EATING DISORDERS
THE WAY FORWARD
An Australian National Framework

The National Eating Disorders Collaboration
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the Commonwealth Department
of Health and Ageing
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Foreword from the Chair

**Eating Disorders: The Way Forward - An Australian National Framework** seeks to address the pervasive and grievous cruelty of a serious mental illness within our community, that of eating disorders. The statistics are alarming. For example, 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. Anorexia Nervosa has the highest rate of mortality of all psychiatric disorders.

However, to this point at least, the national focus on eating disorders has been fragmented, under-funded, and under-researched. There has been a notable lack of resources directed at prevention, early intervention, treatment and research for eating disorders in Australia. There are no national standards of care, no national patient data register, and a scarcity of evaluated research outcomes. The result is a glaring lack of parity for eating disorders with other major illnesses and diseases that result in similarly high mortality rates and burdens on sufferers, carers and the health system.

The needs are starkly plain - to break down systemic barriers within a system of health that is failing to adequately cater for eating disorders; to continue to develop a system that is based on evaluated outcomes; and to retain the capacity for creativity and flexibility to ensure that we continue to adopt best practice going forward.

We also cannot shut our eyes to cultural change where this is appropriate and necessary to fully respond to the needs of those who we seek to serve by this process - sufferers, carers and health service professionals. This will require innovation in our administrative arrangements so as to facilitate cooperation between public and private health systems; and, in recognition of the multi-faceted nature of the illness, the spreading of responsibility for treatment and prevention beyond health to education, youth, sport, women and the community.

The opportunities presented by the Australian National Framework are as exciting as they are profound. It is an opportunity to open the pathways to prevention, early intervention, treatment and support; to increase community awareness and understanding of the problem so as to facilitate pathways towards successful prevention and treatment; to address the underlying cultural contributing factors; and build a society that places less emphasis on personal looks and more emphasis on internal values within individuals. Perhaps above all, there is an opportunity to build resilience and a sense of self-worth which is so desperately lacking in many of our young people. This is a cry we cannot ignore.

The National Framework will provide the single most significant step forward in the history of the illness in this country.

Through it we enter a bold new era in the field. The project identifies an opportunity for the Australian eating disorder health professionals to break new ground – to make more broadly accessible what is known to work, to explore the depths of that which is unknown, and to test the outcomes in programmes of rigorous evaluation.

**Eating Disorders: The Way Forward** is a remarkable enterprise. It has been the product of a unique collaborative effort drawn together from the many researchers, clinicians, consumers and stakeholders Australia wide. Together they identify what we know and what we don’t know and how we should proceed on the future voyage of discovery.

My deep thanks are extended to all of you who have participated. It is upon your broad and solid foundation we can so confidently charter the way forward.

Claire Vickery
Chairperson
National Eating Disorders Collaboration
The development of this Australian National Framework – *Eating Disorders: The Way Forward* - and its suite of supporting reports has been a truly 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.

The formal members and supporters of the NEDC are identified in Appendix B of this report. The support provided by these organisations has been critical to the success of the NEDC.

There are also many individuals – people with a lived experience, family members and carers, clinicians and volunteers – who have helped to make the Review Forums and the Australian National Workshop successful. Their drive, commitment and valuable experience are reflected in the outcomes of the NEDC.

Finally, particular thanks must go to the members of the Steering Committee who have made an extraordinary contribution through their leadership of the NEDC.
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Executive Summary

Eating Disorders are highly complex mental illnesses that also involve significant physical impairment and medical complications. Although there are several defined categories of Eating Disorders, they present in many different variations and their treatment and management requires an individualised, flexible and multidisciplinary approach.

Eating Disorders occur most frequently in adolescent girls, although all ages and both genders can be affected. They have been experienced in someone as young as 7 and as old as 70 years. Eating Disorders can be fatal and the morbidity rate is the highest of psychiatric illnesses. There is also a high level of co-morbidity with other psychiatric illnesses, including depression, anxiety, personality disorders and substance abuse.

The causes of Eating Disorders continue to be explored, and form a key focus of research in the sector. While no single cause has been identified, there are known risk factors, one of the highest of which is disordered eating and dieting. Not everyone who diets will develop an Eating Disorder, but everyone with an Eating Disorder has a history of dieting and disordered eating. Disordered eating has become a societal norm in Australia, doubling in the last decade. Our young people, in particular, are engaging in these potentially harmful behaviours at increasing rates.

The costs to the individual and community are high. The burden of disease and injury measured in disability adjusted years is in the top 10% of all illnesses; treatment options both in and out of hospital are expensive; the illnesses affect not only sufferers but also their families; and they most commonly occur at what is potentially the most exciting and developmentally important time in a young person’s life – in their teens and early twenties.

The Eating Disorders sector in Australia includes clinicians, researchers, community based organisations, carers and families, and, of course, those with the lived experience of an Eating Disorder. Due to funding, resource and time constraints it has historically been a fragmented, albeit committed, sector.

The National Eating Disorders Collaboration (NEDC) is an initiative supported and funded by the Commonwealth Department of Health and Ageing with the aim of bringing together all those involved in the Eating Disorders sector, and others from education, media and industries such as fitness and fashion to develop a consistent, coordinated national continuum of care approach to the promotion, prevention, early intervention, treatment and management of Eating Disorders in Australia.

The work of the NEDC has been based on identifying, analysing and then building on the available evidence. Every voice in the collaboration has been an important one in contributing to the current knowledge base.

This work has identified key recurring issues:

- Significantly more research is needed to evaluate treatment services that are being used by clinicians and which appear to have a positive impact for consumers and carers.
- There is no national patient register and this severely impacts on the ability to accurately and fully assess the incidence of Eating Disorders.
- Prevention programs need funding to ensure they can be properly piloted and evaluated – the maxim of ‘first do no harm’ is a paramount one but the urgency to act is very real.
- Early intervention initiatives need to be accessible to all with pathways into care needing urgent improvement.
- Workforce development programs are needed across all areas of health and education.
- Treatment services need to be multidisciplinary, individualised, flexible and be provided in a continuum of care.
- Consumer and carer opinion needs to be better coordinated into all stages of the prevention, treatment and management of Eating Disorders

- The community needs to be educated on Eating Disorders - that they are a serious mental illness with high physical impairment – negative stigma must be removed.

Underpinning all of these issues is the need to raise Eating Disorders to being a mainstream health priority in Australia.

In addressing these key issues the priorities for action become clear:

- Increased research funding and coordination of research activities

- Piloted and evaluated prevention programs in schools and elsewhere

- Development of multidisciplinary treatment options delivered in a continuum of care

- Treatment services to be individualised, flexible and accessible to all

- Workforce development in health, allied health, education and youth sectors

- Increased awareness campaigns aimed at educating the community and reducing stigma

Underpinning the deliverability of these improvements is a sophisticated, effective communications strategy.

The work of the NEDC provides a basis for a quantum shift and lift in the Eating Disorders sector. With access to increased resources, a clear focus on the pathway ahead and what is needed to make a real difference as outlined in this National Framework, and the coordination of activities that can be done in an ongoing collaboration, there is a real opportunity for Eating Disorders to be raised to the level of a mainstream health priority in Australia.

The fundamental principles outlined in the Worldwide Charter for Action on Eating Disorders resonate with the vision and aims of the NEDC. It is possible to recover from an Eating Disorder; it is possible to prevent an Eating Disorder. By harnessing the experience, skills and strengths of the sector and combining this with a real commitment from government and the community those who are affected by or who are at risk of developing an Eating Disorder can receive the services they so urgently need – and deserve.
CHAPTER 1
Purpose of the National Framework

Eating Disorders are highly complex illnesses, with significant psychological and medical issues. They present in many different ways in patients, and their treatment requires a sustained, flexible and multidisciplinary approach. There are no easy answers.

In 2010 Australia does not have a coordinated, contextualised, evidence based framework to guide Eating Disorders promotion, prevention, and treatment. Resources, including treatment options, for people with Eating Disorders or people who are at risk of Eating Disorders in Australia are currently insufficient and those that do exist are inaccessible to many.

The Eating Disorders National Framework has developed from the activities of the National Eating Disorders Collaboration (NEDC) during 2009 which have included an in-depth review of the current evidence base for approaches to Eating Disorders and national consultation with practitioners, consumers and carers and other interested stakeholders.

"Eating Disorders: The Way Forward" provides an evidence based and sector informed framework to guide the development of responses to the promotion, prevention and treatment of Eating Disorders in Australia.

As the first National Framework for Eating Disorders, this report identifies a range of evidence based strategies that could contribute to a reduced incidence of Eating Disorders in Australia and increased availability of effective treatment and support to enhance the health and quality of life of people who have an Eating Disorder. The Framework takes a staged view of development for the sector through planned, progressive and comprehensive actions.

In developing this framework, the NEDC has drawn upon research evidence and consultation with clinicians, researchers, community based organisations, consumers and their carers and other interested stakeholders.

The National Framework is one component of a suite of documents which are intended to be read together to provide a complete and evidence based picture of the current status of Eating Disorder promotion, prevention and management in Australia.

The full suite of documents comprises:

1. Eating Disorders Prevention, Treatment and Management: An Evidence Review
2. Eating Disorders Information and Support for Australians: Resources Review

The effective promotion, prevention and treatment of Eating Disorders require a ‘whole of community’ and ‘whole of Government’ approach.

The Eating Disorders National Framework will be used to support effective, coordinated and cost effective collaboration and development within the Eating Disorders sector, and between the Eating Disorders sector and other sectors that contribute to the prevention, early identification and provision of care for people living with or at risk of an Eating Disorder.

The NEDC’s objectives in preparing this framework have been to:

- Disseminate the findings of the NEDC research and consultation processes
- Provide evidence based information on Eating Disorders for the Australian community
Identify principles and priorities for the development of the Eating Disorders sector and approaches to the promotion, prevention and treatment of Eating Disorders in Australia

Identify the key stakeholders who should be engaged in the development of approaches to Eating Disorders

Provide indicative guidelines for the development and implementation of communication strategies.

The National Framework has developed around four key aspects of the continuum of care: Promotion and Prevention, Identification and Early Intervention, Treatment Standards and Strategies, and Consumers and Carers.

The framework conveys a shared, informed vision to address the gaps between the current and desired management of Eating Disorders, across the full spectrum of health promotion. The framework offers guidelines for action and encourages partnerships between the Eating Disorder sector, levels of government, the health care system, and other sectors whose interests or activities overlap with the Eating Disorder sector.

Vision

As serious mental disorders with significant consequences for physical health and quality of life as well as mental health, Eating Disorders require the same quality, breadth and accessibility to treatment as other serious physical or mental illnesses.

The collective vision of the NEDC encompasses effective treatment and support for people living with an Eating Disorder and their carers, and a collaborative approach to prevent the development of Eating Disorders, including reducing the stigma associated with Eating Disorders to foster increased awareness, prevention and accountability. The vision consists of three parts:

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, treatment, care and ongoing recovery support.**

The Eating Disorders National Framework has been developed to work towards this vision by fostering a collaborative, coordinated and evidenced based approach to the research, promotion, prevention and treatment of Eating Disorders to reduce the incidence and impact of the illness and to engage the whole of community and the whole of government.
There are several types of Eating Disorders, including Anorexia Nervosa, Bulimia Nervosa, and a group of disorders classed as ‘Eating Disorders Not Otherwise Specified’, which includes Binge Eating Disorder. It is not uncommon for a person to progress from one Eating Disorder to another, for example somebody with Anorexia Nervosa may later develop Bulimia Nervosa or Binge Eating Disorder, and vice versa.

Eating Disorders involve both abnormal eating behaviours and psychological disturbance. Abnormal eating behaviours include:

- Binge eating (consuming large amounts of food in a short period of time with a sense of loss of control)
- Behaviours designed to rid oneself of food and/or control shape or weight, such as self-induced vomiting, excessive exercise, laxative misuse, diet pills, diuretics, drugs, and excessive dietary restriction (e.g. fasting, skipping meals, and cutting out entire food groups).

Psychological disturbances may include an intense fear of becoming fat, disturbed body image, denial of the seriousness of low weight, and exaggerated emphasis on weight and shape in relation to one’s self-worth.

There is a high level of co-morbidity of psychiatric illnesses with Eating Disorders. It is important to recognise and address the range of co-morbid conditions that can affect sufferers.

Eating Disorders defy classification solely as mental illnesses as they not only involve considerable psychological impairment and distress, but they are also associated with major wide-ranging and serious medical complications, which can affect every major organ in the body.

Common Misconceptions about Eating Disorders

Eating Disorders are often poorly understood and underestimated in contemporary society. There are mistaken beliefs that Eating Disorders are about vanity, a dieting attempt gone wrong, an illness of choice, a cry for attention or a person ‘going through a phase’. Eating Disorders are also frequently believed to affect only adolescent girls.

The NEDC Youth Consultation identified significant levels of stigmatising attitudes amongst 12–17 year olds; 51.3% of 12-17 year olds strongly agreed or agreed that a person with an eating disorder should “snap out of it, there are more important things in life to worry about”.

“There is such a stigma towards Eating Disorders; we have come across an unbelievable amount of judgement over it. To just get out there that it is an illness like so many others would be a huge start and to be able to lose some of that judgement”

NEDC Messageboard Forum
These types of misconceptions are not limited to the general public but all too commonly affect the responses and explanations sufferers receive when they present for help from general practitioners. This leads to a failure to detect and treat these serious illnesses, as well as causing great distress to the individuals who need help.

Onset and Duration

The onset of an Eating Disorder most commonly occurs in adolescence but may occur as young as 7 or as old as 70. There is evidence of two peak periods occurring at puberty and late adolescence. The average duration of Eating Disorders is five to seven years although early diagnosis and intervention can greatly reduce this duration. Binge Eating Disorder appears to have an onset in early adulthood in the early to mid twenties.

Regardless of age of onset, 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, and then waiting again for access to treatment. People with Eating Disorders often hide, disguise or deny their symptoms until it is impossible to do so any longer. Then they may see several doctors before receiving a correct diagnosis. Each delay is likely to further influence duration of the illness and outcomes of treatment.

The long average duration means that care, support and resources are necessary across the whole lifespan, yet these are frequently hard to obtain at stages other than the acute phase of the illness.

“My recovery was (and still sometimes is) a slow, plodding process filled with relapse. Possibly the hardest thing for me to accept was that I would never be finished with recovery. I understand now that it’s ongoing and I will continue to recover throughout my life.”

Female, Personal Story, reproduced courtesy of EDV

“I managed to keep my ED a secret for 12 years before I finally told someone…”

NEDC Messageboard Forum
Risk Factors

While some work has been done on the causes of Eating Disorders, this remains an area that is not well understood. No single cause has been identified.

Like most other psychiatric and health conditions, there are many factors that increase the likelihood that an individual will experience an Eating Disorder at some point in their life. Generally it takes the combination of several factors over a period of time to trigger the onset of an Eating Disorder.

The risk factors for Eating Disorders are often broadly grouped into different types, such as biological, psychological, socio-cultural and external factors. Some examples of these are:

- **Biological:** gender; genetic susceptibility; timing of the onset of puberty
- **Psychological:** low self-esteem; anxiety; depression; feelings of lack of control of one’s life; personality traits such as perfectionism, obsessive-compulsiveness
- **Socio-cultural:** a Western socio-cultural environment that places an emphasis on ‘thinness’ as an inextricable part of beauty and self-worth; valuing of people according to outward appearance and not inner qualities; societal pressure to achieve and succeed; involvement in a sport or industry with an emphasis on a thin body shape and size (e.g. ballet dancer, model, athlete)
- **External:** peer pressure; stress; teasing or bullying (especially when based on weight or shape); trauma; dieting; troubled family or personal relationships.

