with personal experience of eating disorders, their clinicians and carers
- Consistent with the national standards schema
- Regularly monitored and reviewed, including review by service users, to ensure safety, appropriateness and implementation of standards
- Evaluated on an on-going basis at an appropriate level to generate new evidence

review and dissemination of information on emerging promising treatments is also required to ensure that current research informs both policy and practice. Development and evaluation strategies that increase engagement with treatment services and decrease barriers to care are also required to facilitate early intervention and equitable access to treatment.

 Measurement of eating disorder status in future National Health and Wellbeing Surveys, National Mental Health Literacy Surveys and other population-based measures of mental health and wellbeing. • Any review and development of prevention, treatment and the systems that support treatment must be informed by people with personal experience of eating disorders and their support networks. Research and evaluation approaches must draw upon the practical experience of consumers, carers and clinicians.

Evidence from Experience

The active involvement of people with experience of eating disorders, and their families and carers, in the development, planning, delivery and evaluation of services is a mental health standard supported by the Fourth National Mental Health Plan. A significant issue for the future of the eating disorder sector is the development of participation strategies that enable people with experience to participate in meaningful and influential ways, as well as ensuring their safety and integrity.

Participation of people with personal experience as users of health services has been demonstrated to contribute to improved quality, consumer outcomes, accountability and cost effectiveness of services as well as improvements in the wellbeing of participants. Australian studies have reported there are insufficient opportunities for participation and a need to develop new approaches to the effective engagement and support of consumers at all levels of participation (McCann, Baird, Clark, & Lu, 2008; NMHCCAF, 2010).

For people with eating disorders there may be a number of barriers to participation which are specific to these disorders. Current service users and people who are still experiencing eating disorder symptoms may experience anxiety in social situations. This can be exacerbated when in the presence of health specialists depending on their experience in treatment. People with eating disorders may be stressed by the presence of food, other people who are eating or the expectation that they eat in front of strangers.

People with experience of eating disorders and their carers have different experiences and needs. Participation strategies should include criteria for identification of activities and events which require separate engagement for people with experience and carers.

Sustainable participation models and processes that meet the specific needs of people with eating disorders are required applicable to all domains of research, evaluation service and policy development. A useful first step would be to map all current practices in this area to identify the most promising approaches. Strategies are also required to engage existing community support organisations as channels of communication between people with experience, researchers and service providers, and in capacity building, supporting people to participate.

A key step towards participation would be the provision of training specifically for people with experience of eating disorders to prepare them to participate effectively and safely.

Implementing National Standards

There is a need to develop evidence for prevention, early intervention and effective treatments that incorporates evidence from experience.

To achieve this will require the implementation of:

- Integration of evaluation or research strategies into all service contexts including new and existing services in treatment, prevention and community support
- National data collection strategies and the development of a national research agenda
- Measurement of eating disorder status in future national surveys and other population based measures of mental health and wellbeing.
- Continuous review of emerging evidence and application to policy and clinical practice
- Models for participation to support input from people with experience and their carers into all research, evaluation and service development
- Training for people with experience of eating disorders to enable safe and effective participation

Principle: 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 the development of attitudes and practices that support early recovery oriented approach.

A skilled workforce is essential to implement the standards and treatment strategies of the national standards schema. At present few clinicians are specifically trained to diagnose and treat eating disorders.

To ensure access to eating disorder treatment in all communities, especially rural and remote communities, it is essential that primary health care providers are equipped and supported to provide treatment. The full spectrum of professional development activities from initial training to ongoing training, supervision, a multi disciplinary team and consultancy support provided by eating disorder specialists is required to ensure an appropriately equipped workforce.

The essential elements to support early intervention include professional awareness of early signs and symptoms of disorder, proactive screening of people at risk, access to accurate information and referral pathways and, most importantly, professional attitudes that are supportive and non-judgemental (NEDC, 2011).

The workforce required to implement prevention, early intervention, treatment and support for people with eating disorders includes:

- Frontline professionals: people who act as the first point of contact for people with eating disorders and their families including GPs, counsellors, school counsellors, physical activity instructors, social workers, and youth workers
- Primary health care providers: people who provide the first level of intervention, such as assessment, diagnosis, early intervention treatment and referral, including GPs, psychologists, dietitians, social workers, nurse practitioners and mental health nurses
- Secondary level clinicians: people who provide general physical and mental health services required by people with eating disorders, accident and emergency personnel, and those who provide specialist tertiary support for other conditions comorbid with the eating disorder
- Tertiary level clinicians with specialist expertise in the treatment of eating disorders. Tertiary level clinicians should have specialist training, ongoing professional development and expert supervision in the treatment of eating disorders.

Training for professionals as first point of contact

General practitioners are often the first health professionals to be in contact with people with eating disorders. Together with professionals in nongovernment support services and other health professionals, their response to eating disorders can influence access to treatment and support.

To the extent that health professionals are not familiar with eating disorders they may not recognise or respond promptly to early signs and symptoms. For those who do seek help, it may be necessary to see several doctors before receiving a correct diagnosis and each delay is likely to further influence duration of the illness and outcomes of treatment (NEDC, 2010).

At first point of contact, people may frequently seek help for an emotional problem rather than directly identify that they have symptoms of eating disorder. Hudson and colleagues (2007) found that the majority of people who responded to their survey who had bulimia nervosa or binge eating disorder had received treatment at some point in their lives for emotional problems, although less than half of respondents had sought treatment for their eating disorder.

For specific at-risk groups, specialist health services 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); for people seeking treatment for diabetes or obesity, an endocrinologist or a diabetes educator may be the first point of contact (Pereira & Alvarenga, 2007). 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 and access help through a dentist.

A Skilled Workforce requires:

Frontline professionals

- Awareness of eating disorders
- Knowledge of early signs and symptoms of disorder
- Access to information and entry points for help
- Motivational interviewing skills to engage people in appropriate conversation to encourage help seeking
- Understanding of recovery and the potential support needs of a person during and post treatment
- Professional attitudes that are supportive and non-judgemental

Primary health care providers

- Mental health literacy (all of the above) plus:
- Proactive screening of people at risk
- Assessment and diagnosis skills
- Referral pathways and protocols for accessing tertiary consultation
- Person centred and recovery oriented approaches applied to eating disorders
- Working with a multi disciplinary team

Secondary level clinicians should have additional training in treatment interventions for eating disorders.