Risk factors may be modifiable and amenable to change, or non-modifiable such as fixed characteristics like age, gender, and family history.

There is some evidence that Eating Disorders have a genetic basis. Transmission of Anorexia Nervosa, Bulimia Nervosa and Binge Eating Disorder in families has been established.

The genes most implicated are those within biological systems that govern food intake, appetite, metabolism, mood, and reward-pleasure responses.

Specific personality traits have been identified in people with Anorexia Nervosa and Bulimia Nervosa before, during and after their recovery from illness. These traits include perfectionism, obsessive-compulsiveness, neuroticism, negative emotionality, harm avoidance, low cooperativeness, core low self-esteem, and traits associated with avoidant personality disorder.

Socio-cultural influences such as the Western beauty ideal of thinness and its connection to feelings of self-worth may contribute to the development of Eating Disorders. People who internalise these ideals are at heightened risk of body dissatisfaction which can lead to negative emotionality and efforts to restrict food intake, which are likely pathways to bulimic symptoms.

Disordered eating, dieting and body dissatisfaction are the major risk factors with the most significant being dieting.

Disordered Eating and Dieting

Disordered eating and dieting behaviour is the single most important indicator of the onset of an Eating Disorder. While not everyone who diets will develop an Eating Disorder, it would be rare if not impossible to find an individual with an Eating Disorder who has not dieted.

Disordered eating describes a disturbed eating behaviour that is not sufficient to constitute an Eating Disorder. Disordered eating examples include fasting, skipping meals, restrictive dieting, binge eating, self-induced vomiting, unbalanced eating (i.e. restricting a major food group such as ‘fat’ or ‘carbohydrates’), laxative misuse, diuretic misuse, enema misuse, diet pills, excessive or compulsive exercise, and steroid and creatinine misuse. Even without a diagnosis of an Eating Disorder, disordered eating can result in significant impairment, mentally, physically and socially, and significantly increases suicidal thoughts and behaviours in adolescents.
Research conducted in Australia has shown that adolescent females who diet at a severe level are 18 times more likely to develop an Eating Disorder within six months than someone who has not done so. Over twelve months, they have a 1 in 5 chance of developing an Eating Disorder.

Disordered eating is increasing, with one study showing a doubling in disordered eating behaviour within the past decade in Australia. This upward trend is apparent for both males and females, and cuts across age groups from youth through to older adult.

Many studies show that disordered eating is now normative in Australian society. One Australian study found that 90% of 12 to 17 year old girls and 68% of 12 to 17 year old boys surveyed had already been on a diet of some form, and another found that 1 in 16 adolescent females reported fasting (going without food for a day or more) at least once a week and 1 in 5 reported fasting in the preceding month.

Negative Body Image or Body Dissatisfaction

Body dissatisfaction is another major indicator of risk for developing an Eating Disorder as is importance of shape and weight to the person’s evaluation of their self-worth.

Body image involves the thoughts, perceptions and feelings that individuals experience toward their bodies. In Western society dissatisfaction with the body has become a cultural norm and this is integrally tied up with the belief that losing weight will improve body satisfaction. In the Australian Longitudinal Study on Women’s Health, 74% of the women surveyed wanted to weigh less. Tellingly, of those who wanted to weigh less, more than two-thirds were women of healthy weight and one quarter were actually already underweight.

Body image issues and Eating Disorders are primary reasons that young people access the email-based counselling service offered through Kids Helpline. Body image dissatisfaction is also increasing among boys and men. However, unlike females, males are more likely to desire a lean, muscular appearance rather than a low body weight or thin figure, although this ideal can vary.

The NEDC Youth Consultation found that young people are confused about their bodies and healthy eating: 52% strongly agreed or agreed that “all young people are obsessed with their bodies, it’s a normal part of growing up” while 61% strongly agreed or agreed that “it’s normal for young people to want to lose weight”.

Body dissatisfaction is a significant issue in its own right. Long term poor body image is a predictor of reduced mental and physical health on multiple indices, as well as lowered social functioning and poor lifestyle choices in both Australian males and females. Individuals with poor body image are more likely to engage at some point in their lives in dangerous dietary practices and weight control methods, excessive exercise, substance abuse, and unnecessary surgical interventions to alter appearance.

Protective Factors

Protective factors reduce the likelihood of the development of an Eating Disorder. As with risk factors, protective factors tend to be grouped for ease of reference. Some examples are:

- **Individual:** high self-esteem; positive body image; critical processing of media images (i.e. media literacy); emotional well-being; school achievement, being self-directed and assertive; good social skills with success at performing multiple social roles; and problem solving and coping skills

- **Family:** family connectedness; belonging to a family that does not overemphasise weight and physical attractiveness; and eating regular meals with the family.

- **Socio-cultural:** belonging to a less westernised culture that accepts a range of body shapes and sizes; involvement with sport or industry where there is no emphasis on physical attractiveness or thinness; peer or social support structures and relationships where weight and physical appearance are not of high concern.
The Impact of Eating Disorders

Eating Disorders have a significant and highly underestimated impact on Australian society.

For the individual, developing an Eating Disorder can have a devastating impact. From small beginnings, an Eating Disorder grows to take over the person’s life, dominating their thoughts, determining their activities, antagonising and grieving their loved ones, and disconnecting them from friends, schoolmates and work colleagues.

“...What began as a small habit slowly became an uncontrollable addiction. Whilst it felt like I was in total control of my body and my life, I was in fact totally out of control. By the time I reached 17 years of age I was... drowning within a world I couldn’t handle.

Female Personal Story, reproduced courtesy of EDV

Physically, as well as mentally, the person with the Eating Disorder is profoundly affected. Eating Disorders involve wide-ranging medical complications which can affect every major organ in the body. In children and adolescents, Eating Disorders can affect growth and development. Even after resolution of the Eating Disorder people may experience significantly higher levels of anxiety disorders, cardiovascular symptoms, digestive disorders, chronic fatigue, pain, depressive disorders, and limitations in activities due to poor health, insomnia, and neurological symptoms.

The emergence of Eating Disorders in adolescence or early adulthood means they have a particularly significant impact at this critical time in a young person’s life when they are establishing relationships both within and outside the family and laying the educational ground for their careers and vocations. Apart from the direct burden of the illness, which is substantial, the ramifications of Eating Disorders include interrupted or halted education, family disruption, workplace disruption and loss of family income (with one parent or other loved one often having to give up full-time work to become a carer), and caregiver stress.

The NEDC Youth Consultation identified that young people may have an awareness of some of the impacts associated with Eating Disorders: 97.7% strongly agreed or agreed that an Eating Disorder can have long-term negative health effects; 96.8% strongly agreed or agreed that an Eating Disorder can impact on your quality of life.

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 years in Australia, as measured by disability-adjusted life years.

But these are not the only costs. There is a substantial, though as yet unquantified, economic toll which goes beyond the cost of care. Finally, and most seriously, is the cost on human life. Anorexia Nervosa has a standardised mortality rate that is 12 times higher than the annual death rate from all causes in females aged 15 to 24 years of age. All types of Eating Disorders – Anorexia Nervosa, Bulimia Nervosa and Eating Disorders Not Otherwise Specified are associated with significantly higher completed suicide than the general population.
Prevalence of Eating Disorders

Eating Disorders and disordered eating affect a significant percentage of individuals in the Australian community. Estimates of the prevalence vary across studies, and Australian data are sparse. In the absence of large-scale community-based prevalence studies in Australia, international estimates identify the lifetime prevalence of these illnesses as:

- **Anorexia Nervosa** – in women 0.3%-1.5% (higher if the amenorrhea criteria is waived) and in men 0.1%-0.5%
- **Bulimia Nervosa** – in women 0.9%-2.1% and in men 0.1%-1.1%
- **Binge Eating Disorder** – in women 2.5%-4.5% and men 1.0%-3.0%

As can be seen from these estimates, while Anorexia Nervosa and Bulimia Nervosa present most highly with women and girls (with males comprising approximately 10% of cases), there is a similar prevalence between men and women for Binge Eating Disorder.

A South Australian population-based survey conducted in 2005 identified the current prevalence of Eating Disorders as 0.3% for Anorexia Nervosa (80% female), 0.9% for Bulimia Nervosa (84% female), and 2.3% for Binge Eating Disorder (67% female).

Negative or poor body image is also increasing in prevalence. In the Australian Longitudinal Study on Women’s Health referred to earlier in this chapter only 22% of women in the healthy weight range reported being happy with their weight. 74% of the women in the study wanted to lose weight, including 68% of women who were of a healthy weight and 25% of women who were underweight. Mission Australia national surveys identify that body image is, and continues to be, a major concern of Australian young people aged 12 – 25 years. Body image dissatisfaction is also increasing among boys and men.

Types of Eating Disorder

A brief description of each of the diagnostic category is given below.

**Anorexia Nervosa**

Anorexia Nervosa involves having a lower body weight than is normal for that individual, a relentless pursuit of thinness, a lack of menstruation among post-pubertal girls and women, over evaluation of the importance of shape and weight and/or an intense fear of gaining weight or becoming fat, and a disturbed view of one’s actual shape and weight.

“I almost died from anorexia. Some of the physical effects of anorexia include when your body has been starved for so long that your major organs such as your heart or liver basically give up on you as they become so weak. My heart became severely weakened by the years of starvation. I started seeing the doctor on a monthly basis as I was so scared by the consequences of what I was doing, but could not bring myself out of the habits which perpetuated the health dangers”

**Male, 30 years old - Personal Story, reproduced courtesy of EDV**

A poor body image is a central feature of this Eating Disorder, as is the over-importance attributed to attaining a desired body weight and shape. Physical shape and weight become the individual’s point for self-evaluation. Females typically overvalue thinness while males with Anorexia Nervosa are more likely to value and strive toward a lean body shape that is muscular and low in fat.

Despite being starved or malnourished, individuals with Anorexia Nervosa can see themselves as overweight, and become intensely preoccupied with eating or the avoidance of it, food, and shape and weight control. They engage in a range of extreme weight-control
behaviours, including severely restricting their food intake, compulsive and excessive exercising, laxative and diuretic misuse, and purging to expel kilojoules. They may eat small quantities and portions of food, skip meals, and become overly concerned about the macronutrient content of food, particularly avoiding fats and, to a lesser extent, carbohydrates.

If starvation is prolonged it can have a very severe, long-lasting impact on the physical health of the individual, impacting upon nearly all bodily systems and major organs.

Anorexia Nervosa can damage the heart, the brain, the liver, kidneys, stomach and bowels, muscles and bones, and reproductive system. Health problems can arise from this damage such as kidney failure, heart failure, osteoporosis, infertility, and sudden cardiac arrest. Children and adolescents with Anorexia Nervosa can also experience arrested growth and development.

**Bulimia Nervosa**

Bulimia Nervosa is characterised by recurrent episodes of binge-eating, described as consuming a very large amount of food within a short period of time with an accompanying sense of loss of control; and regular use of inappropriate behaviours designed to compensate for binge eating. These behaviours include fasting, vomiting, laxative and diuretic misuse, enemas, diet pills and compulsive exercising.

"I was 18 when my bulimia developed and the primary reason for its development was a feeling of lack of control. Bulimia was my coping mechanism for the stresses of university study and personal relationships and the hang-ups I had about my body."

**Female, Personal Story, reproduced courtesy of EDV**

As with Anorexia Nervosa, body image becomes an overvalued means of evaluating self-worth. However, people with Bulimia Nervosa tend to maintain an average or even slightly above average weight for their age and height. Typically this is achieved by engaging in a vicious cycle of self-starvation, binge eating, and purging.

The most common physical consequences of Bulimia Nervosa are dental, gum and other mouth problems. Self-induced vomiting erodes dental enamel contributing to cavities, inflames salivary glands and causes mouth sores. Severe and repeated purging can cause many serious medical and physical effects, including gastrointestinal bleeding and rupture, heartbeat irregularities or even heart failure.

**Binge Eating Disorder**

Although Binge Eating Disorder is diagnosed as a subcategory of Eating Disorders Not Otherwise Specified, it has gained widespread acceptance by clinicians and researchers worldwide as an Eating Disorder in its own right.

"I felt so out of control and completely powerless against this demon desire to eat. I recall many times walking around, cramming food into my mouth with tears streaming down my face. The thing I recollect most vividly is the extreme loneliness and isolation I experienced. The emotional despair and shame made me so frightened. It was at this time in my life that I had thoughts of suicide."

**Female Personal Story, reproduced courtesy of EDV**

Binge Eating Disorder is characterised by recurrent episodes of binge eating without the regular use of compensatory behaviours. People with Binge Eating Disorder are generally well above their healthy weight range.
People with Binge-Eating Disorder usually suffer from a range of psychological problems including guilt and self-hatred. Physical and medical complications tend to be those associated with overweight and obesity, such as Type II diabetes, high blood pressure, menstrual problems and gastrointestinal problems. Data on women with Binge Eating Disorder indicate that they experience a higher rate of medical problems than women who are obese without Binge Eating Disorder.

**Eating Disorders Not Otherwise Specified (EDNOS)**

Eating Disorders Not Otherwise Specified is a diagnostic category for individuals who do not meet the full criteria for Anorexia Nervosa or Bulimia Nervosa, but nonetheless present with extreme disturbances in eating behaviours and body image, and fear of weight gain, that are sufficiently distressing and disabling as to warrant classification as a psychiatric condition. For instance, a woman may present with all the diagnostic features of Anorexia Nervosa – emaciation, disturbed body image and an intense fear of becoming fat – but still have a regular menstrual cycle.

The category of Eating Disorders Not Otherwise Specified includes disorders that involve the use of inappropriate compensatory behaviours such as repeated chewing and spitting of food, and extreme kilojoule restriction despite insubstantial weight loss.

The diagnostic category of Eating Disorder Not Otherwise Specified is sometimes mistakenly assumed to describe individuals with milder or less serious forms of Eating Disorders. Individuals with Eating Disorders Not Otherwise Specified have a severe mental illness and experience significant impairment compared to people without Eating Disorders and comparable impairment to individuals with Anorexia Nervosa and Bulimia Nervosa.

**A Significant Public Health Problem**

Eating Disorders constitute a complex, significant public health problem, that impact the individual, family and whole of community. They are often long-term, disabling and destructive disorders, and they carry substantial costs – economic, social and loss of life. Eating Disorders, disordered eating and body dissatisfaction are pervasive in our culture and society.

As with most mental illnesses, Eating Disorders require a multidisciplinary approach. To improve the health outcomes of those with Eating Disorders it is imperative that the co-occurrence and interdependence of the mental and physical symptoms and presentations of these illnesses are acknowledged and treated holistically for both the body and mind.

Initiatives and resources to prevent, identify, treat and manage Eating Disorders in Australia are urgently needed. Eating Disorders need to be recognised as a significant priority within mainstream health, requiring a partnership of care approach between primary care, acute care, specialist care, families and communities.

**References**

A more detailed description of Eating Disorders and supporting references may be found in the National Eating Disorders Collaboration report “Eating Disorders Prevention, Treatment and Management: An Evidence Review” (2010). A list of references for this chapter may also be found in the Appendices to this report.
CHAPTER 3

The Eating Disorders Sector in Australia

The Eating Disorders sector in Australia comprises the agencies, resources, and activities purposefully directed toward Eating Disorders prevention, care, support and knowledge development. The sector includes treatment service providers, other service providers and research. It also importantly includes and represents people with a lived experience of Eating Disorders, their families and carers.