Tertiary level clinicians should have specialist training, ongoing professional development and supervision/consultation in the treatment of eating

Early intervention and encouragement of help seeking behaviours can only be effective when knowledgeable professionals and effective intervention strategies are available (Commonwealth Department Health and Aged Care, 2000).

The implementation of a nationally consistent approach to eating disorders will require a professional workforce across health disciplines, education, social welfare, and sport, who have a shared understanding of eating disorders and an appropriate level of skill to work collaboratively towards prevention or recovery.

All health professionals should be required to have basic education, as part of their professional training, in the identification, assessment, treatment planning and treatment of eating disorders.

Providers of community based primary health care, and accident and emergency services should be able to assess (including diagnose) and facilitate appropriate treatment pathways and provide initial care beyond mental health first aid. Providers of secondary level care, including both inpatient and outpatient services, require additional training and expertise in the treatment of eating disorders to enable the provision of first-line therapies and treatments.

Providers of tertiary level care, including residential, day program and outpatient programs, will have specialist training and expertise in eating disorders and the capacity to manage complex disorder with co-morbidities.

The NEDC consultation with people with experience of eating disorders (NEDC, 2011) identified the following information and resources as important for frontline professionals:

- Standardised screening checklist to support recognition of symptoms
- Training on how to support someone in denial including motivational interviewing
- An understanding of recovery and relapse.
 An important first message for people with eating disorders is that recovery is possible.
 Motivation to take action and to continue to engage with treatment is influenced by an understanding of what recovery looks like.

Underpinning all of these approaches is the need to be able to develop a relationship of trust with an informed person in order to engage successfully with treatment. Education on eating disorders is key for the community of frontline professionals – including teachers, counsellors, GPs (NEDC, 2011).

Developing expertise in eating disorder treatment

As with treatment of other health conditions, the effectiveness of eating disorders treatment is mediated by the experience and skills of the treatment team. There is evidence that outcomes are poor when therapy is provided by non-specialists without expertise. Without appropriate skill and expertise,

early intervention and treatment for eating disorders may do harm, prolonging the duration of illness, building resistance to treatment, and increasing the loss of hope in recovery and the risk of suicide. Professional development is not limited to training. Skilled, experienced supervision may also support the effectiveness of treatment and the continuing engagement of people who don't respond to standard treatment with appropriate adaptations. Provision is required to enable health professionals working with people who have eating disorders to access tertiary level consultation, supervision, and mentoring when required.

The importance of therapeutic relationships

People with eating disorders and their families identify the attitudes, values and approaches of professional staff as an important factor in the motivation to engage with treatment and the effectiveness of treatment. For a person centred approach, working with each individual's unique experience, health professionals need to be able to work with empathy in a non-judgemental way (NEDC, 2011).

People with eating disorders generally experience very low self-esteem and need to develop feelings of safety, security and hope before they can actively engage in treatment. Building personal relationships to provide the best context for the delivery of treatment is consistent with the philosophy of person-centred approaches.

These opinions are consistent with the findings in the general literature on psychotherapy effectiveness. It has been suggested that a positive therapeutic relationship and personal situational factors are the most significant contributors to perceptions of effectiveness for clients and their families, especially for those with complex needs.

Implementing National Standards

The key to treating eating disorders is to make it 'core business' ensuring that all health professionals are trained to participate in multi disciplinary treatment of eating disorders using a person-centred and family inclusive approach.

At the introductory level, one consistent training program for all health professionals may be the most efficient approach to ensure consistency. The development of training resources in online formats and assertive dissemination to professional bodies and educational institutions would facilitate rapid development of appropriate levels of knowledge and skill.

A similar approach could be developed for non-health professionals, such as school counsellors, youth workers and physical activity instructors, drawing on and further developing existing resources from community support organisations.

Opportunities to participate in inter-disciplinary training and professional networks could facilitate the development of collaborative capacity to support a multi disciplinary team approach.

An endorsement scheme for existing and newly emerging training at all levels would assist to ensure a consistent approach to knowledge and skill development.

However, training alone is unlikely to be sufficient to maintain a skilled workforce in the long term. Anecdotally, professionals working with people with eating disorders experience high levels of burnout with subsequent withdrawal from the treatment of people with eating disorders. The development and maintenance of a skilled workforce will require a multi disciplinary team approach with specialist consultation support to ensure a consistent level of expertise in the workforce. The use of video conferencing must be considered to support a multi disciplinary approach and tertiary consultation. Principle 2.2 should be developed as an integrated response with Principle 1.4, partnering for a multi disciplinary team approach and 1.6, tertiary consultation.

Principle: 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 stigma which 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, youth workers) are trained to recognise and respond appropriately to eating disorders.

Communication with the community, with frontline professionals and between health professionals is essential to support a nationally consistent approach.

The term 'communication' as used in this principle refers to all strategic approaches to disseminate messages to specific audiences including governments, health professionals, other industries and sectors, families and the general community. The purpose of communication is to influence these audiences in a way that will support the implementation of the national standards for prevention and treatment of eating disorders.

In the opinion of the NEDC, there is an urgent need to:

- Raise awareness of eating disorders broadly across the community and more specifically in target groups including frontline professionals, health professionals, families and young adults.
- Address the known risk factors and environmental influences on those risks (e.g. weight concerns, appearance concerns, dieting, unhealthy eating patterns, low self esteem)
- Increase appropriate help seeking in individuals at risk of or having eating disorders
- Address known risk factors or correlates of stigmatisation
- Increase professional engagement with the eating disorders sector to facilitate the development of a skilled workforce

A consistent national approach to communication related to eating disorders will require collaboration and integration of activities across many sectors.

Communication will be required in four domains:

Awareness: Communication with the general community and specific sub-groups within the community to raise awareness of eating disorders as serious and complex illnesses, raise awareness of risk factors for eating disorders, and counter-balance dominant cultural messages about weight and body shape.

Professional Knowledge: Communication with health professionals and professionals who influence the health decisions of others, especially young people, to equip them to model and teach healthy behaviours, recognise risk factors for eating disorders, screen and assess for eating disorders and respond appropriately to people seeking help.

Prevention Programs: Communication to support the uptake of evidence based prevention programs; communication to foster environments that support healthy self esteem, mental health, body image and eating behaviours.

Access: Supporting help and information seeking by ensuring that people have access to consistent, evidence based information, and to prevention and early intervention initiatives. Access underpins all other communication actions.

Changing the Social Environment

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).

Vulnerability for eating disorders is affected by many different aspects of a person's community environment including school curricula, peer relationships (e.g. teasing) (Hart, et al., 2009) workplace expectations, sports involvement, and adult attitudes, especially as modelled by family, teachers, sports coaches and youth leaders. It is also affected by wider social factors such as media reporting, entertainment and advertising and cultural stereotypes and stigma (O'Dea, 2005).

The risk factors for eating disorders, and therefore communication about eating disorders, intersect with other health issues including obesity and depression, and are influenced by the same social environments and lifestyle issues, including appearance, eating and dieting (Becker, 2011).

Misalignment between public health messages, particularly those related to obesity, eating disorders and body dissatisfaction can undermine the impact of these efforts and generate unintended consequences. a focus on health rather than weight may be an important step in avoiding harm (AED, 2011).

Expert knowledge in eating disorders prevention is required to inform the development of public health messages. There is a need for strong cross sector partnerships to promote a culture of physical, social and emotional wellbeing.

Obesity and eating disorders may be viewed as occurring at the same end of a spectrum with healthy beliefs, attitudes, and behaviours at one end, and problematic beliefs, attitudes, and behaviours (and ultimately syndromes) at the other end (AED, 2011).

Integrated, coordinated messages targeting both obesity and eating disorders are possible. Although further research is required, conceptually, this would involve targeting shared risk and protective factors, and avoiding increasing risk of specific problems. There is an urgent need to develop integrated prevention initiatives which encourage body esteem, healthy eating and lifestyle behaviours without prompting engagement in fad diets, weight loss attempts and the diet-binge cycle (Darby, et al., 2009; Neumark-Sztainer, 2005; O'Dea, 2005; Russell-Mayhew, 2007).

Integrated messages require a shift in focus - from weight or shape to health; from comparison to individual identity and self worth; from negative motivators such as fear of illness or social exclusion to positive motivators of personal wellbeing and achievement. Integrated messages require a holistic view of health that addresses both physical and psychological risk and protective factors.

Achieving a cultural change of this magnitude will take time. It will also require a committed collaboration across many sectors to ensure consistency of messaging.

Facilitating prevention and early intervention

Early intervention is dependent on the capacity of community members, both professionals and lay people, people with symptoms of eating disorders and their supporters (Kelly, et al., 2007), to recognise the health problem (Commonwealth Department Health and Aged Care, 2000). Lack of mental health literacy has been identified as a significant barrier to help seeking for mental illnesses (Rickwood, Deane, & Wilson, 2007).

Recognition requires knowledge of the illness and warning signs, plus knowledge of pathways to access appropriate professional intervention. To be willing to act on this knowledge, people must perceive that help seeking is a positive behaviour and that acknowledgement of a health problem will not incur stigmatisation.

Prevention requires support for the implementation of evidence based prevention programs at all levels from universal to indicated prevention. The long term impact of prevention messages may be strongly influenced by the social environment, therefore to be most effective prevention programs should be delivered within a broader context of cultural change founded on widespread understanding of risk and protective factors (Commonwealth Department Health and Aged Care, 2000).

Eating disorders are associated with some of the highest rates of mortality of any psychological disorder and, once established, will have long term impacts on a person's physical, mental and social wellbeing. For adolescents and young adults at risk, they represent a significant threat to physical and mental development. Consequently, even quantitatively small preventative effects could be important (Fingeret, et al., 2006).

A positive environment for the prevention and early identification of eating disorders would be one in which the community at all levels from public policy, to organisations, professions and individuals has an understanding of eating disorders as serious and complex mental illnesses and the capacity to support the social and emotional wellbeing of members, respecting and valuing difference. Engaging the whole

community starting from engagement of governments in "multilevel public policy initiatives to prevent eating disorders is the key to prevention on a population scale" (Paxton, in press).

Achieving a cultural change of this magnitude will take time. It will also require a committed collaboration across many sectors to ensure consistency of messaging.

Implementation of National Standards

To support prevention, early identification and intervention, recovery and professional development, communication strategies are required to:

- Raise general community awareness of eating disorders as serious illnesses
- Develop eating disorders mental health literacy in frontline professionals and parents
- Promote training in eating disorders for health professionals
- Promote implementation of prevention programs

A more detailed discussion of communication to support prevention and early intervention appears in the separate NEDC publication Clarity in Complexity (2011).

Principle: Systems support integration, collaboration and on-going 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. On-going 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

Working collaboratively across disciplines and service providers in multi disciplinary treatment requires new approaches to communication within health services.

There is no single treatment approach, such as a pharmacological solution, to eating disorders. The complexities of eating disorders require a multi disciplinary team and a supportive environment with the capacity to provide collaborative intervention for an extended period of time.

Collaborative Governance

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 multi disciplinary team approach to eating disorders and the departments involved in the provision of care will contribute to the effective implementation of the safe, flexible, person centred and multi disciplinary treatment approaches that form the core of the National Framework for eating disorders.

Collaborative Policy

To achieve a collaborative multi disciplinary team approach will require the implementation of mechanisms to support professional networking across traditional treatment and professional boundaries. The multi disciplinary 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.

One approach to working in a multi disciplinary team which is inclusive of key family or support network members is to define the treatment approach as a team approach with agreed protocols for the sharing of information with team members. In a person centred approach, the person with an eating disorder would be at the centre of decision making about who is included in the team and the scope of information to be shared. This would then create a base for a charter or service contract.