Treatment Service Providers

Treatment service providers comprise public, private (for-profit and not-for-profit), and non-government organisations (NGOs). The services provided include inpatient, day programs and outpatient models of care.

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

Due to the complex physical and psychiatric nature of Eating Disorders, treatment needs to occur within a multidisciplinary context that may include medical doctors, psychiatrists, psychologists, nurses, dietitians, pharmacists, social workers, counsellors and occupational therapists. Most treatment services in Australia, even the few available programs that offer a high-intensity model of care, do not include the full range of professionals that a person with an Eating Disorder needs during the course of their illness.

One of the most significant and ongoing challenges of the field is being able to provide accessible and seamless delivery of treatment services across the full continuum of care. Collaborative service development, cross-sector professional networks and specialist Eating Disorder centres are approaches which have been considered to address this challenge but have yet to be effectively implemented.

The importance of day hospital programs is gaining increased awareness in Australia and some state health departments are establishing day centres. However, there is still much to be done to evaluate the efficacy of such programs.

Residential programs are important where care in transition between home and hospital settings is required. Although a small program exploring residential innovations has commenced at The Children's Hospital at Westmead (Sydney) there is no established residential program in Australia.

Some states are also providing some funding for specialist teams with a focus on improving clinical resources and professional development in the sector: the Centre for Eating and Dieting Disorders in New South Wales; the Victorian Centre of Excellence in Eating Disorders; the Eating Disorders Outreach Service in Queensland, and the Eating Disorders Training and Evaluation Centre in Western Australia.
Community-Based Organisations

Community-based organisations are a vital component of the sector and their lifeline and roots are commonly volunteers. Carers and those with a lived experience of Eating Disorders have spearheaded not-for-profit community-based organisations across Australia despite the inherent resource and personnel challenges. These organisations have underpinnings in activism and play significant roles in advocacy, information and support and are a key point at which appropriate referral and direction can be provided.

The community based organisations serve community needs at many levels of the health promotion spectrum, including health promotion, prevention, early intervention, acute illness, and recovery and relapse prevention. They assist carers and families of loved ones with Eating Disorders to access support and information. At optimum capacity, they can offer peer support groups, community training and education programs, telephone and online counselling, resource libraries, prevention programs for schools and the community, carer support and training programs, training and treatment sponsorship, and media advocacy and public awareness campaigns to reduce stigmatisation of body image issues and Eating Disorders. However, the breadth of their activities is heavily dependent upon their degree of funding, which in turn can be heavily reliant on fund raising activities and philanthropic support. Some are partly supported by state funding. Rarely are they sufficiently funded to meet the needs of consumers and carers.

Regardless of funding support, maintaining operations for community based organisations is challenging and heavily reliant upon volunteers. Volunteers are generally individuals with lived experience of Eating Disorders, health professionals, student health professionals and carers or family members. They need to be equipped with adequate training for their support roles.

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

**National and New South Wales:**
The Butterfly Foundation (offices in Melbourne and Sydney)

**Australian Capital Territory:**
Eating Disorders Foundation of the ACT

**Queensland:**
Eating Disorders Association Incorporated;
Gold Coast Eating Disorders Association

**South Australia:**
Panic and Anxiety, Obsessive Compulsive and Eating Disorder Associations

**Tasmania:**
Tasmanian Eating Disorders Support Service

**Victoria:**
Eating Disorders Foundation of Victoria Incorporated

**Western Australia:**
Bridges Association Incorporated
Consumer and Carer Participation

Consumer and carer participation reach across advocacy, service review and advisory boards, and service development and provision for both not-for-profit and publicly funded services. The latter includes assisting in developing self-help programs, peer mentoring, and development of resources. There is much more that needs to be done to fully harness this important participation by consumers and carers in service development and provision.

Some examples of consumer and carer involvement in service development and provision include:

- The Body Esteem Program in Western Australia - a self-help group program facilitated by people who have previously experienced an Eating Disorder, with the support of training and supervision;
- The Oak House and Bridges Association provide Inspirational Evenings, which are events where people with a lived experience of an Eating Disorder offer hope, understanding and inspiration to others in a safe environment;
- The Eating Disorder Foundation of Victoria and The Butterfly Foundation involve people with lived experience in their support services, with appropriate support and supervision structures;
- The Eating Disorders Foundation of Victoria, the Eating Disorders Association Queensland and The Butterfly Foundation have carer and consumer input into their board and management structures.

Some state health services are also developing strategies for involving consumers and carers; e.g. The Eating Disorders Program at Princess Margaret Hospital for Children in Western Australia operates consumer and carer advisory groups and works with a consumer participation coordinator to carry out initiatives such as producing youth friendly resources and peer mentoring; Queensland has consumer and carer representation on the state-wide Mental Health Network Eating Disorders Sub Network and the Royal Brisbane, and the Women’s Hospital Eating Disorders Service employs consumers and carers to review its clinical and operational management on a regular basis; at the Austin Hospital in Victoria, an Eating Disorders working group comprised of carers and practitioners devised a short practical information booklet to assist families of patients to understand aspects of the Austin Hospital treatment process, as well as home management tips such as meal planning.

The involvement of consumers and carers in government and non-government Eating Disorders programs is essential if the traditional structures that exclude them from service provision and development, research and training programs and policy making are to be changed. Their inclusion has only recently commenced, having previously been excluded due to negative stigmas. There is a very long way to go to integrate their involvement in all aspects of the promotion, prevention and treatment of Eating Disorders in Australia.

At the international level Australia was involved in the launch of the Worldwide Charter for Action on Eating Disorders in June 2006, written by the Academy of Eating Disorders (currently chaired by Professor Susan Paxton, Australia) and The Bronte Foundation of Australia. It outlined five key rights for those affected by Eating Disorders, being the right to:

- 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 and appropriate support education and resources for carers

A common international response by people with a lived experience of an Eating Disorder has been to join together in national groups to capitalise on the capacity of the collective voice, with the establishment of organisations such as the National Eating Disorders Association in the USA and BEAT in the UK. Feedback from the National Workshop convened by the National Eating Disorders Collaboration in October 2009 in Canberra was that consumers and carers have a strong desire to have such a collective voice also in Australia.

Professional Associations

Professional associations build community capacity to address health issues by improving the skills and practices of health professionals. The Australia and New Zealand Academy for Eating Disorders is a peak professional body for Eating Disorders in Australia, and represents the interests of a variety of professional disciplines. It contributes to the Eating Disorders sector by providing advocacy, networking, public education, and training and education for professionals working within the sector. Its management executive is multidisciplinary including professionals who work within the fields of psychiatry, clinical psychology, nursing, medicine, dietetics and social work, across public and private treatment facilities within Australia.

Cross Sector Services Engagement

There are other services located within the broader health sector and other specific sectors that need to be engaged with the Eating Disorders sector. These services offer resources or activities relevant to or intersecting with Eating Disorder prevention, care, support, and knowledge development. Examples are varied and include:

- Generalist treatment services (e.g. primary care, secondary services such as Child and Adolescent Mental Health Services, university clinics)
- Specialist treatment services for other disorders (e.g. anxiety, depression, personality disorders, substance abuse) when they present as co-morbid with Eating Disorders
- Carer focussed organisations (e.g. Carers Australia)
- Early intervention programs (e.g. Mental Health First Aid)
- Crisis intervention organisations (e.g. Reach Out, Kids Helpline, Lifeline)
- National strategies (e.g. MindMatters, Mindframe Media and Mental Health)

Research Inputs

While Australian researchers are contributing significantly to the body of knowledge on genetic susceptibility, prevalence, risk and protective factors, prevention, early identification and intervention, treatments, and burden of disease of Eating Disorders, there is an urgent need for increased resources and coordination of research activities.

Many researchers have collaborative relationships and networks with experts in the Eating Disorders field internationally. Researchers are located across a variety of institutions, with inputs coming from academics within universities, clinical and research professionals within treatment facilities, and researchers at health and medical research centres.
Adopting a National Framework

What will a National Framework mean for the sector?

By comparison with other health sectors, the Eating Disorders sector is relatively new as a distinct field and has yet to establish a clear national identity. The recognition and coordination of a health sector provides the platform for strategic responses to the prevention and management of an illness. The Eating Disorder sector has faced a chronic shortage of resources, leaving the sector fragmented and generally incapable of pursuing integration and collaboration. During the course of the National Eating Disorders Collaboration project for the development of a National Framework, stakeholders expressed the strong view that it was important to address the seriously deficient and urgent gaps in clinical, community, and scientific needs. While the sector has no shortage of vitality, it has evolved disparately with few opportunities for integration. As a consequence, the sector has been unable, to date, to form a collective vision or strategy.

In establishing the National Eating Disorders Collaboration, the Commonwealth government has provided an opportunity for collaboration, the development of a shared vision, and the impetus to develop a coordinated, contextualised and evidence-based framework to guide Eating Disorders promotion, prevention, treatment and management.

Some limited progress has been made in the Eating Disorders field within recent years, and research has identified some prevention, early intervention, and treatment interventions that can effectively assist those in need. This National Framework conveys a shared, informed vision to address the gaps between the current and desired management of Eating Disorders, across the full spectrum of health promotion including prevention, early intervention, treatment and management. It is arguably the greatest milestone event to occur in the Eating Disorders sector to date, as it paves the way forward for the promotion, prevention, treatment and management of Eating Disorders in Australia based on best available evidence and stakeholder input.
The urgent need for funding for research and resources created a highly competitive environment which was not conducive to collaboration. In this environment, the voices of the clinicians in the field, those with the lived experience of an Eating Disorder and their carers and families were often not heard.

In late 2008, The Butterfly Foundation acted as the catalyst for the development of a formative coalition bringing together interested individuals in the field of Eating Disorders representing service providers, consumer support services and research institutions. This initial group was provisionally called the Eating Disorders Australian National Network (EDANN).

The aim of EDANN was to work together to reduce the impact of Eating Disorders on the Australian community. The primary purpose was to establish a broad and inclusive network that would provide the mechanism for communication nationally and across sectors to support the development of a coordinated and evidence-based response to Eating Disorders and weight related disorders.

In November 2008 the opportunity arose to express interest in the Federal government’s Department of Health and Ageing initiative to fund a National Eating Disorders Collaboration. The objective of this collaboration was to bring together Eating Disorder experts and those with an interest in Eating Disorders, to help develop a consistent, coordinated national continuum of care approach to the promotion, prevention, early intervention, treatment and management of Eating Disorders.

This project acknowledged the need for a coordinated and collaborative approach to Eating Disorder treatment and management in Australia. Key issues identified as impacting on the effectiveness of approaches to Eating Disorders included limited research evidence, lack of access to effective treatment and support, and lack of a coordinated cross-sector approach.

EDANN, auspiced and led by The Butterfly Foundation, was contracted to develop the National Eating Disorders Collaboration in February 2009.

The National Eating Disorders Collaboration (NEDC) has brought together more than 70 leading organisations in research, clinical practice and consumer representation at the state and national level as members. During 2009, seventy-three organisations had joined the collaboration as formal members representing the following sectors: public and private health, mental health, allied health, research, academia, education, media, the fitness industry, and carers and those with a lived experience.

The NEDC also has supporters who are not formal members but who participate in activities of the collaboration and offer general support for the goals and work of the collaboration. There are 13 formal supporters (those who have provided letters of support) but a much larger contingency of people and organisations that have become involved through the various activities of the NEDC, including Review Forums and the National Workshop.
The first members of the NEDC were motivated by:

- A strong common goal to contribute to the development of a national response to Eating Disorders
- A strong desire to increase research in Australia to establish more evidence-based prevention and treatment strategies
- A genuine interest in what each other member was doing in the sector
- The opportunity to develop a profile for Eating Disorders in the health sector and mental health sector
- A desire to pool and share expertise, knowledge and resources for the good of all.

**NEDC Objectives**

The objective of the Collaboration is to bring together Eating Disorder experts to help develop a consistent, coordinated national continuum of care approach to the promotion, prevention, early intervention, treatment and management of Eating Disorders.

A key aim of the project was to contribute to ensuring that young people with Eating Disorders are able to access evidence-based, consistent information through avenues such as schools, the media and health service providers.

The intended outputs and outcomes from the project include:

- The establishment, in consultation with the Department of Health and Ageing, of a collaboration network of key organisations and Eating Disorder experts involved in mental health, public health, health promotion, education and research as well as media experts;
- A literature review of the evidence for effective promotion, prevention, early intervention, treatment and management of Eating Disorders;
- A review of information currently available to young people and their families on the prevention, early intervention, treatment and management of Eating Disorders through the web and existing organisations;
- The promotion of evidence-based messages and information about the prevention, early intervention, treatment and management of Eating Disorders to schools, the media and to health service providers;
- An evidence-based framework for the development of a continuum of care of promotion, prevention, early intervention, treatment and management of Eating Disorders for whole of population but with a particular focus targeting school aged children;
- The provision of evidence based continuum of care information to Government on how to progress and target effective messages around both obesity and Eating Disorders.
NEDC Project Governance

A Steering Committee of member representatives has been responsible for the development and direction of the NEDC project.

<table>
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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Ms Claire Vickery</td>
<td>The Butterfly Foundation</td>
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<td>Ms Christine Morgan</td>
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<td>Professor Susan Paxton</td>
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<td>Professor Tracey Wade</td>
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<td>Professor Phillipa Hay</td>
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<td>Professor Stephen Touyz</td>
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<tr>
<td>Associate Professor Michael Kohn</td>
<td>The Children's Hospital at Westmead; The University of Sydney</td>
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<td>Ms Belinda Dalton</td>
<td>The Oak House</td>
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<td>Ms Kirsty Greenwood</td>
<td>Eating Disorders Foundation of Victoria</td>
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<td>Ms Julie McCormack</td>
<td>Princess Margaret Hospital for Children</td>
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<td>Ms Elaine Painter</td>
<td>Eating Disorders Outreach Service Queensland</td>
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<td>Associate Professor Susan Byrne</td>
<td>The University of Western Australia, Centre for Clinical Interventions</td>
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<tr>
<td>Ms Rachel Barbara-May</td>
<td>Alfred Child and Adolescent Mental Health Service</td>
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Project Methodology

An interactive process of review of the existing resources and evidence and consultation with clinicians, researchers, consumers and their carers and families was adopted to achieve the objectives of the NEDC project.

The Four Review Forums provided the foundation for the National Collaboration’s activities during the year.

- **Promotion & Prevention**
  Focusing on the identification of evidence based prevention and health promotion strategies for body dissatisfaction, Eating Disorders and disordered eating; and the development of strategies and resources to promote evidence based messages to school aged children, young people, families and communities

- **Identification & Early Intervention**
  Focusing on looking at services that meet the needs of people who are at high risk of developing an Eating Disorder, who potentially have an Eating Disorder that has not yet been diagnosed, or who may be in the early stages of an Eating Disorder, including looking at identification methods and services aimed at early intervention; and the development of resources for health professionals, including workforce development strategies, standards and guidelines

- **Treatment Standards & Strategies**
  Focusing on integrated cross sector treatment strategies, national coordination, treatment policy and standards, gaps in research evidence

- **Consumers & Carers**
  Focusing on consumer and carer input to the evidence base and the development of consistent information and resources for individuals and families affected by Eating Disorders

Meeting strategies included face-to-face workshops, teleconferences and online forums in order to facilitate participation and maximum sector contribution to the Project outcomes.
Each Review Forum was convened and led by two or more members of the Steering Committee who are experts in the Eating Disorders field. The leadership of the Forums ensured a high level of communication and coordination between the different Forum activities. Membership of Review Forums was open to members of the NEDC and other interested individuals and organisations, including key stakeholders from other sectors such as general health, mental health, media, and education.