Tertiary consultation is the recommended mechanism to ensure that all health professionals, including General Practitioners and specialists in other health fields, have access when they need it to an appropriate level of specialist expertise. Tertiary consultation can also play a role in convening and supporting the multi disciplinary team when required. The provision of tertiary consultation support also enables people to have access to eating disorders treatment, at least in the first instance, within their local community.

Shared clinical guidelines across health professions and on-going processes of review and shared learning will support the consistent implementation of multi disciplinary evidence based approaches.

Health systems that support collaboration have:

- Tertiary consultation and support accessible to all levels of service provision
- 2. Protocols for a team approach engaging the person, their support network and multiple service providers
- 3. Shared standards and clinical guidelines across disciplines

Other implementation recommendations made in this framework include:

Systems

- Adoption of national standards for the prevention and treatment of eating disorders
- Shared clinical guidelines across health professions
- One consistent introductory training program on eating disorders for all health professionals
- Protocols to support a 'team approach' to treatment
- 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
- Adoption of individual care plans and case coordination to support implementation of complex, multi-provider care plans
- A review of Medicare and health fund criteria for funding eating disorder treatment
- Integration of evaluation or research strategies into all service contexts including new and existing services in treatment, prevention and community support
- Models for participation to support input from people with experience and their carers into all research, evaluation and service development
- National data collection strategies

Service Development

- Support for community based organisations as soft points of entry to treatment
- Review of the current range of services to ensure a full suite of services is accessible, taking into consideration issues associated with the geographic location, economic circumstances and individual treatment needs of people with eating disorders

The Way Forward

Eating Disorders are highly complex illnesses, and their prevention and management requires an integrated, multi disciplinary approach that is continuously informed by research, clinical expertise and the lived experience. Integration and coordination across sectors, services and specializations are essential to address this level of complexity.

The first phase of the NEDC published a suite of documents in 2010, including the first National Framework *"Eating Disorders: The Way Forward"* to provide an evidence based and sector informed introduction to guide the development of responses to eating disorders in Australia.

Building on that foundation, An Integrated Response to Complexity articulates the essential principles for

the effective prevention and management of eating disorders in the Australian context.

Finding the way to implement these principles most effectively presents the next challenge.

Achieving early intervention and prevention will involve collaboration between health, education, sport, the media and related sectors to identify achievable approaches to reducing risk, promoting resilience and early help seeking, and implementing evidence based prevention programs. This can only be achieved with an informed and supportive community.

For the effective management of eating disorders this will involve identifying effective approaches to support multidisciplinary treatment; removing the obstacles posed by economic and geographical challenges; finding practical strategies to ensure that eating disorders specialist knowledge and experience is available to advise and inform every level and aspect of care.

It is clear that the challenge continues to be a significant one. What should not be lost in addressing this challenge is the importance and significance of small steps of change.

National Standards Schema

Principles for the Prevention and Management of Eating Disorders

Person and family centred care that addresses the
needs of individuals
Prioritization of prevention, early identification and
early intervention
Safety and flexibility in treatment options
Partnering to deliver multi disciplinary treatment in a
continuum of care
Equity of access and entry
Tertiary consultation is accessible at all levels of
treatment
□ Support for families and carers as integral members
of the team
Evidence informed and evidence-generating
approaches
A skilled workforce
Communication to ensure an informed and
responsive community
□ Systems support integration, collaboration and on-
going development
These standards are consistent with the National Mental

These standards are consistent with the National Mental Health Standards (2011)

Next Steps for the National Eating Disorders Collaboration

As an evidence based and expert informed document, the National Framework will develop to reflect emerging evidence and good practice. From April 2012 to June 2013 the Framework will be disseminated to all key stakeholders, including state and territory governments and professional bodies, in Australia and will be continuously reviewed in response to feedback.

Stakeholders are invited to join with the NEDC to directly work with the eating disorders sector on mutual problem solving and the development of national standards that are effective for all Australian contexts.

Identifying Opportunities to Develop a Nationally Consistent Approach

In 2012 the NEDC will be working towards identification of opportunities to implement the principles and standards from the National Framework. The focus will be on practical action to implement a nationally consistent approach¹⁴ to eating disorders, in the context of current policy, resources and practice.

The scope of this project will include services, information and resources, professional training and development, community awareness and communication strategies.

To achieve this, the NEDC will be liaising with the key stakeholders involved in the prevention and management of eating disorders in Australia to profile current achievements in this field and identify practical opportunities.

A companion report to the National Framework, with the working title of 'A Nationally Consistent Approach to Eating Disorders: Opportunities to Implement National Standards', will be published in 2013.

Consistent Evidence Based Information

In addition to promoting a consistent evidence based national approach to eating disorders; the NEDC will continue to pursue its objectives of:

- Providing or facilitating access to helpful, evidence based information to young people and their families on the prevention and management of eating disorders and healthy eating;
- Developing and assisting in implementing a comprehensive national strategy to communicate appropriate evidence based messages to schools, the media and health service providers.

Projects for 2012 that will support the implementation of the National Framework include:

¹⁴ For the purposes of the NEDC project, a nationally consistent approach is defined as one in which approaches to eating disorders are developed within a common framework of national standards

• The National Eating Disorders Collaboration Website

To be launched in March 2012, the website will provide a central access point for consistent and appropriate information about eating disorders, including a clearinghouse of recent research on eating disorders. The website will act as a portal facilitating access to other websites providing information and services for people with or at risk of developing eating disorders.

• Prevention and Early Intervention Report

A report detailing evidence based options for early intervention and prevention will be published in 2012 as a key contribution to the implementation of prevention and early intervention principles from the National Framework. This will be supported by workshops for the key frontline professionals engaged with people at risk of developing eating disorders, including school counsellors, teachers, physical activity instructors and youth workers.

• Professional Development Resources

Professional resources and links to professional training will be accessible through the NEDC website. A professional e-network will be accessible through Facebook. The series of Annual National Workshops will be continued in 2012.

• Developing Community Understanding of Eating Disorders

Raising awareness will require a partnership approach:

- The NEDC will work with existing providers of information, health promotion and prevention programs to identify mutual needs and align information resources
- The NEDC will work with professional associations and peak bodies to identify resource and training needs and to promote the awareness of the warning signs of eating disorders.
- The NEDC will work with State and Commonwealth governments to identify social marketing opportunities to promote awareness of eating disorders amongst adults, with a focus on families, frontline professionals, young people and adults in target 'at risk' groups.