The overall Review Forum membership comprised over 100 individuals from across Australia and included:

- Individuals with a lived experience of an Eating Disorder, family members, and carers;
- Health professionals and administrators (including psychologists, dietitians, counsellors, general practitioners, pharmacists, paediatricians, psychiatrists, social workers, occupational therapists, nurses etc.);
- Primary, secondary, and tertiary education professionals;
- Community-based Eating Disorder associations, charities and support groups,
- Researchers;
- Media professionals.

All individuals had an interest in Eating Disorders and either self-nominated or were recommended by others to participate in the Review Forums.

Research Team

The collaborative dialogue in and between Review Forums has focussed on evidence and resources provided by the NEDC project team. A Research Project Coordinator, Dr Hunna Watson, worked with the Review Forum leaders collating and reviewing relevant evidence and presenting this for consideration by the Review Forums and the Steering Committee. A small team of other researchers in the field of Eating Disorders also provided input.

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<tr>
<td>Dr Hunna Watson</td>
<td>The Butterfly Foundation National Eating Disorders Collaboration Project; Princess Margaret Hospital for Children; Centre for Clinical Interventions; The University of Western Australia</td>
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<td>Ms Renee Elphick</td>
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<td>Dr Carl Dreher</td>
<td>Curtin University of Technology</td>
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<td>Dr Anna Steele</td>
<td>Flinders University</td>
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<td>Dr Simon Wilksch</td>
<td>Flinders University</td>
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Evidence Review

The research team conducted a review of the best available evidence for the promotion, prevention, early intervention and treatment of Eating Disorders. The review process focussed on the following key questions:

**Promotion and Prevention:**
- **Key Question #1** What is the evidence for the efficacy of universal prevention interventions for Eating Disorders?
- **Key Question #2** What is the evidence for the efficacy of selective prevention interventions for Eating Disorders?

**Identification and Early Intervention:**
- **Key Question #3** What is the evidence for the efficacy of treatments or combinations of treatments for Anorexia Nervosa in a) young people and b) adults?

**Treatment Standards and Strategies:**
- **Key Question #4** What is the evidence for the efficacy of treatments or combinations of treatments for Anorexia Nervosa in a) young people and b) adults?
- **Key Question #5** What is the evidence for the efficacy of treatments or combinations of treatments for Bulimia Nervosa in a) young people and b) adults?
- **Key Question #6** What is the evidence for the efficacy of treatments or combinations of treatments for Binge Eating Disorder in adults?

A level of evidence scheme was used to organise the study retrieval and selection process, so that studies of very high methodological quality were considered first. Studies from lower levels were used to inform the evidence review process if data from a hierarchically adjacent upper level is absent. The level of evidence scheme adopted for this review was developed by the National Health and Medical Research Council (NHMRC).

To be included in the evidence review, studies needed to:
- be relevant to at least one key review question
- have a publication date of 2004 or more recent, or in the case of systematic reviews or meta-analyses, an original or updated search date of 2004 or more recent
- report on at least one standardised outcome measure assessing a risk or protective factor, a biomarker of Eating Disorders, a psychological or psychiatric outcome, or an Eating Disorder-related outcome
- have data that can be reported in a useable form; and
- have undergone peer-review prior to publication.

The scope of the evidence review on the treatment of Eating Disorders was limited to the diagnoses of Anorexia Nervosa, Bulimia Nervosa and Binge Eating Disorder (a diagnosis within the category of Eating Disorders Not Otherwise Specified). Examination of other conditions within the Eating Disorders Not Otherwise Specified spectrum was not feasible due to the limited availability of data.

Studies on mixed Eating Disorder samples were excluded, unless they reported on outcome by single-diagnosis subgroups (descriptive data or inferential results) or reported a moderator analysis which examined the influence of diagnosis. Non-English studies and unpublished theses were also excluded.

In addition to the systematic review of evidence, an annotated bibliography was developed. This provided an opportunity to acknowledge the significant contribution that Australian researchers and institutions have made to the advancement of research on Eating Disorders.
Resource Review and Resource Portfolio

Members of the National Collaboration are the authors and users of many of the existing information resources on Eating Disorders in Australia. Resources identified by NEDC members were reviewed by the Research Coordinator and the Review Forum Chairs, from the perspective of youth, families and frontline professionals.

A rating scale was developed to assess the resources for inclusion in the review based on the evidence base for the content and the development process for the resource. The resources were collated for consideration by the Review Forums and the Steering Committee.

From this review process, a core portfolio of evidence-based resources has been compiled as an exemplar resource for national dissemination. Review Forum chairs nominated resources in their Review Forum category and the full portfolio was reviewed and endorsed by the Steering Committee. Issues that were taken into consideration in the final review process included whether the resource had been evaluated; whether it is suitable for the Australian context; recent publication date, and inclusion of most practical resources (e.g. symptom monitoring devices, etc).

The Australian National Eating Disorders Workshop

In October 2009, the Collaboration hosted the Australian National Eating Disorders Workshop. The first event of its kind, this was an opportunity for participants to contribute to the development of a National Framework in a collaborative environment.

The Workshop was attended by approximately 200 individuals with experience, an interest or expertise in Eating Disorders including public and private health, mental health, allied health services, education, the fitness industry and media and fashion. All states and territories were represented.

Workshop sessions were aligned to the four Review Forums. These sessions provided an opportunity for participants to:

- Identify priority areas for action to achieve the Collaboration’s vision
- Contribute supporting opinion and evidence for proposed actions based on their experience
- Identify issues for further consideration that may fall outside the immediate scope of the National Framework

Further information on the National Workshop may be found in the Appendices to this report.

A National Evidence Based Framework

This Eating Disorders National Framework is an outcome of the review and consultation processes adopted by the NEDC. It draws upon the evidence review, resource review, outcomes of the Review Forums, feedback from the National Workshop and expert advice from the Steering Committee and external consultants.

This National Framework has been reviewed and approved by the members of the NEDC.

The significant contributions of members and supporters to these achievements are gratefully acknowledged. Their knowledge, experience and expertise in Eating Disorders have been invaluable in setting the future agenda, and in facilitating change in an area of real need.
For the purpose of this review the following terminology has been used. ‘Promotion’ refers to public health campaigns directed towards the whole or large segments of the population. In the Eating Disorder field, such campaigns aim to reduce risk factors for Eating Disorders, such as poor body image, by providing information or changing attitudes. These are frequently media advertising campaigns. Evaluation is usually at the population level. ‘Prevention’ refers to specific programs or classroom curricula designed to reduce risk factors. ‘Universal’ prevention programs are ones that are delivered to the whole group and are not specifically for those at greater risk of body image and Eating Disorders. ‘Selective’ prevention programs are ones that aim to reduce risk factors in high risk groups only, such as adolescent girls. Evaluation is usually at the individual level.

Both promotion and prevention are founded on the theory that if particularly salient risk factors are reduced within individuals or environments, then the likelihood of developing an Eating Disorder will also be reduced. A risk factor is a factor that occurs before the disordered eating or Eating Disorder emerges and its presence increases the likelihood that disordered eating or an Eating Disorder will emerge. The development of an Eating Disorder may be conceptualised as falling on a continuum from no Eating Disorder, to problem eating, to clinical Eating Disorder. A risk factor is one that contributes to a person moving up the continuum. Thus, if risk factors are reduced, movement up the continuum is less likely. Although ultimately promotion and prevention aim to reduce the incidence of Eating Disorders, the preliminary aim is to reduce the presence of salient risk factors. In this review, positive outcomes were those that reduced known salient risk factors for Eating Disorders.

Having identified potentially valuable promotion and prevention interventions, it is also important to consider factors that could, in fact, contribute to harm amongst recipients, such as programs that may inadvertently teach Eating Disorder symptomatology. From a practical perspective, ways to enhance availability and potential for dissemination also need to be considered. Further, it is essential to identify areas in which further research and evaluation are required. Finally, analysis of these factors led to identification of priority areas for action.

Before effective public health promotion and prevention strategies can be achieved, it is necessary to have a firm understanding of existing research and input from professionals, people with a lived experience and their carers about existing practice in the field.

The conclusions described below are based on a rigorous examination of existing research and identification of gaps in the understanding of promotion and prevention and are also informed by the national Promotion and Prevention Review Forum and opinions of those with the lived experience of Eating Disorders, their carers and clinicians.
The Promotion and Prevention Context

Consistent with trends across the Western world, in Australia body dissatisfaction, use of extreme weight loss behaviours and clinical Eating Disorders, especially of the bulimic type, are being observed more frequently and in both younger and older age groups.

The positive support provided by governments in Australia for the development of public health promotion campaigns to reduce risk factors for Eating Disorders is internationally unique. Notably, in Victoria, the ‘Fad Diets Won’t Work’ and the ‘Real Life Doesn’t Need Re-Touching’ advertising campaigns are very innovative. These campaigns were based on risk factor research and were evaluated with focus group methodology during their development phase, although there has been a lack of follow-up exposure and evaluation of effectiveness. In addition, the Victorian and Federal governments have launched voluntary Body Image Media Codes of Conduct. Further, the Victorian Government has provided some financial support for the dissemination of one body image and self-esteem program and for community grants to support body image initiatives. Thus, at least in some parts of Australia, there is recognition that risk factors for Eating Disorders should be addressed in promotion and prevention activities and positive steps have been taken.

Prevention interventions within the Australian context are still in their infancy but it is notable that there is very high awareness of the need for such programs especially within schools. Schools are supportive and enthusiastic about the development of curricula that may readily be translated into educational environments. This is very positive for the future dissemination of evidence based interventions. One drawback in this environment, however, is that programs without a strong evidence base may be implemented and may have little positive effect. In addition, there is insufficient awareness that teaching about Eating Disorders may in some cases actually inadvertently teach Eating Disorder symptoms. Although there is enthusiasm for prevention in schools, there is little prevention activity in the tertiary sector, one of the peak times for the onset of Eating Disorders.

Australian researchers are at the forefront of development and evaluation of innovative prevention intervention programs. Not only does this mean that interventions can be evaluated specifically in the Australian context, but it also means that there is a rapid flow of information into Australia from international sources.

Taken together, it is clear that Australia is in a strong position to capitalise on current knowledge and to implement effective promotion and prevention interventions.

The Evidence for Effective Promotion and Prevention Strategies

A variety of risk factors for disordered eating and Eating Disorders exist. Risk factors that have been identified include the following:

**Physical:** High body mass index; genetic factors; pubertal timing interacting with social pressures; neonatal complications

**Social:** Being an adolescent female in modernised society that values thinness; Western acculturation; direct modelling of body image and eating disturbances by family members and peers; perceived pressure to be thin from peers or media; appearance teasing

**Psychological:** Negative affect; body dissatisfaction; thin ideal internalisation and a strong belief in the importance of thinness to social success; interactions between body dissatisfaction, self-esteem, perfectionism and weight concerns; experiencing conflicts when growing up; child abuse and adversity; low social support; avoidant coping style; childhood anxiety disorder

**Behavioural:** Dieting and use of extreme weight loss behaviours.
In order for promotion and prevention approaches to be considered effective and thus disseminated in the public domain, a long-term (i.e. 2-years or more) reduction of important risk factors for disordered eating or Eating Disorders should be observed within a randomised controlled trial (RCT). This decrease in risk should be associated with a decreased incidence of the development of disordered eating or Eating Disorders. In reality, in most promotion and prevention approaches, what will be observed is significantly less growth in risk factors and incidence of disordered eating compared to a comparison group that was not exposed to the promotional or prevention approach.

There is little evidence at present that supports public health promotion campaigns (e.g. media advertising) designed to reduce risk factors for body dissatisfaction. This is partly because there are very few promotional approaches that have been used for Eating Disorders. Those approaches which have been used in Australia exist in Victoria. They have been the first of their kind and designed with risk factors in mind. However, they have only been available briefly and have not been evaluated systematically with respect to impact.

Research does suggest that there are some approaches that should be avoided in public health campaigns. Harm could inadvertently be done by public health campaigns if they:

- Describe the behaviours associated with Eating Disorders in a way that may give young people ideas for unhealthy weight loss
- Use images of healthy weight bodies and attractive people which may actually increase body dissatisfaction
- Focus on healthy weight rather than healthy behaviours in a manner that may increase emphasis on the importance of weight rather than behaviours

All of these concerns require evaluation in order to ascertain their validity, and public health campaigns in this area require evaluation to ensure no harm is done.

There has been much more research that has addressed the efficacy of programs for the prevention of Eating Disorders. However, generally the findings have been disappointing, showing only short-term increases of knowledge about Eating Disorders or healthy eating with no short- or long-term impact on risk factors. Although some approaches show promise, these effects have either not been replicated or examined over long-term follow-up. Prevention approaches which cannot yet be considered to be effective include self-esteem enhancement, decreasing unhelpful perfectionism, healthy eating, and some media literacy packages such as BodyThink and Go Girls! While the Planet Health obesity prevention package has been shown to protect girls against increased risk of misuse of laxatives and vomiting on single-item self-report measures, this evidence cannot be considered robust in the absence of the impact on a greater range of Eating Disorder risk factors.

There are some specific prevention approaches that can be considered effective, and this effectiveness tends to vary with the age of the participants. For younger participants (i.e. 13 years of age), a specific media literacy approach called ‘Media Smart’ developed by Simon Wilksch and Tracey Wade has been shown to significantly protect girls and boys from the growth of weight concern, dieting, body dissatisfaction, ineffectiveness and depression compared to a group that did not receive the intervention over a 2.5 year follow-up period. The 8-session ‘Media Smart’ program targets internalisation of the thin-ideal by helping young people become critical consumers of the media messages to which they are exposed every day. It also includes content on self-esteem enhancement (celebrating difference) and exploring ways to stand up to pressure, whether from the media, peers, or parents. Importantly, such an approach was not found to be effective in the short-term with 15-year olds, despite the same presenter being used, indicating that media literacy may be most appropriate for younger adolescents or older children.
For older participants (i.e. late teens and early twenties), long-term effects have consistently been observed for an intervention developed by Eric Stice that uses cognitive dissonance, where older adolescent girls with body image concerns who have internalised the thin ideal voluntarily engage in verbal, written and behavioural exercises in which they critique this ideal (e.g. write essays and engage in role plays that are counter-attitudinal). This intervention has produced significant reductions in thin-ideal internalisation and Eating Disorder symptoms. Alternatively, among college-age women with high weight and shape concerns, an 8-week Internet-based cognitive-behavioural intervention called “Student Bodies” developed by a team at Stanford University that is combined with an online, asynchronous, moderated discussion group can significantly reduce weight and shape concerns for up to 2 years and decrease risk for the onset of Eating Disorders in some high risk groups. Part of the content of this program focuses on healthy weight regulation, a reduction of binge eating, and increased knowledge about the risks associated with Eating Disorders.

**Consumer and Carer Perspectives on Promotion and Prevention**

People with lived experience of Eating Disorders and their carers are subject to judgement, discrimination and stigma on a daily basis, arising from myths about Eating Disorders and a lack of education of the general public. They are also bombarded with words and images in the media and their communities that contribute to the development of their disorders and impede their recovery.

To reduce the stigma associated with Eating Disorders it will be necessary to increase public awareness of Eating Disorders in the general community using a no blame model aimed at eliminating the stigma and shame experienced by individuals experiencing Eating Disorders.