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 help develop a nationally consistent approach to the prevention and management of Eating Disorders. This is a long term approach.

The NEDC invites all stakeholders to join in the continuing collaborative problem solving that will lead to an effective nationally consistent approach to eating disorders in Australia.

For more information about the National Eating Disorders Collaboration and this report please contact the National Director of the NEDC and CEO of the Butterfly Foundation, Christine Morgan at:

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Appendices

Appendices in this report:

1. Treatment Options: An Overview

Appendices available as separate documents:

- 2. Eating Disorders: A Current Affair an introduction to eating disorders
- 3. References
- 4. Evidence from Experience Report

Appendix 1 Mental Health Interventions: An Overview

The evidence base for effective treatment is limited, in part due to the complexity of eating disorders and the challenges in implementing randomized controlled trials of significant size. The evidence that is available only evaluates a small proportion of the treatments available and the people requiring treatment. Few trials, for example, identify the appropriateness of treatments for males, specific cultural groups or sexual minorities. Limited evidence does not equate with limited effectiveness. There is a need to continuously evaluate treatments and monitor emerging research to identify promising as well as proven practice.

This appendix provides brief information on mental health interventions that are specific to eating disorders that are established in clinical practice and have the best evidence support at this point in time, together with an indication of areas of emerging evidence.

Psychotherapy is one important component of safe treatment. It should be delivered as part of a multi disciplinary approach that includes nutritional and physical health assessment and intervention, and assessment and treatment of co-morbid conditions. For children and young people, family education and support should also be considered as part of the essential suite of treatment actions to ensure safety.

Depending on individual needs, adjunctive medication, physical therapy, occupational therapy and education may also be essential components of treatment.

Family Based Treatment

FBT is currently the best-established treatment for adolescents with anorexia nervosa demonstrating efficacy (Smith & Cook-Cottone, 2011). On the basis of current evidence, FBT should be made available to adolescents with anorexia nervosa, in line with the recommendations of key eating disorder guidelines (American Psychiatric Association, 2006; NICE, 2004). The choice of FBT as the treatment model should be made in the context of the national standards, identifying the best treatment options for the person and their family and working flexibly with the person and their family within the evidence based treatment model, as required.

Family therapy, or family systems therapy, is a form of psychotherapy that aims to alter the intrinsic modes of function of the family. Family-Based Treatment (FBT) specifically refers to a manualised treatment modality originally developed at the Maudsley Hospital in London, which has come to be known as the "Maudsley Method".

Loeb & Le Grange (2009, p.244) define FBT as:

"FBT for adolescent AN is a short-term treatment designed to mobilize parents in assisting their ill child reverse his/her state of starvation acutely and ultimately achieve remission from AN... FBT challenges the practical factors maintaining the AN, such as allowing the ill adolescent to make his/her own food choices, and makes no assumptions about the cause of AN. The treatment does not presuppose a familial pathology and in fact works to reduce parental self-blame regarding etiology. Moreover, FBT externalizes the illness, thereby reducing blame toward the ill adolescent for the symptoms s/he is experiencing."

A FBT manual has been published titled *Treatment Manual for Anorexia Nervosa: A Family-Based Approach,* supporting fidelity in implementation of the treatment model and aiding efficacy and research.

Fisher, Hedrick and Rushford's Cochrane Review (2010) of family therapy approaches for adolescents with anorexia nervosa, compared the efficacy of family therapy with standard and other treatments. The review found that there is some evidence to suggest that family therapy may be effective compared to standard treatment. Recovery rates of between 74 and 90% have been recorded for adolescents participating in FBT with a history of illness of less than one year (Lock, Couturier, & Agras, 2006). The drop-out rate from FBT is low compared to most other treatments for psychiatric problems.

However, FBT may not be easily implemented in different family contexts (Couturier, Isserlin, & Lock, 2010). Two of the factors that should be taken into consideration when offering FBT to families include:

- **Duration and type of illness** FBT provides an effective first line of intensive treatment early in the course of illness (Lock ,et al., 2006). Outcomes may be more significant and sustainable in patients with an onset of illness before age 18, and duration of illness of less than three years (Couturier, et al., 2010).
- Extent of family resources FBT places considerable demands on the family. There is an expectation that all members of the family will be actively involved which may necessitate parents taking time away from work, disruption of sibling schedules, and complicated travel arrangements (Eisler, Lock, & Le Grange, 2010). While two studies have been published suggesting that families find FBT to be an acceptable treatment (Eisler, et al., 2010), some single parent families, low income families, and families in which other family members have specific support needs may experience difficulty with the FBT treatment approach. These families may require additional support to implement FBT.

Positive research findings support the usefulness of FBT. The evidence base is still developing and there is no comparable level of research to indicate whether other treatment approaches might work equally well or differently in comparison to FBT (Eisler, et al., 2010).

Family Based Treatment - Variations

The FBT model has continued to be developed since its introduction in the 1980's and a number of variations address the needs of different families, children, young adults, and patients with bulimia nervosa e.g.:

- Separated FBT Parents are seen separately from the child. Originally conceived to help families with high expressed emotion, identified as the families most likely to drop out of the original FBT mode of treatment. (See Le Grange, Eisler, Dare, & Russell, 1992; Eisler, et al., 2000; Eisler, Simic, Russell, & Dare, 2007)
- FBT for Bulimia Nervosa a more collaborative process between parents and child (See Le Grange, Crosby, Rathouz, & Leventhal, 2007; Le Grange, Crosby, & Lock, 2008)
- Multiple Family Group FBT (See Eisler, et al., 2010)
- Intensive FBT –5-day program based primarily on FBT but including other ideas (See Rockwell, Boutelle, Trunko, Jacobs, & Kaye, 2011)
- Family Admission FBT 2-week whole family admission to hospital for intensive FBT plus other treatments (See Wallis, et al., in press).
- Young Adult FBT FBT targeting young adults (See Chen, et al., 2010)
- FBT with added parent to parent consultation standard FBT with the addition of a session for parents to meet successful parents to get ideas (See Rhodes, Baillee, Brown, & Madden, 2008)
- FBT for prodromal clinically significant presentations of anorexia nervosa (See Loeb, Craigen, Goldstein, Lock, & Le Grange, 2011)

While these adaptations have received preliminary support there is no clear evidence of effectiveness at this point in time. However, they have all developed from the original values and tenets of FBT and are developed from an evidence based foundation. The decision to implement one of these variations should be made in the context of the emerging evidence, identifying the best treatment option for the person and their family.

Cognitive Behavioural Therapy (CBT)

There is now a clear convergence of data from the more traditional review of published research as well as meta-analyses that the treatment with the most empirical support for the treatment of bulimia nervosa and binge eating disorder is manual based cognitive behaviour therapy (CBT) (Wilson, 2005). CBT provides a collaborative, problem focussed and present-future oriented approach.

CBT for Bulimia Nervosa (CBT-BN)

CBT-BN addresses the overvaluation of body shape and weight which is the core psychopathology of Bulimia Nervosa (Fairburn, 1981; Fairburn, Marcus, & Wilson, 1993). CBT-BN focuses on reducing the behavioural symptoms of the disorder (dieting, binge eating, purging) and the distorted cognitions about body weight and shape.

CBT-BN is conducted over a series of 18-20 sessions that initially may be twice-weekly, decreasing to weekly and then having one or two follow-up sessions over a period of around four months. The first involves psycho-education and the introduction of regular eating. The second broadens the focus to all forms of dieting, and addresses cognitive distortions, especially those concerning weight and shape. The

third stage focuses on maintenance and relapse prevention. The goal of therapy is normalising eating patterns and reducing extreme weight and shape concerns. By the end of therapy, the goal of a regular pattern of eating of varied and normal-sized food portions should be achieved. Binge-eating and self-induced vomiting and other behaviours should be reduced or absent and food, eating and weight no longer central to the patients self-view.

The treatment has been empirically validated, and is endorsed by the National Institute for Clinical Excellence (2004) and by the American Psychiatric Association (2006). It has been tested in many randomised controlled trials (RCTs) and a number of systematic reviews have been conducted with all consistently finding CBT to be well supported. In these reviews (NICE, 2004; Shapiro, et al., 2007; Hay, et al., 2010), CBT has been found to be superior to weight list control groups with abstinence rates of 40% or more at the end of treatment, compared to much lower (as low as 10%) abstinence rates for weight list control groups. It has also been found superior to other psychotherapies, most notably Interpersonal Psychotherapy (IPT), in the short-term. However, at one year follow-up, there are reduced differences in outcomes between CBT-BN and Interpersonal Psychotherapy. CBT has also been found to be effective compared to pharmacotherapy, most notably anti-depressant therapies (Hay & Claudino 2012?). Research indicates that half of patients, who receive CBT-BN, will make a full and lasting response (Fairburn, Cooper, & Shafran, 2003).

Enhanced CBT (CBT-E)

Because of the recognition of common features among different ED diagnoses and the relatively low recovery rate in CBT-BN, Fairburn and his colleagues developed a trans-diagnostic theory and treatment (Fairburn, et al., 2003; Fairburn, 2010). This 'Enhanced' CBT (CBT-E), designed to treat all types of EDs, identifies the possible role of four additional maintaining mechanisms (mood intolerance, core low-self esteem, interpersonal difficulties and perfectionism,) which are hypothesised to contribute to, and/or interact with the restrict-binge-purge cycle identified in BN. The trans-diagnostic model also accounts for symptoms observed in AN, where dietary restriction results in severe weight loss and starvation.

There are four stages in CBT-E. Stage One involves engagement, psycho-education, the creation of an individualised formulation and the introduction of regular eating. Stage Two is a review. Stage Three involves addressing the overvaluation of control over eating, weight and shape, and the mechanisms maintaining this. Stage Four focuses on maintenance of progress and prevention of relapse.

There are two forms of CBT-E: Broad (CBT-Eb) which includes addressing (in Stage Three) one or two additional maintaining mechanisms if relevant; and Focussed (CBT-Ef) which does not. Mood intolerance is now included in both forms. This module involves education about moods and offers cognitive and behavioural interventions to prevent exacerbation of moods and to accept mood states. Problem solving and alternate mood modulation strategies are introduced and practiced via behavioural experiments.

Core low self-esteem is addressed through exploring and challenging the cognitive schemas that promote core beliefs e.g. selective attention to information that supports a negative view of self-worth.

The interpersonal module closely follows that developed by Fairburn et al. (1991) and Fairburn (2010) as a standalone control therapy for CBT-BN. Clinical perfectionism and the need to attain this through the eating disorder is also explored in a formulation that mirrors that of the role of over-concern about weight and shape in promoting ED behaviours.

Outpatient CBT-E has been evaluated empirically in three studies, and shows promising results. A RCT (N=154) in the UK (Fairburn, et al., 2009) included people with BN and EDNOS and a BMI of >17.5, and a community-based effectiveness trial (N=125) in Australia (Byrne, et al., 2011) included people with the full spectrum of diagnoses, including AN. By the end of treatment, both studies found strikingly similar outcomes in those who completed treatment: 66% had achieved 'good outcomes' and about 40% had achieved binge-purge abstinence. The community-based study is the only published account of the effectiveness of CBT-E with AN. Half of those with AN who completed treatment achieved a 'good outcome', a rate that was not significantly different to that found in other diagnoses. However, the dropout rate was high for patients with AN (around 50%)

Further research is required to compare CBT-E against other alternatives, however at present; CBT-E appears to be a promising trans-diagnostic treatment.

Interpersonal Psychotherapy

Interpersonal Psychotherapy (IPT) is recognized by the NICE guidelines (2004) as an appropriate treatment for adults with bulimia nervosa and binge eating. IPT is a short-term and goal-oriented therapy that is based on the belief that interpersonal problems led to the development and the maintenance of the eating disorder. The goal of treatment is to identify areas of interpersonal problems and address these in order to reduce eating disorder symptoms. Sessions are held weekly and treatment generally takes up to 6 months. IPT can be offered as an alternate therapy to CBT but may take longer to achieve a desired outcome for people with bulimia nervosa (Fairburn, et al., 1991; Agras, Walsh, Fairburn, Wilson, & Kraemer, 2000).