The media play an important role in disseminating negative or inaccurate views on Eating Disorders, promoting negative body issues and unhealthy eating practices. Standards and regulation – voluntary or mandatory – are required to ensure that the media communicates appropriate messages regarding Eating Disorders, healthy eating and body image. Failure to address the media’s role in the promotion of unhealthy social norms, including the ‘thin ideal’, would limit the effectiveness of any Eating Disorder promotion strategy.

“The media also has a responsibility. Media contributes to low self esteem which contributes to poor body image and eating disorder”

Schools, families and communities all play a vital role in helping children, youth and young adults build coping skills, self-esteem, well-being and positive body image. There is a need to develop and actively promote effective prevention programs through schools and community organisations, supported by training for parents, teachers and youth workers.

Obesity prevention programs need to incorporate an Eating Disorder prevention focus. There is an important role for people with a lived experience of Eating Disorders and their families and carers in the development of health promotion programs that relate to Eating Disorders and Eating Disorder risk factors.

The first building block towards both professional and community knowledge is to improve the quality and accessibility of evidence based information resources. Suggested strategies include:

- Collate information aimed at improving understanding of body image and Eating Disorders
- Target the general community and people in the health, para-professional, fitness, sporting and education domains
Deliver information through a central clearing house as well as through a range of mediums e.g. ongoing education workshops, DVD’s, television adverts, mail outs and web based resources

Include a number of resources for parents and primary care, for example, a brief checklist of warning signs or assessments

“A society we need to understand and de-stigmatise Eating Disorders so people do get noticed and can access treatment without shame”

Summary of Priorities for Promotion and Prevention

In both the promotion and prevention domains, given that information provided to children and adolescents, though well-intentioned, has the potential to cause harm, all promotion and prevention initiatives require thorough piloting and evaluation to ensure that they are safe. Before effectiveness can be demonstrated, there should first be an assurance that “we do no harm”.

1. Establishing Collaborative Cross-sector Approaches

There is a need to establish working strategies with related health promotion fields to ensure that health promotion interventions, especially those targeting obesity, contribute in a positive way to the reduction in risk factors for Eating Disorders.

Effective promotion interventions need to be identified. This will require better cooperation between public health researchers, Eating Disorder researchers and obesity researchers. Particular issues that need to be addressed in this context include:

- A broader range of evaluation approaches in order to evaluate programs that aim at local community change, such as whole-of-school health promotion programs, which can potentially make a powerful and important contribution to the prevention of disordered eating
- Improved integration of Eating Disorder and obesity prevention messages
- Messages related to obesity prevention being reviewed to ensure that they also promote healthy body image and healthy eating patterns and do not contribute to the development of poor body image, disordered eating and Eating Disorders
- Engagement of people with a lived experience in the development of promotion and prevention programs, including obesity prevention programs
- While mental health promotion programs are currently in use across many Australian schools (e.g. MindMatters), outcomes related to Eating Disorders are rarely if ever evaluated. These programs are unlikely to confer as optimal a benefit to Eating Disorder prevention compared to programs where content is specifically designed to reduce Eating Disorder risk, but nevertheless evaluations of outcome that include Eating Disorder risk factors should be incorporated. Consideration should be given to integrating existing school-based programs with Eating Disorder-specific prevention theory and evidence, with associated evaluation.

2. Identifying safe and effective evidence based initiatives

All promotion and prevention initiatives require thorough piloting and evaluation to ensure that they are safe.

- A wider range of evaluation approaches needs to be drawn on to identify effective promotion interventions
- Prevention approaches should be developed and evaluated that target relevant social and environment factors, including peers, teachers, parents and the wider school community.
3. **Communication and Dissemination**

- Effective prevention approaches need to be assertively disseminated to schools, service providers and community groups, accompanied by appropriate training and support.
- Effective prevention approaches need to be disseminated over an extended time period so as to maximise reach and effectiveness.
- A public information campaign targeting the entire community needs to be developed, with content aimed at raising awareness, reducing stigma and debunking the myths, delivered through a range of communication channels.
- Eating Disorder prevention needs to be part of wider mental health promotion initiatives, both in terms of content and evaluation.
- Exposure to negative media coverage of Eating Disorders and related issues needs to be reduced through media regulation and voluntary codes of conduct.
- Information for parents, schools and health professionals needs to be delivered through a central clearing house.
- The strategy employed in the UK over the last 5 years for the dissemination of effective mental health interventions would provide a useful benchmark. Adoption of this approach would require:
  - A website presence which provides guidelines for consumers and clinicians that describe the approaches and the evidence that supports them.
  - Training for teachers and other community groups in both the conduct and content of effective prevention approaches.
  - Further robust evaluation of prevention approaches; both to examine those that look promising but have insufficient research as yet to support them and also to extend knowledge about the effectiveness of those prevention approaches already identified as efficacious. Such research should address gaps in the evaluative literature, namely whether Eating Disorder programs reduce Eating Disorder incidence and disordered eating, the degree to which peer-based prevention approaches can be effective, and which prevention approaches are appropriate for which developmental stages.
  - Use of more flexible evaluation procedures that examine the effectiveness of these approaches in real world settings, including the role of the facilitator.

4. **Research and Knowledge Development**

Further research, including large scale controlled trials of universal public health interventions, needs to be conducted into identifying risk factors for disordered eating and Eating Disorders that can inform development of future promotion and prevention approaches.

This research should be guided by the investigation of endophenotypes for Eating Disorders, which are measurable components unseen by the unaided eye along the pathway between genetic vulnerability and the manifestation of the disease. Possible candidates are perfectionism, obsessiality, drive for thinness, anxiety, negative emotionality, dysregulation of food intake, increased physical activity, problems with cognitive set shifting, and impulsivity. In addition, risk factors should include investigation of societal and social variables that may increase genetic vulnerability for disordered eating.
CHAPTER 6
Identification and Early Intervention

Epidemiologic studies have found that the average age of onset of Eating Disorder behaviours and symptoms is in adolescence and young adulthood. However, many people with an Eating Disorder continue to suffer into their mid-life, and may never access evidence based treatments.

There is a pressing need to identify and facilitate effective interventions for people with Eating Disorders early in the course of the illness or those at high risk of developing an Eating Disorder, with the aim of reducing the significant community, family and individual burden from Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Eating Disorder Not Otherwise Specified in Australia. Such approaches encompass individuals with both full syndrome and partial syndrome Eating Disorders and include indicated prevention as well as early treatment.

The goal of early intervention is to lower the incidence and prevalence of Eating Disorders and counter the all-too-common experience of people living with the impact of Eating Disorders throughout their young and mid-adulthood. 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. This is particularly relevant among adolescents, where response to family-based treatment for Anorexia Nervosa or Bulimia Nervosa is significantly better in individuals who are treated early in the course of the illness, with recovery rates of between 74 and 90% in those with a history of illness of less than one year compared with recovery rates of 21% in those with a history of illness of four years or more.

“The Identification and Early Intervention Context”

In Australia there has been a notable growth in mental health awareness and active efforts by government, media and the wider community to reduce stigma and improve mental health literacy. A successful example has been the changes in community attitudes and beliefs towards people with depression in recent years with organisations such as BeyondBlue linking evidence, research and practice with community programs and public health campaigns. While issues of stigma are common to both Eating Disorders and depression, there are unique challenges in improving mental health outcomes in Eating Disorders.

Despite efforts to improve access and treatments generally for people with mental health problems, it is striking how few people with Eating Disorders receive evidence based, or indeed any specific, treatment. Up to 90% of individuals with the more common Eating Disorders such as Bulimia Nervosa and Binge Eating Disorder do not receive treatment for their disorder, while for the most severe Eating Disorder, Anorexia Nervosa, only 50% of affected individuals receive therapy.
Barriers in the pathway to care include issues of stigma, cost, accessibility and acceptability of care, and the skills and knowledge of health care professionals. Some of these are related to attitudes and beliefs that may be overcome with targeted health literacy education and training, while others will require changes in the way care is provided.

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 and delayed presentation of the seriously ill to specialist services. When people do seek help it is often for other problems and health care professionals often fail to look beyond the presenting issue. All too commonly, for example, women (and men) with hidden Eating Disorders have treatment for infertility.

When people do seek treatment there are localised but widespread problems with access to specialist services. The development of Eating Disorder services in Australia has been uneven both within and between states, and between the public and private healthcare sectors. Specialist services are concentrated in large metropolitan centres with access to care in rural and remote regions extremely limited or, in many cases, non-existent. Similarly, the availability of care for different age groups, types of Eating Disorders and specific treatment interventions is more often reflective of clinician interest and expertise than coordinated planning.

The development of evidence based, cost-effective treatments that can be delivered in the community particularly to people in rural and remote Australia and by non-specialists is urgently needed. There are a number of promising initiatives in this regard, for example studies supporting the efficacy of self-help approaches in Binge Eating Disorder, guided self-help in Bulimia Nervosa, and internet and tele-medicine delivery for both people in the early stages of an Eating Disorder (secondary prevention) and those with sub-syndromal illness or at high risk of developing an Eating Disorder (indicated prevention).

Another important initiative is the training and supervision of generalist inpatient and outpatient mental health services in the assessment and treatment of people for Eating Disorders (most commonly Anorexia Nervosa). Rural outreach programs exist in Queensland (Queensland Eating Disorder Outreach Service), NSW (Paediatric Clinical Network Program) and Western Australia (Princes Margaret Eating Disorder Service).

There are several excellent examples of primary care and family doctor education programs, both in identification as well as shared care and treatment conducted by the Centre for Eating and Dieting Disorders in Sydney. Further afield, CD-ROM, telemedicine and internet based self-help for Eating Disorders are being developed and trialed in North Dakota and London to name just two regions of innovation in development of early and accessible treatments.

“It’s hard to identify the true beginning of an Eating Disorder. When I look back on mine, it’s almost impossible to pick a spot to start the story. The influencing factors, the random triggers, the little decisions that fed my Eating Disorder are still intertwined in the past and my memory of it. It’s like trying to find the end of a very tangled knot”

Female, Personal Story, Reproduced courtesy of EDV

One of the most common presentations in primary care is with weight concern and request for help to lose weight, irrespective if the person is under, normal or over weight. This is of concern as the prevalence of people in Australia with both an Eating Disorder and a weight disorder is increasing, predominantly among young women. Stigma, 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.
The Evidence for Early Intervention Strategies

There is a growing body of high-level scientific evidence for effective early intervention strategies based on both local and international randomised controlled trials (RCTs) and meta-analyses of RCTs.

Indicated prevention programs have aimed to educate about the risks of Eating Disorders and ameliorate predisposing factors for Eating Disorders including high levels of body image dissatisfaction and perfectionism in adolescent and young women. Such programs have used techniques modified from established therapies such as cognitive-behaviour therapy with positive outcomes. Both face to face and computer-based programs trialled among women with high levels of weight concern have been shown to reduce Eating Disorder pathology, with effects that continue to persist for at least 12 months after treatment.

An alternate approach has focussed on the impact of the media in promoting unhelpful expectations of shape and weight and the desire for extreme thinness. These ‘media literacy’ programs analyse, discuss and challenge covert and overt media messages and educate about the ‘tricks’ used to maximise thinness such as digital photographic enhancement. Further they promote advocacy and activism skills allowing young people to directly challenge these approaches by the media. While study findings have been mixed there have been promising long-term improvements in body image disturbance and self-esteem from Australian researchers.

While other approaches have been advocated they have either little testing and/or less demonstrated efficacy in RCTs. These include both non-specific interventions like yoga and meditation and highly specific education programs for Eating Disorder health literacy programs. ‘Multi-component’ programs have been developed that incorporate a range of the above approaches including media literacy, challenges to attitudes and beliefs around weight, shape and eating, and enhancement of features that increase resiliency such as self-esteem. However, again results have been mixed.

Identified Issues for Effective Identification and Early Intervention

While there is a need for further testing of indicated prevention programs in Australian schools and with people in the general community with disordered eating, it is equally important that interventions for which there is strong evidence are consistently applied to at risk populations. In fact many individuals continue to be exposed to untested indicated prevention programs when effective interventions already exist.

Improved Eating Disorder health literacy of medical, educational and other professionals, such as those working in the weight-disorder and exercise sectors, is imperative to improving early identification of individuals in the early stages of their Eating Disorders or at risk of developing Eating Disorders even though such interventions are less easily evaluated in RCTs.

Similarly, public health campaigns to improve community recognition of Eating Disorders may also be tested only in quasi-controlled trials whereby one Australian state may serve as a control for another. A successful example of this is the changes in practice around low back pain following a public health program in Victoria.

If early identification is to have a positive impact on outcomes in Eating Disorders, pathways into care also need to be improved. How and when to access help is poorly understood by those living with an Eating Disorder, particularly families and carers of those with the most severe and early onset illness of Anorexia Nervosa.
Barriers such as perceived and actual stigma and fear of weight gain (as well as the desire to lose weight) need to be reduced but as yet there is little evidence of ‘what works’. The “Mental Health First-Aid” for Eating Disorders resource developed in Victoria is an encouraging start but requires evaluation for effectiveness.

Research into treatment interventions that can be successfully instituted in non-specialist settings, particularly rural and regional centres, and implementation of evidence base models is critical. There are a number of promising treatments that have been shown to be effective in RCTs in treating certain Eating Disorders although their role in Anorexia Nervosa and those at risk of developing an Eating Disorder is unknown. Notably, guided self-help (whereby therapy may be effectively delivered by a non-specialist working in primary care) for Bulimia Nervosa and pure self-help (whereby therapy may be delivered via the medium of a book or CD-ROM) for Binge Eating Disorder, are supported by RCTs, but as yet are under-utilised in Australia.

Secondary prevention and indicated prevention requires close co-ordination with universal and selective prevention and treatment service delivery. These must be integrated with obesity prevention and treatment, not only because of the clear overlap in approaches and needs but also to ensure conflicting messages are not provided as exemplified in this comment by an adolescent engaged in qualitative research into the impact of health education in schools.

“Consumer and Carer Perspectives on Early Intervention

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: increasing existing public service capacity to provide access to diagnosis, referral, assessment and treatment options for all individuals and families irrespective of where they live
- Clear signposting of referral/care pathways which promote available resources and services and provide clarity of referral and 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
- Increasing regional and remote access through training of rural professionals, and improved access to city based treatments through the provision of accommodation and support for rural individuals and families when a patient is in hospital.

“This week we did ‘anorexia’ and I was told dieting was a serious risk factor, but last week we did ‘obesity’ and I was told I was overweight and needed to reduce”

Personal communication to Professor Christine Halse

“It is like searching for a needle in a haystack to find help”
Summary of Priorities for Effective Identification and Early Intervention

- Research and Knowledge Development
  - Dissemination of indicated prevention programs with evidence to support their efficacy
  - Randomised controlled trials of most promising school-based indicated prevention programs in the Australian setting
  - Randomised controlled trials and quasi-controlled trials of community-based and targeted health-care professional, health literacy programs
  - Evaluation of resources to facilitate effective help-seeking
  - Further evaluation of cost-efficient and effective therapies that can be delivered in non-specialist settings and to remote communities
- Access to an evidence-based continuum of care for those living with an Eating Disorder and health and education professionals

- Improved pathways into early intervention including access to information; early identification tools; training for frontline professionals and ‘gatekeepers’; and a reduction of system barriers to service such as diagnostic criteria and geographic boundaries for referral for professional assessment and early intervention

- Communication between health, education and other professionals engaged with the weight-loss and fitness industries

- Workforce Development of general and mental health professionals (particularly in primary care)

- Collaboration across the public and private health, education (primary, secondary, tertiary), fitness and weight loss sectors in the provision of healthy and accurate messages about weight, fitness and Eating Disorders.
Eating Disorders are characterised by one or more serious disturbances of eating behaviours such as food avoidance, self-induced vomiting, excessive exercising, recurrent episodes of uncontrolled eating and misuse of laxatives or diuretics in an effort to control weight in conjunction with significant psychological pathology. Although DSM-IV-TR describes the criteria for diagnosis of specific Eating Disorders, symptoms have been known to occur on a continuum between these disorders. While patients cannot be diagnosed concurrently with Anorexia Nervosa, Bulimia Nervosa or Eating Disorder Not Otherwise Specified, their disordered eating behaviours can cross over between these Eating Disorders over time.

The prevalence and incidence of Eating Disorders in Australia is increasing and constitutes the third most common chronic disorder in adolescence. The health burden of Eating Disorders also continues to increase as the average age of onset is decreasing and greater numbers of young people experience impairment of their growth and development when developing an Eating Disorder before completing puberty. The impact of Eating Disorders on the future health of Australians is further affected by its chronic and relapsing nature especially when it persists into or occurs in adult life.

The key issues identified across Australia in the treatment of Eating Disorders are:

- **Accessibility to treatment** - geographical, structural and systemic barriers create varying degrees of resources for patients to access. In addition, Medicare rebates are mismatched to the chronicity of the illness presentation and mismatched to support delivery of evidence based treatment (e.g. Family based treatment) by multidisciplinary teams.

- **Integrated, coordinated options for treatment** are limited or inconsistent – there is a lack of coordinated care and referral pathways across the sector and inconsistent and limited options of models of care across the full spectrum of Eating Disorders, e.g.:
  - Acute to chronic, across the lifespan, trans-diagnostic
  - Inclusive of carers
  - Specialist care in rural/regional settings
  - Specific treatment options that address multi-cultural issues

- **Education, training and support for health professionals and carers** is required and ongoing specialist support and training from tertiary services to disseminate best practice is urgently needed around Australia.

- **No national unified standards of care** for treatment.

- **Limited treatment related research** that is of high quality, collaborative across disciplines, sites and areas of expertise and delivers outcomes that informs practice.
There is now consensus that the treatment outcome amongst adolescents with Anorexia Nervosa is generally good whereas among adults it is poor. This makes it very important for investment in services, training and resources for early diagnosis and intervention for those with Eating Disorders, as the window of opportunity for successful outcome starts to fade after 3-4 years of illness. This is one disorder when early intervention is absolutely crucial and therefore access to evidence based best practice is essential.

The treatment of Eating Disorders in Australia needs also to recognise the significant difficulties in trying to provide care in rural and remote settings. Here mental health resources are scant and the multidisciplinary approach advocated as ‘best practice’ is unavailable as a result of the tyranny of distance, the lack of local clinical training, and the lack of tertiary support from specialist services. The perception within mental health services that Eating Disorders are not ‘core business’ affects both rural and city communities and ultimately denies access to effective treatment.

Treatment of Eating Disorders on the Australian landscape therefore requires the development of a ‘hub and spoke’ model of care. This promotes integrated, coordinated options for treatment across Australia. Major population centres need specialist Eating Disorder units providing excellence in care and resourced to provide support for the development of peripheries of competence in rural and remote settings. City centres in area health regions have the capacity to link with clinicians in the public and private sectors and with university based professional units to provide seamless care across the age spectrum and duration of illness for Australians with Eating Disorders. They are able to innovate and evaluate clinical outcomes as well as provide satellite support to urban and remote areas.

The Eating Disorder sector’s awareness of the need to intervene early and the success of treatment approaches such as Maudsley family treatment make it essential that the Australian health system develops the capacity to provide evidence based Eating Disorder treatments delivered by trained health professionals. There is the need to develop treatment approaches to further minimise the impact of these chronic and disabling conditions for all Australians and thereby also decrease the burden and cost of Eating Disorder treatment in Australia.

Eating Disorders are devastating illnesses affecting the family as well as the individual, irrespective of age of the patient. A patient with an Eating Disorder may receive individual psychological support but this is not always available to the parents, siblings or carers.

Treatment resources are invariably limited and typically directed to the individual person with an Eating Disorder. Surveys conducted among family members often reveal that the treatment of their child is considered adequate but that they remain feeling ‘inadequate or ill equipped’ as to how best to cope with the myriad of problems arising from living with a person who has an Eating Disorder.

Parents and siblings have to be considered as part of the treatment team and are as deserving of treatment resources as the patient. Funding and capacity to support parents and other carers remain very limited in Australia.

The collaborative development of resources from treatment facilities and carer organisations to carry out this important role is strongly supported by the sector. It is imperative that those with a lived experience of an Eating Disorder be included in the development of treatment approaches and be actively involved in research and provision of care.
The complexity of Eating Disorders involving physical, mental and social impairment necessitates a multidisciplinary and multi-pronged approach. There is no one treatment that suits all. The multidisciplinary team needs to include medical doctors, psychiatrists, paediatricians, psychologists, nurses, dietitians, pharmacists, social workers, counsellors and occupational therapists. It is essential that carers and families also be involved. The educational needs of children in care need to be addressed.

Most treatment services in Australia do not include the full range of professionals that a person with an Eating Disorder needs during the course of their illness.

Anorexia Nervosa

Family oriented interventions are recognised as an integral component of any treatment model for children and adolescents with Anorexia Nervosa.

Maudsley family based treatment is the most researched treatment approach for adolescents with Anorexia Nervosa and has the most empirical support for the treatment of this condition. For adolescents, involving the family in treatment, such as in Maudsley family based treatment, is currently viewed favourably by families and has achieved positive results in treating children and adolescents with Anorexia Nervosa. It has the advantage of being relatively inexpensive and manualised, allowing clinicians in both centres for Eating Disorder treatment and clinicians in peripheral or rural settings to be trained in providing this model of care. Despite the evidence for Maudsley family based treatment for adolescents with Anorexia Nervosa, other treatment options should also be considered to provide scope for effective treatment where family based treatment is unsuccessful or not acceptable to the family; no one treatment is suitable for all.

The goal of treatment is to strengthen the parents and families resource and to place them in a position to best support the young person to challenge the core symptomatology associated with Anorexia Nervosa.

Many young people with Anorexia Nervosa present with academic and peer related difficulties including perfectionism, high self-expectations, and fear of failing, leading to excessive preoccupation with academic performance. For others, social anxiety impacts on peer relationships, often with the young person withdrawing from social networks. The combination of these can make school attendance stressful or in fact see the young person avoiding school. A further consideration, therefore, is the re integration of the young person back into their home school following hospitalisation. Services need to integrate strong links with school systems and, where feasible, employ specialist teachers attached to hospital or mental health community school services.

At the present time for Eating Disorders other than Anorexia Nervosa occurring in adolescence, “there is no evidence to support the use of one treatment or setting over another” especially for patients who develop a more chronic form of Anorexia Nervosa. Despite cognitive behaviour therapy being the widely used treatment, there is little evidence that such treatment succeeds with most patients and the role of other approaches, such as medication and dietary interventions require investigation. It is important to reiterate here that there are two “uncontested points of unity”. The first is that there is no standard treatment as yet and the second is that patients with Anorexia Nervosa are usually extremely reluctant to engage in treatment. Further investigation is required to better engage patients with Anorexia Nervosa.

The need to develop more effective treatments and long-term management and support strategies for adults with Anorexia Nervosa is urgent, especially because of their poor long-term outcomes. In Australia a response to this dilemma has been initiated by the National Health and Medical Research Council which...
has now funded a randomised controlled trial to investigate the effectiveness of psychological treatments in adult patients with Anorexia Nervosa. Further development will be required to provide effective long-term support for adults for whom Anorexia Nervosa becomes embedded as a chronic illness.

Day hospital programs are gaining increasing popularity in Australia. Though day centres for Eating Disorder treatment are being established by state health departments, too little is known about the efficacy of such programmes. A recent Australian study has reported very promising results, showing that the gains achieved during day hospital care are retained at a 3 months follow up.

Residential programs have been proposed to support treatment, providing care in transition between home and hospital settings. Pilot programs exploring such innovations in treatment, such as was commenced at The Children’s Hospital at Westmead in 2009, need to be further developed and evaluated to assess their impact on treatment outcomes and costs for patients with Eating Disorders.

Restrictions in access to care, such as the 21 day limit on coverage by private health insurers, results in patients being prematurely discharged adding to the high recidivism in inpatient treatment of these illnesses and consequently a high cost in care. Partnerships are required to provide sufficient inpatient beds for adolescents and adults within the public and private health sectors, preferably in dedicated Eating Disorder units.

Further consideration also needs to be directed to private health funds supporting hospital substitution services such as day programs and prevention programs including early intervention strategies. These services reduce the cost burden of inpatient hospitalisations reducing frequency of admission and length of stay.

Bulimia Nervosa

Although patients with Bulimia Nervosa typically present for treatment, it is often after many years of secretly hiding their behaviours, at great cost physically and emotionally. There is now a sound body of evidence as to the treatment of choice and clinicians are more confident with regards to their choice of psychological intervention for patients with Bulimia Nervosa.

The treatment with the most empirical support is manual based cognitive behaviour therapy (CBT). There is a clear convergence of data from the more traditional review of published research as well as meta-analyses. CBT usually comprises 16-20 sessions over a 6-month period and is both directive in nature and problem oriented. The National Institute of Clinical Excellence (NICE) has given CBT the grade of ‘A’ reflecting the evidence of strong empirical data. Particularly noteworthy is the fact that this represents the first occasion NICE has recommended a psychological therapy as the initial intervention for a psychiatric disorder.

Another slightly less known form of psychological intervention, Interpersonal Psychotherapy (IPT), has received a grade of ‘B’ in the NICE guidelines. Of particular interest is that IPT, which stands in marked contrast to CBT, is non-directive and non-interpretive and does not focus on Eating Disorder symptomology. IPT can be offered as an alternate therapy to CBT but it takes longer to achieve a desired outcome e.g. 8-12 months.

However, it is important to note that not all patients respond to the above or even to pharmacological interventions (e.g. SSRI’s such as fluoxetine). They are likely to be those patients with features of borderline personality, impulsivity, concurrent history of substance misuse and a prior history of obesity. There is an urgent need to explore new avenues of treatment to better assist the approximately 40% of Bulimia Nervosa patients who fail to respond to current evidence-based treatments.
Patients with Bulimia Nervosa should be treated in an outpatient setting by clinicians with the appropriate training and skills in CBT or IPT. Only when bingeing is intractable, there is evidence of suicidal intent or where there are worrisome medical complications such as hypokaelemia, should an admission to hospital be considered.

In Australia, the tyranny of distance often precludes patients with Bulimia Nervosa gaining access to clinicians who are well trained in psychological interventions. There is a growing body of evidence that guided self-help (GSH) can be used effectively as the first line of treatment. GSH has an added advantage in that it can be administered by an experienced nurse therapist or general practitioner in a primary care setting. Patients are only referred to a more experienced therapist if they fail to progress in treatment. More recent trends focus on the development of online treatment packages and, if successful, such interventions will be invaluable to those living in rural and remote parts of Australia.

The hub and spoke model supports patients and carers accessing effective treatment using a step-up model from GSH to individual therapy being delivered by trained health professionals.

**Eating Disorders Not Otherwise Specified**

Patients with a diagnosis of Eating Disorders Not Otherwise Specified (EDNOS) constitute the majority of patients seen at Eating Disorders facilities across Australia. Despite this, there is no evidence-based literature to inform treatment. These disorders are considered no less clinically severe than Anorexia Nervosa or Bulimia Nervosa. In the absence of evidence, clinical consensus is a legitimate basis for action. 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.*
Accessing a Continuum of Care

Seamless care is required, with integration between care providers, adolescent and adult services, and public and private health care settings. In addition, access to case management is crucial for people with Eating Disorders to ensure the right treatment is being accessed at every stage of illness.

“Continuum of care means supporting the person after weight restoration so they can be living full and happy lives… outreach keeps people feeling like they are important and not forgotten by the program when they go home”

There is insufficient capacity within the public health sector alone to service the demand created by Eating Disorders. This significantly impacts on the accessibility to the continuum of care for the duration required to facilitate effective outcomes for Eating Disorder patients. The chronicity of the illness, in conjunction with the multidisciplinary team required to provide intensive therapy, makes accessing only private services economically non-viable. In addition, those accessing private health because they have no other treatment options often do so without being able to afford such services, resulting in economic hardship and sometimes the sale of the family home.

One solution to improve access to effective continuity of care would be to establish a separate Medicare item number to enable adequate inpatient and outpatient care, especially since patients often move from one setting to another and from public to private or vice versa and the treatment required exceeds the current 12-18 sessions funded through Medicare. Essentially, Medicare funding needs to match the course of this illness and the evidence based treatment needed for patients with Eating Disorders. Another area to focus on is the development and enhancement of community based services delivered through non government organisations.

Consumer and Carer Perspectives on Treatment Standards and Strategies

The Attitude of the Professional and the Importance of the Therapeutic Relationship

Necessary strategies include the provision of training and supervision of the professional workforce to ensure that their attitudes are appropriate to building a therapeutic relationship with people affected by Eating Disorders; prioritisation of therapeutic relationships in the delivery of services including a focus on engagement at all stages of care; and maintaining therapeutic relationships, especially during transitions in care.

“Trust comes from being down to earth and genuine and not treating a patient as just another patient... outreach keeps people feeling like they are important and not forgotten by the program when they go home... it’s about continuing being cared for... professional attitudes need to be flexible to suit individual needs and not treat everyone the same”

Rights to Care

All treatment issues need to be underpinned by the principle that people with a lived experience and their carers deserve the same rights as other health care users, the right to an accessible, informed, competent health care system that is educated to respond to their specific needs across a spectrum of care, in a variety of treatment and non-clinical settings, in a coordinated and planned manner that engages them to develop an individualised and flexible treatment plan that reflects their needs without stigma and prejudice.
Continuum and Coordination of Care

Priority factors for the development of a continuum of care approach to Eating Disorders include:

- Protocols and professional development to encourage collaboration to provide seamless transitions between care levels, especially during changeover between services
- Development of specialised facilities and appropriate environments for the care of people with Eating Disorders that address the whole person, body and mind, and address relevant issues across all domains of a person in addition to food and weight focused interventions
- Prioritisation of purpose-built specialist Eating Disorder services in health planning ensuring equitable access to specialist care in each state including the need for dedicated inpatient beds with specialised staff and facilities with such inpatient services being attached to step-down / ambulatory services such as the hub and spoke model
- Diverse treatments options provided with sufficient intensity and during all phases of care, addressing a wide range of issues:
  - Psychological e.g. self-esteem, stress management, group therapy
  - Social skills and quality of life
  - Nutritional knowledge: cooking, shopping, meal support, nutritional counselling, as well as re-feeding
  - Complementary treatments such as art therapy, massage, pilates, other natural therapies and spiritual support

Interventions for Carers and Significant Others

Inclusive and individualised approaches to the involvement of carers and families in the treatment and support of people with Eating Disorders are required. Strategies should recognise the role of carers, adequately support them and include them where possible with individualised and family sensitive interventions. These strategies should include:

- Provision of emotional and financial support to enable carers to fulfil their roles - this could include carer allowances, travel allowance, information, advocacy and skills-training
- Family treatment, family therapy and family based therapy (FBT) models that adopt individual, rather than blanket, approaches to family involvement are a priority
- Where possible family members should be included in assessment and treatment

“There are so many aspects of an Eating Disorder that aren’t just eating and weight related” … “treatment should help to develop other ways for the individual to define themselves to help them re-build their identity”

“Families suffer just as much as patients and I think it is really important that they are included and their feelings are validated too so they are not left on the outside feeling helpless... they need to be properly informed of the whole process and be kept in the loop”

Provision of a range of interventions including information, support, education, skills training for parents / carers, therapy groups for parents, dad’s groups, siblings’ groups and family support. Family interventions should be based on a wide definition of families to include significant others and communities.
Professional Development

There is a need to improve workforce knowledge and skills in the identification, treatment and management of Eating Disorders.