Specialist Supportive Clinical Management (SSCM)

SSCM is an integrated, non-specialized therapy for anorexia nervosa. The primary goals of SSCM are the resumption of normal eating and the restoration of weight. These goals are achieved through the development of a supportive and positive relationship between the patient and therapist that facilitates the return to normal eating and enables other life issues that impact on the eating disorder to be addressed. SSCM has demonstrated efficacy with adults with anorexia nervosa in research trials (McIntosh, et al., 2006).

Emerging Evidence

The evidence base for the treatment of eating disorders continues to develop. A number of current and recent evaluations or trials have shown promising results and these should be taken into consideration National Framework March 2012 95

when considering the most appropriate treatment option. Promising results have been demonstrated for cognitive analytical therapy, focal psychodynamic therapy, couples-based cognitive behavioural therapy, cognitive remediation therapy, exposure and response prevention therapy, parent/carer skills based training and variations on family based treatment.

Application of Treatment Options

No single treatment approach has been shown to be effective for every person with an eating disorder therefore the selection of approaches must always take into consideration the individual, their family and social context, the diagnosis, the stage and longevity of illness, and comorbid conditions.

Clinical Guidelines

New guidelines are required to support a nationally consistent approach to eating disorders in Australia.

In the absence of these guidelines, there are a number of established treatment guidelines, which may be helpful including: NICE, APA and RANZCP. Evidence on effective and safe treatment approaches continues to emerge and these guidelines should be implemented in the context of this emerging evidence. When determining which guidelines to utilise, the date of publication should be taken into consideration and the guidelines should be interpreted in the context of the clinical environment, the individual patient and the national standards for eating disorders treatment.

Treatment Options for Anorexia Nervosa

There is no standard treatment as yet for people with anorexia nervosa (Strober, 2009). For adolescents, FBT is currently the treatment with the strongest evidence base. "There is no evidence to support the use of one treatment or setting over another" for adults with anorexia nervosa, particularly those with a more chronic form (Fairburn, 2005).

The literature supports the view that effective well delivered psychotherapy in combination with good quality nutritional rehabilitation is more effective than 'treatment as usual' for people with Anorexia Nervosa, and specialist care is more effective than non-specialist care.

CBT has had some success. Pike, Walsh, Vitousek, Wilson and Bauer (2003) found that CBT-AN had a better outcome and longer time before relapse when compared to nutritional counselling therapy following hospital care and weight gain restoration. Amongst malnourished people with anorexia nervosa, McIntosh et al. (2005) found that SSCM was superior to IPT and CBT, demonstrating a faster rate of recovery. However, at 7 year follow-up, outcomes were equivalent for all three therapeutic approaches with a good outcome in 49% of participants (Carter, et al., 2011).

Enhanced Cognitive Behaviour Therapy (CBT-E; Fairburn, et al., 2003; Fairburn, 2010) is showing early promising results. Unpublished data from the UK and Italy, and an effectiveness study from Australia

(Byrne, et al., 2011) which included people with Anorexia Nervosa, indicate that provision of CBT-E over approximately 40 sessions is as effective treatment for people with Anorexia Nervosa.

Treatment Options for Bulimia Nervosa

Patients with bulimia nervosa should be treated in an outpatient setting by clinicians with the appropriate training and skills in CBT or IPT. The National Institute of Clinical Excellence (NICE) has given CBT the grade of A for treatment of bulimia nervosa reflecting the strength of empirical data. This represents the first occasion that NICE has recommended a psychological therapy as the initial intervention for a psychiatric disorder (Carney, et al., 2006).

There is a growing body of evidence (NICE) that guided self help (GSH) can be used effectively as the first line of treatment for bulimia nervosa (Wilson, 2005). GSH can be administered by an experienced nurse therapist or general practitioner in a primary care setting with referral to a more experienced therapist only required for patients who fail to progress in treatment. Treasure, et al., (1994) have shown that GSH is helpful as a first step in managing bulimia nervosa.

Alternative treatments should be explored if the patient fails to progress using these approaches. Despite CBT being the treatment of choice approximately 40% of bulimia nervosa patients fail to respond (NEDC, 2010). Less than half of people with bulimia nervosa have been found to be abstinent at follow-up (Fairburn & Harrison, 2003) with a typical drop-out rate of about 25% (Shapiro, et al., 2007). CBT-E is a promising treatment which in early studies has been shown to have better outcomes than CBT-BN.

Only when there is intractable bingeing, evidence of suicidal intent, uncontrollable exercising or worrisome medical complications such as extensive vomiting and/or hypokaelemia, should an admission to hospital be considered.

Treatment Options for Binge Eating Disorder

There are several options for psychological therapies for patients with binge eating disorder (BED) that have some empirical support. The manual-based CBT for BED has the most support with interpersonal therapy (IPT) and dialectical behavioural therapy (DBT) also showing promising results (Wilson, Wilfley, Agras, & Bryson, 2010; Robinson & Safer, in press). CBT-E has also been shown to be successful in a study which included participants with BED.

A stepped care model is appropriate for BED, in which patients are first exposed to GSH. Should they fail to respond to either GSH then either CBT, CBT-E, IPT DBT can be brought into play.

The setting for the delivery of treatment for patients with BED must be taken into consideration. Some patients with binge eating disorder (BED) are overweight or obese and may be referred to obesity clinics National Framework March 2012 97

where there is often little or no expertise in managing binge eating behaviours. On the other hand, they often feel alienated and disinclined to continue with treatment in eating disorder units which focus on the treatment of anorexia nervosa.

Weight disorders and obesity

There is evidence that obesity is a serious and common outcome for people with bulimic eating disorders and binge eating disorder (Fairburn, Cooper, Doll, Norman, & O'Connor, 2000). Patients who are overweight may require help in addressing weight-loss. However, this is very variable and many patients at the end of therapy conclude that they are comfortable with their weight, albeit that their BMI has not changed (Paxton & Hay, 2009).