“\textit{I should not have to tell my doctor that she should test for the electrolytes on someone who is purging daily}”

Collaboration in treatment is also a key area for change. Relationships and values are especially important in service delivery and of more significance than the type of treatment offered. Those with a lived experience of an Eating Disorder and their carers desire health care providers who are compassionate, knowledgeable, caring and hopeful, and who engage in a trusting and collaborative relationship which respects their individuality and stage of change.

It is therefore important to provide opportunities for staff to develop appropriate attitudes and values towards individuals and families experiencing Eating Disorders. A knowledgeable and competent workforce is critical to the provision of effective early intervention strategies and management of Eating Disorders. The workforce in this instance includes people in frontline and gatekeeper roles.

Summary of Priorities for Effective Treatment Standards and Strategies

National Treatment Standards

The knowledge about Eating Disorders has increased significantly over recent decades, but people in the front line of delivering services are trying to provide care in a climate of lack of resources and, at times, a lack of appropriate training. This unfortunate state of affairs requires urgent addressing through the development of national treatment standards.

Adopting the Worldwide Charter for Action on Eating Disorders would be a positive first step. A copy of the Charter may be found in the Appendices to this report.

Supporting the Continuum of Care

Seamless multi-disciplinary care is required that matches the course, complexity and duration of Eating Disorders. Achieving this continuum will involve:

- A review of health fund practices 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, including hospital substitution services and prevention programs. This would require separate Medicare item numbers
- Partnership and integration between the various care providers and care settings including public and private health and community organisations
The Right Treatment Model

Establishing a “hub and spoke” model of clinical care and training that is able to:

- Establish and evaluate outcomes from a diversity of approaches
- Develop person centred approaches
- Include working with families and carers
- Fund research and development of evidence based practice
- Establish a nationwide framework of standards and guidelines
- Provide resources to support professional training and development – including undergraduate and professional teaching as well as access to information about treatment and the illness for carers.

Resourcing and Supporting Families and Carers

It is imperative that those with a lived experience of an Eating Disorder and their carers and families, be included in the development of treatment approaches and be actively involved in research and provision of care.

A practical step to resource families and carers would be inclusion, in the Medicare item number for patients with Eating Disorders, of an item for skilling, counselling and support of parents, carers and the siblings of the patient who have often been traumatised having to deal with a critically ill sister, brother, child or partner.

“Carers need training in ... how to support and encourage someone with an Eating Disorder to cope with challenges that seem too overwhelming... how to recognise danger signs, how to support loved ones in eating and in understanding, how to know when to seek higher level of care, how to cope with stress, how to not get dragged into a dialogue with the ED voice”

Research and Knowledge Development

Research needs to be focussed squarely on the significant gaps in both current knowledge and where evidence-based treatments are still needed to guide practice, most particularly to address the paucity of knowledge about Anorexia Nervosa.

With the interest in Eating Disorders both within Australia and abroad, new more effective treatments with a sound evidence-base could be around the corner subject to sufficient resources for the research of clinical practices and new ideas. They cannot come soon enough.

Professional Development

The development and delivery of information, training and protocols to enable professionals encountering people experiencing Eating Disorders, including frontline and gatekeeper staff, to possess the appropriate attitudes, knowledge and skills is required.
CHAPTER 8
Consumers and Carers

The Consumer and Carer Review Forum was established to enable the knowledge and experience of individuals experiencing Eating Disorders, and their carers, to be represented in the National Framework and resources review, as well as to develop a strategy for ongoing consumer, family and carer participation within the National Eating Disorders Collaboration. Individuals with a lived experience, and their carers, are in the unique position of having a birds’ eye view of promotion, prevention, early identification and the treatment of Eating Disorders, and have a vested interest in seeing positive outcomes in all areas.

Evidence was obtained through an extensive Consumer, Carer and Community Consultation which involved a review of pre-existing consumer and carers surveys from around Australia, teleconferencing with members of the consumer and carers review forum, the National Workshop, online forums for consumers, carers and community members, message boards and written and email feedback from the National Workshop (refer to the Consumer and Carer Consultation Paper which is in the Appendices to this report).

Definition of Key Terms as applied in this chapter

1. **Consumers** are individuals with a lived experience of an Eating Disorder who have utilised health or community services. Consumers may be children, youth or adults from across Australia and may be currently experiencing an Eating Disorder or have recovered from an Eating Disorder.

2. **Carers** are people who care for an individual experiencing an Eating Disorder. It is important to acknowledge the range of carers and their different needs e.g. parent, brother, sister, friend, child, grandparent, or partner.

3. **Consumer and Carer Participation** refers to people with lived experience participating in decision-making across a number of levels including service delivery, planning and policy. Meaningful consumer participation moves beyond satisfaction surveys and public forums and includes involvement in the development, delivery and evaluation of services, contributing to training, recruitment, research and policy development, peer support, engagement in working groups or representation on committees.

Consumers’ and Carers’ lives are affected by all aspects of Eating Disorder prevention and management. The Consumer and Carer Review Forum provided an opportunity for consumers and carers to have input to all of the National Eating Disorders Collaboration (NEDC) review areas: promotion and prevention, identification and early intervention, and treatment standards and strategies. A summary of the key issues identified during the consultation process is presented here.
Consumer and Carer Participation

The consultation process revealed that for many people across Australia the experience of an Eating Disorder was associated with feelings of alienation from a system that left them depleted emotionally, spiritually, physically, socially and financially.

Consumer and carer perspective and participation will benefit future Australians who experience Eating Disorders as well as the general community, service providers and government. By utilising the lived experience, the quality of prevention, treatment, training and research programs will be fundamentally enhanced and this will have significant impact on incidence, prognosis and outcomes.

Consumers and carers are also in the unique position of being able to use their “insider” knowledge to identify risks associated with current prevention, promotion and treatment strategies and illuminate the road less travelled. So far in the field of Eating Disorders, the information, feedback, ideas and strategies from those with lived experience remains a largely untapped precious resource.

Many people who have lived with an Eating Disorder have felt silenced by stigma, isolation and powerlessness. The opportunity to “have a voice” and be influential in a positive way, such as by improving knowledge and services for Eating Disorders, can be both empowering and healing to peoples’ suffering. Increasing participation will move consumers and carers from a passive role in their journey to a positive one that allows them to be active and confident participants in the wider community.

In Australia there has been a very real shift from viewing individuals as passive users of health services to active collaborators in their treatment, and also in the design and review of services, research and policy. The National Mental Health Plan (2003 to 2008) stated that “The rights of consumers, and their families and carers, must shape reform” and that mental health care should be responsive to the continuing and differing needs of consumers, families and carers, and communities. Outcome 25 of this plan required “Increased levels of full and meaningful consumer, family and carer participation in policy and in service planning, delivery and evaluation at all levels with evidence of improvement in quality”.

The Fourth National Mental Health Plan (2009-2014) launched during the NEDC review process includes as the first of its overarching principles “Respect for the rights and needs of consumers, carers and families” stating that “consumers, their carers and families should be actively engaged at all levels of policy and service development”.

Consumer and carer participation strategies have also entered the research agenda in Australia. The National Health and Medical Research Council has developed a statement and set of strategies to increase consumer participation in health research which includes increasing the information provided to consumers about research, ensuring consumer representation on the research committees and involving consumers and the community in the design and evaluation of research.

Active participation of Australian consumers and carers in the field of Eating Disorders is not new; they have spearheaded many not-for-profit community-based organisations across Australia despite the inherent resource and personnel challenges. These organisations have strong underpinnings in activism and play significant roles in advocacy, information and support and are a key point at which appropriate referral and direction can be provided.

Consumer and carer participation extends across advocacy, service review and advisory boards, service development, and provision for both not-for-profit and publically funded services. There are some encouraging examples of active consumer and carer involvement in service development and provision in the field on Eating Disorders in Australia. These strategies are described in more detail in Chapter 3 of this report.
The growing involvement of consumers and carers in government and non-government Eating Disorders programmes is just the start in challenging the traditional top down structures that have alienated them from service provision and development, research and training programs and policy making. There are still many gaps in implementation of policy and practices across Australia.

At an international level Australia has been actively involved in the launch of the Worldwide Charter for Action on Eating Disorders (June 2006). The document was penned by the Academy of Eating Disorders (currently chaired by Professor Susan Paxton – Australia) and The Bronte Foundation (Australia). It outlined five key rights which cover the right to: 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; and accessible appropriate support education and resources for carers.

A common international response by people with lived experience has been to join together in national groups to capitalise on the capacity of the collective voice, with the establishment of NEDA in the USA and BEAT in the UK. In the Review Forum, consumers and carers expressed their desire to also have a collective Australian voice.

The field of Eating Disorders is relatively new and rapidly expanding, and Australia is at the forefront with the potential to lead the way in international strategic direction. Many people experiencing Eating Disorders are willing and ready to contribute to the knowledge base, research and intervention for Eating Disorders.

**Identified Issues for Consumer and Carer Participation**

The NEDC has been very successful in overcoming the widespread problem of consumer and carer opinion not being accessible or being taken less seriously.

The Consumer and Carer Review Forum provided the NEDC with a powerful tool to obtain and utilise evidence obtained from the lived experience. The knowledge base that was developed spanned the entire spectrum of body image and Eating Disorders and the information developed in this Review Forum crossed over into all the other Review Forum areas. This has provided the NEDC with an influential mechanism to access the real-world validity and utility of strategies derived from research and clinical practice opinion.

The NEDC has also established that there is a need to review evidence and resources from a consumer and carer perspective, in addition to the usual mechanisms.

For example, the mechanisms used to evaluate resources for the NEDC Resources Review identified research based content and potential for harm, but were insufficient to identify qualitative evidence or factors such as ‘readability’ of ‘consumer-friendly’ language. There is a need to establish new criteria for these purposes, such as a consumer friendly rating for resources directed primarily at consumers and carers.

The most significant issue for the future of the NEDC and the Eating Disorder sector is the development of consumer and carer participation strategies that enable them to participate in meaningful and influential ways to ensure their knowledge informs research and clinical practice, as well as ensuring their safety and integrity.
The Evidence for Effective Consumer and Carer Strategies

The issues identified in the Consumer and Carer Forum arose mostly from the consultation process, because of the limited scope of the evidence base. As noted in the Literature Review, there is little Level I evidence for this Review Forum. In general, there is a paucity of qualitative and quantitative research into what individuals with a lived experience of an Eating Disorder and their carers experience. The research that does exist is mostly limited to consumer and carer opinion and needs analysis, generally in the form of satisfaction surveys. There is only one research study that evaluates a consumer participation strategy and very few studies on consumer and carer perspectives on aetiology, prevention, recovery or treatment. The Eating Disorders field needs to draw from other areas of health research in order to inform the development of research in this area.

Strategies to incorporate consumer and carer participation in the design and implementation of research, as well as consumer and carer perspective in the content of research studies, is an urgent and crucial discussion for the research agenda in this field. Although not yet adopted in the Eating Disorders field, there are models and approaches from other fields that could be explored. For example, consumer-driven, participatory research is often the preferred methodology in Africa and South America and is more common in nursing research than medicine.

The small amount of consumer and carer research that does exist provides support for:

- A range of treatment modalities, housed within a continuum of care
- Treatments that target psychological support
- Active strategies that involve loved ones in treatment
- Knowledgeable or specialist staff
- The importance of the attitude, values and approach of professional staff
- A recovery oriented approach that attends to wider dimensions than reduction of Eating Disorders symptoms.

The competence and knowledge base of the primary care workforce, and mental health literacy in the community, especially parents, are also identified as key target areas for change.

Of the consumer participation strategies, peer support was the most widely studied and there is preliminary evidence for the effectiveness of peer support for individuals, parents and specifically fathers.

Families and Carers

Eating Disorders potentially have a significant impact on families, including siblings, partners, parents, grandparents and carers. Caring for a person with an Eating Disorder involves substantial personal, social, occupational, and economic burdens on carers and loved ones. Significant effects have been demonstrated on carers in the areas of levels of distress and burn-out; extreme emotional strain (including anxiety, confusion, guilt, shame, hopelessness and doubt) and complex practical challenges such as providing meal support and meeting financial costs.

In most circumstances, it is preferable to manage Eating Disorders patients on an outpatient, community basis; therefore family members play an instrumental role in supporting and caring for individuals with Eating Disorders. The needs of families, loved ones, and carers for non-specific and skills-based support is substantial and imperative.
Qualitative research with carers indicates that they have three key areas of need: non-specific emotional and psychological support in the form of talking to others who understand their experience (e.g. support group), knowledge and information support, and skills-based guidance.

There is some evidence that interventions such as guidance and support reduces carer distress, strain, and burden, and can promote the health and well-being of the person with an Eating Disorder.

Carer treatment needs that have been investigated include:
- Care coordination
- Information about Eating Disorders as early as possible in the illness
- Skills training
- Financial support
- Community-based support (e.g. community care services, respite services, in-home assistance)
- Advocacy training.

Carers desire practical strategies, guidance and skills-based support to assist them to interact with the individual with an Eating Disorder in a beneficial and constructive manner that promotes recovery and self-care. They need advice and access to resources that assist them to manage or obtain help for difficult behaviour, interpersonal relations, or co-morbidity that frequently accompanies Eating Disorders (e.g. medical and psychological co-morbidities such as depression, anxiety, substance abuse, deliberate self-harm, suicide attempts).

Similar research has not been done with consumers, or with a wider range of carers such as children of people with Eating Disorders.

### Consumer and Carer Priorities

1. **Collaboration**

Collaboration is understood by the Consumer and Carer Review Forum as a reciprocal relationship between consumers, carers, clinicians, researchers and trainers. This collaboration needs to occur in the development and delivery of all knowledge, policy, services, training, prevention and research.

The underlying premise of collaboration is equality of perspective and contribution. In terms of the consumer and carer perspective, this can be achieved by ensuring representation and participation in all key structures and processes of systems involved with Eating Disorders. All action items outlined in this section require consumer and carer participation in their development, implementation and evaluation.

2. **Consumer Participation**

The most significant issue for the future of the Eating Disorder sector is the development of consumer and carer participation strategies that enable them to participate in meaningful and influential ways, as well as ensuring their safety and integrity.

There is a need to foster a culture in the field that reduces the barriers to consumer and carer involvement and accepts and values their perspective as having equal status. This can be achieved by developing meaningful and sustainable participation models and processes in all domains of service provision, policy development, training and research for Eating Disorders.

To achieve this goal it will be necessary to prioritise:
- Support for and national coordination of the existing NGO community Eating Disorder associations
- Review and development of structures and processes that enable consumer participation.
To ensure effective, safe and equitable participation, this would encompass training for consumer and carer representatives, and funding and on-going support

- Improve networking and reciprocal communication between consumers, carers and researchers
- Implementation and evaluation of peer support and peer mentoring programs

“A book written by those who have experienced the same issues. Compiled with ‘real’ stories of recovery to help people feel like they are more ‘normal’ as they are getting better and facing new challenges that are associated with that but rarely spoken of”

- Development, regulation and standardisation of consumer produced and influenced resources.