Weight stabilisation with normalisation of eating patterns and attitudes and beliefs about eating and eating behaviour may be a better initial goal than weight loss (Paxton & Hay, 2009).

For those who have a BMI higher than 30 and/or complications such as diabetes, initial stabilisation for the eating disorder may be followed by a supported weight loss program, mindful that weight loss need only be very modest, around 5-10% of body weight, to help prevent diabetes and cardiovascular disease (NHMRC 2003b, Vidal, 2002).

It is important that patients are educated and encouraged to set modest weight loss goals, as studies on the factors relating to weight regain following obesity treatment, have indicated that those people who regain weight are more likely to set unrealistic weight goals, not reach these goals, and remain dissatisfied with weight following any weight loss (Byrne, Cooper, & Fairburn, 2003).

It is also important that weight loss advice and treatment does not undo the work achieved in CBT including eliminating dieting. Strategies should be individualised for each patient and will depend on their current eating behaviours, dietary intake and physical activity levels (Paxton & Hay, 2009).

Some strategies that may be employed to assist the patient achieve minor weight loss include; encouragement to increase physical activity; minor alterations to meal and snacks choices to ensure meal patterns and serving sizes are in line with dietary guidelines, and not too many choices are excessively high in energy whilst low in other nutrients; education on cooking methods; education on how to read nutrition information panels on processed foods to enable the client to make informed decisions when choosing between two or more similar products; and strategies to modify 'unhealthy' patterns such as eating when stressed or habitually overeating when not hungry. It is always important to emphasise health and that having a healthy diet and healthy levels of physical exercise is more important than any absolute weight (Paxton & Hay, 2009).

Treatment Options for Variant Presentations of Eating Disorders (EDNOS)

Patients with a diagnosis of EDNOS constitute the majority of patients seen at eating disorders facilities across Australia. These disorders are considered to be as clinically severe as anorexia nervosa and bulimia nervosa. Despite this, there is no evidence-based literature to inform treatment. NICE (2004) guidelines provide good pragmatic advice to follow.

In the absence of evidence to guide the management of Eating Disorders Not Otherwise Specified, it is recommended that the clinician consider following the guidance on the treatment of the eating problem that most closely resembles the individual patient's eating disorder (p 71).

CBT-E has been shown to be successful in a study where more than half the participants were diagnosed with EDNOS (Byrne, et al., 2011).

The following table summarizes the principle evidence based approaches to treatment that are currently in use. This table has drawn on research evidence and internationally recognised consensus of expert opinion, including NICE guidelines (2004) and the NEDC Evidence Review (2010). It provides an overview of evidence based prevention and treatment approaches which are discussed in more detail in the relevant chapters of the National Framework. The table does not purport to include all possible forms of prevention or treatment.

Core	Tertiary Consultation and Professional Development						
Standards	Multi disciplinary treatment						
	Intervention early in treatment and early in episode Individually tailored and coordinated care						
Level of	Primary Care	Secondary Care	Tertiary Care	Recovery Support			
Care	Universally accessible early intervention	First-line therapies and treatments,	Specialized care that includes advanced	Tertiary Prevention with strategies to reduce			
	and treatment provided in the community: diagnosis, initial care and facilitation of treatment pathways	provided by medical specialists usually in a hospital outpatient or inpatient setting	diagnostic capacity, specialist treatment and consultation for people with complex needs.	the impact of mental ill-health on a person's life through approaches such as rehabilitation and relapse prevention. It also includes actions to ensure people have access to supports within the community.			
Focus of treatment	 Psychological intervention with Medical monitoring Coordination of other health and social support services e.g. Dietitian, OT, Physiotherapy, Social Worker, Support Service Recovery and wellbeing services 	 Inpatient medical care for physical resuscitation or stabilization Outpatient multidisciplinary treatment Psychotherapy and/or inpatient psychiatric intervention if needed Nutritional counselling Medical monitoring Physiotherapy 	 Specialist eating disorder inpatient services Specialised outpatient services e.g. day and residential programs Nutritional psychotherapy Medical monitoring Recovery and wellbeing services (meal support therapy, nutritional assessment and education) Physiotherapy 	 Psychological intervention with Medical monitoring Coordination of other health and social support services e.g. Dietitian, OT, Physiotherapy, Social Worker, Support Service Recovery and wellbeing services 			
Location	Services provided in the local community		Services provided in hospital or specific purpose medical centres				
Evidence based approach	 Cognitive behavioural therapy Nutrition education and support Cognitive behavioural therapy 			 Recovery programs (e.g. meal support therapy, nutritional assessment and education) 			
			jement	Peer support and telephone support services			

Eating Disorders Treatment Table

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Common to all eating disorders	Specific to anorexia nervosa	Specific to bulimia nervosa	Specific to Binge Eating Disorder	Specific to Eating Disorder Not Otherwise Specified
 GP monitoring weight and medical complications Local eating disorder support provided through community based organisations. Psychotherapy. CBT-E Mindfulness Therapy Anxiety / stress management Nutritional management/monitoring/support Psychoeducation Supportive family education Combined treatments e.g. psychotherapy + nutritional rehabilitation + medication 	 Family based treatment Motivational Interviewing Interpersonal Psychotherapy (IPT) Specialist (Formerly Nonspecific) Supportive Clinical Management Nutritional rehabilitation/refeeding Adjunctive medication e.g. antipsychotices 	 CBT guided self-help Mindful eating/nutritional management Crisis intervention Family based treatment for children and adolescents Adjunctive medication e.g. antidepressants 	 CBT guided self-help/pure self-help Interpersonal Psychotherapy (IPT) Behavioural weight loss e.g. Lifestyle, Exercise, Attitudes, Relationships & Nutrition (LEARN) program Adjunctive medication e.g. antidepressants Obesity treatment/obesity medication Combined treatments e.g. Psychotherapy + behavioural weight loss + medication 	Treatment follows the eating disordered behaviours most like AN, BN or BED

Treatment Approaches

Appendix 2 Steering Committee Members

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Founder and Director of the Butterfly Foundation

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