3. **Research and Knowledge Development**
   
   As part of the priority to support consumer and carer participation, there is a need to increase consumer and carer engagement in research. Consumers need support to conduct research, be informed participants in research, and to contribute to research questions, priorities, study design and funding / ethics decisions.

   To achieve this priority it will be necessary to:

   - Establish a new set of criteria to review the evidence from consumers and carers
   - Prioritise qualitative and participatory methodologies in Eating Disorder research
   - Increase the number and quality of research studies investigating individual and family experience and perspective of body image, Eating Disorders and treatment
   - Conduct research into consumer participation strategies to evaluate effectiveness and risks.
   - Establish research into prevention, causes (social and genetic), early indicators, early intervention and effective treatment options for Eating Disorders as priority areas for the national research agenda.

4. **Consumer and Carer priorities on the following issues are integrated with the review of evidence in other chapters of this report. In summary these issues include:**

   **Promotion and Prevention- Chapter 5**

   **Awareness Raising Campaign Strategy:**
   Increase public awareness of Eating Disorders in the general community using a ‘no blame’ model aimed at eliminating the stigma and shame experienced by individuals experiencing Eating Disorders.

   **Media Regulation:** Reduce exposure to negative media coverage of Eating Disorders and related issues, promotion of positive body issues and health messaging for community members, especially youth, through media regulation and voluntary codes of conduct.

   **Prevention programs:** Produce programs that help schools, families and communities build coping skills, self esteem, well-being, positive body image and a healthy society.

   **ED prevention focus in obesity prevention programs:** people with knowledge of Eating Disorders to be involved in the development of obesity prevention programs and communication strategies.

   **Professional Development:** Develop and deliver information, training and protocols to enable professionals encountering people experiencing Eating Disorders, including nurses, frontline and gatekeeper staff, to possess the appropriate attitudes, knowledge and skills.

   **Disseminate information:** Deliver information through a central clearing house as well as through a range of mediums e.g. ongoing education workshops, DVD’s, television adverts, mail outs and web based resources. Include a number of resources for parents and primary care, for example, a brief checklist of warning signs or assessments.
Identification and Early Intervention - Chapter 6

**Geographic access to services:** Increase existing service capacity to provide access to diagnosis, referral, assessment and treatment options for all individuals and families irrespective of where they live.

**Clear signposting of referral / care pathways:** Promote available resources and services and provide clarity of referral and care pathways.

**Removing barriers to access:** Remove diagnostic criteria as a point of access to services and adopt more lenient criteria for referral that do not exclude any Eating Disorder diagnosis.

Treatment Standards and Strategies – Chapter 7

**The Attitude of the Professional and the Importance of the Therapeutic Relationship:** Collaboration in treatment was identified as a key area for change. Relationships and values were raised as especially important in service delivery and of more significance than the type of treatment offered. What was desired most was health care providers who were compassionate, knowledgeable, caring, and hopeful, who could engage in a trusting and collaborative relationship which respects their individuality and state of change.

Provision of training and supervision of the professional workforce to ensure that their attitudes are appropriate to building a therapeutic relationship with people affected by Eating Disorders; prioritisation of therapeutic relationships in the delivery of services including a focus on engagement at all stages of care and maintaining therapeutic relationships, especially during transitions in care.

Rights to Care: All treatment issues were underpinned by the principle that people with a lived experience and their carers deserve the same rights as other health care users, the right to an accessible, informed, competent health care system that is educated to respond to their specific needs across a spectrum of care, in a variety of treatment and non-clinical settings, in a coordinated and planned manner that engages them to develop an individualised treatment plan that reflects their needs without stigma and prejudice.

Continuum and Coordination of Care: Priority factors for the development of a continuum of care approach to Eating Disorders include diverse treatment options; protocols and professional development to encourage collaboration to provide seamless transitions between care levels; specialised facilities and appropriate environments that attend to the whole person; prioritisation of purpose-built specialist Eating Disorder services in health planning ensuring equitable access to specialist care in each state.

Interventions for Carers and Significant Others:

- Provision of emotional and financial support to enable carers to fulfil their roles.
- Family treatment, family therapy and family based therapy models that adopt individual approaches to family involvement are a priority.
- Provision of a range of interventions including information, support, education, skills training and therapy for parents/carers and family members.
- Where possible family members should be included in assessment and treatment.
The complexity and serious nature of Eating Disorders cannot be overstated. There is no single approach that will adequately address the treatment and management needs of someone suffering from an Eating Disorder, their carers and their families. A multipronged, whole of government and whole of community solution is required.

An effective national strategy to address Eating Disorders will recognise and address this complexity, while providing a clear pathway to achieving an Australian society where Eating Disorders are a mainstream health priority.

Success will be measurable by a reduction over time in the incidence of Eating Disorders, increased early identification, and the provision of evidence based treatments in a continuum of care which is accessible to all in both public and private health. Carers and families will be recognised as integral in all aspects of treatment and management and they will have strong support structures and services to educate and sustain them through the treatment and recovery phases.

Communities will be aware of the danger signs and will actively work to prevent Eating Disorders. Public health prevention campaigns will involve a cross government, cross sector, whole of community approach. People will be empowered to reach out and help, encourage and support someone at risk of developing an Eating Disorder, without negative stigma standing in the way of accessing treatment.

The way forward is guided by evidence and the voices of those with lived experience. Research shows that Eating Disorders’ prevention – specifically, reducing risk and enhancing protective factors – is possible and achievable. Treatment research, personal recovery stories, and clinicians’ experiences give countless stories of hope that recovery from Eating Disorders is possible, with the best outcomes achieved by those who receive help as soon as possible.

A National Framework

Common themes and needs emerge from the detailed analysis undertaken in and by the Review Forums. The existing evidence, and the gaps in existing evidence, discussed in the preceding chapters all point to research, accessible evidence based treatment as a continuum of care, and workforce development as the essential components for the National Framework. This Framework takes these themes and weaves them into a coordinated, coherent pathway to improved prevention, identification, treatment and management of Eating Disorders as a mainstream health priority.

Communication is fundamental, both within the sector and through public awareness campaigns, to reduce stigma and increase awareness. Communities have a vital role in identifying and supporting those with Eating Disorders, recognising they are not a lifestyle choice but a serious mental illness with physical, psychological and social consequences. Communities also need to be actively engaged in programs to reduce the stigma still associated with Eating Disorders and engaging in prevention programs and strategies. A detailed communications strategy which addresses the need for cultural change and which is delivered in a Strategic Communication Framework is another element of the National Framework.
The operating principle for the National Framework is cross sector collaboration engaging the whole of community and the whole of government. It is only by working together in such a fashion that the incidence and impact of Eating Disorders will be reduced in Australia.

It is not sufficient to rely on Eating Disorders specialists to identify, treat and manage Eating Disorders, or to seek to prevent them. The assertive dissemination and implementation of evidence-based interventions and treatments require state and territory health services and public and private health sectors to be communicating and collaborating with each other. Multidisciplinary approaches need health service providers that are working together. Effective promotion and prevention strategies require the input of teachers and other educators, the weight loss, fitness and fashion industries, and the media. It is also important that the Eating Disorders National Framework resonates and is coordinated with other mental health issues such as personality disorders, anxiety and depression. Clarity and consistency of message is essential. At every stage of this process the input of the person with the lived experience and their carers will link the reality of Eating Disorders with the strategies being developed and implemented.

Collaboration is also needed within the Eating Disorders sector to ensure the work that has been identified and included in the National Framework is continued and implemented. The National Collaboration component is the third part of the National Framework.

This collaboration within the sector includes the development of strong networks of support for health professionals who are treating those with a lived experience, working with their carers and families. The challenges of treating and managing Eating Disorders, the lack of evidenced based treatment options and the need for individualised treatment plans place significant burdens on clinicians and therapists. They need collegiate support and input to help sustain them through such challenges.

These three components of the National Framework have been identified as the minimum essential requirements to address the complexity of issues relating to Eating Disorders in Australia.

The National Framework integrates the continuum of care for people with or at risk of Eating Disorders – from promotion, prevention and early intervention to treatment, management and consumer support – with the three components for priority development.
Research & Evaluation

Accessible Continuum of Care

Workforce Development

Communication

Collaboration

National Framework Action Domains

National Framework Continuum of Care

The National Framework is based on the evidence gathered and reviewed by the NEDC in 2009 and presented in the Evidence Review, Resources Review, Strategic Communications Framework and in this report.

1. Framework for Development

Research

Developing an Australian knowledge base to support effective prevention, early intervention, treatment and support

Effective, evidence based intervention and treatment strategies are achievable with the development of the necessary research resources and infrastructure.

The gaps in the current evidence base are clear (as referenced in the Evidence Review). They form the basis for a National Research Agenda, which also needs to be influenced by the results of what clinicians, and consumers and carers are experiencing as being effective. Piloting evaluations of such treatments, and then developing the results of such pilots into randomised clinical trials will provide a more efficient pathway to marrying rigorous research to treatment strategies. Such a National Research Agenda will provide validation of evidence based approaches in the Australian context and ensure that evaluation strategies are identified and implemented for all Eating Disorder strategies.

The impact of research will be experienced only with the assertive dissemination and implementation of programs that are founded on the research evidence. In considering the development of research it is also essential to consider the development of dissemination strategies.

Research must therefore be integrated with all of the action domains within this framework: development of the continuum of care, workforce development, and communication underpinned by collaboration.

The Australian Eating Disorders research fraternity is small, dedicated and comprised of individuals who manage the competing pressures of academic posts and clinical practices in addition to their research projects. The research being undertaken is excellent, but the resources and available time of researchers are too restricted to enable the progress that is
needed to be made. There is no clear succession path for young graduates to encourage them to join the research in this sector, and too few academic positions. To ensure the growth and sustainability of Australia’s brains trust in this sector an infrastructure that profiles the significance, importance and urgency of this research is required. The current fraternity has a wealth of knowledge to inform the next generation but that generation needs to be attracted and supported into the field. Establishing Chairs of Eating Disorders would provide a strong and positive indicator.

Mainstream health issues are granted priority in research funding through the National Health and Medical Research Council and other grants. Eating Disorders need to be included as such a priority, with a corresponding heightened surety of research funding.

A collaborative approach is fundamental to success, with established networks both nationally and internationally. There is a need to work beyond the traditional boundaries of Universities and Research Institutes to establish a truly collaborative national research community – a research institute ‘without walls’ – to encourage inter-discipline and cross-discipline research that will target and address the complexity of the illnesses and accelerate the identification of causes and treatment options. Given their complexity, the key to unlocking a cure for Eating Disorders and effective prevention strategies is likely to be found in a multidisciplinary approach.

National data collection including a national patient register is essential to monitor the incidence and progression of Eating Disorders and ensure that this is included in service planning and evaluation.
An accessible evidence-based continuum of care

Addressing issues that may prevent people from accessing the most effective prevention, early intervention, treatment or support

Eating Disorders cannot be effectively treated with a one dimensional approach. Rather, a highly individualised approach that recognises and addresses the different phases of the illness, the different presentations, and the need for sustained relapse prevention support needs to be accessible to every patient. Diverse evidence based treatment strategies need to be available in a continuum of care with step-up and step-down options, and the ability to opt in at different life stages. While recovery is possible, ongoing support to prevent relapse must be an integral part of treatment.

Expertise is needed to navigate such complexities. All too often it is the patient’s carer who carries this onus. If each person with an Eating Disorder could have access to a case manager their individual needs could be more efficiently and effectively addressed. Eating Disorders are not static in their presentation. It is essential that the delivery of the required multi-faceted treatment strategies be underpinned by a stable consistent case manager with oversight for the duration of the illness. Carers and families must be engaged but in a way which recognises not only their integral role but also their needs for education and knowledge, support and inclusion in consideration of treatment options.

Effective intervention and treatment strategies are strongly dependent on the development of a trusting therapeutic relationship between clinician and patient. A person with an Eating Disorder is entitled to be treated in a non-judgemental and non-discriminatory manner, without blame. They and their carers and families should be empowered to identify what constitutes ‘good’ service and how to articulate any concerns during treatment.

The quality and availability of care should not be an accident of the person’s physical location, gender, age or ethnicity. At present the discrepancies are widespread: between and within states and territories, between options provided for adolescents and adults, and between the different Eating Disorders. People living in Australia’s rural, regional and remote areas continue to suffer from a significantly lower level of expertise and resources than in the major metropolitan cities. As indicated in the Evidence Review, evidence based treatment for children and adolescents is much more advanced than is the case for adults. This is also reflected in the availability of hospital beds and specialist services. Aboriginal and Torres Strait Islanders, and people from non-English speaking backgrounds, do not have available to them culturally sensitive and appropriate treatment strategies. This needs to be addressed as a matter of priority. National standards of care are essential, as is the consistent national dissemination of evidence based approaches. The use of innovative web based technology could be incorporated, particularly in developing and supporting expertise in those states and territories where resources are severely lacking such as the Northern Territory.

Accessibility to treatment is not just a function of availability. It is also significantly impacted by affordability. The incidence of Eating Disorders in the population is such that, if each and every person with a lived experience is to be provided with the care and treatment they need, it is imperative that there be strong workable partnerships between public and private health. Private health funds need to be encouraged to support hospital substitution services and to more accurately and appropriately align their funding to the profile of the illnesses. Although the treatment of Eating Disorders can be lengthy, early identification and coordinated targeted treatment strategies offered without time limitations (based on funding rebates) are likely to increase the rates of recovery, reduce relapse and minimise the longer term consequences of the illness (such as osteoporosis, infertility, cardiac and other organ related complications).
Workforce Development

Skilled and knowledgeable professionals able to implement evidence based standards and strategies for prevention, identification, early intervention, treatment and support

A continuum of care from prevention to early intervention, treatment and recovery support is predicated on the availability of a skilled workforce appropriately trained in evidence based approaches to Eating Disorders.

This workforce includes not only specialists in Eating Disorders but also other health professionals, teachers and educators, and those from other relevant fields such as the fitness, fashion, modelling, advertising and weight loss industries.

Eating Disorders can be hidden illnesses for long periods unless there is someone with the necessary expertise to identify signs and symptoms. Appropriate training for primary health professionals, particularly general practitioners, would ensure they have the skills to assess whether someone is at risk of developing an Eating Disorder. In many instances a patient will seek help or treatment for another issue, such as infertility or weight loss, when the real and underlying illness is the Eating Disorder. It takes skill and experience to accurately diagnose in such circumstances.

Every professional involved in primary care, together with dietitians, psychologists, family therapists, nurses and other health and allied health service providers, requires a strong foundation in Eating Disorders knowledge delivered as part of their mandatory professional training. Courses on Eating Disorders should be assessed for quality, consistency and rigour and accreditation for the sector should be developed and implemented.

Early identification of Eating Disorders enhances the prospects of recovery and can significantly reduce the duration of the illness. However, the nature of the illness is such that it is common for the sufferer to either hide their illness or not want treatment. Educating others to recognise signs that could be of concern and encouraging the person to seek appropriate treatment will help address this particularly difficult aspect of Eating Disorders. Teachers, parents, fitness instructors, counsellors, youth workers and health service professionals are all well placed to take this role.

2. A Strategic Communication Framework

Communication has been a recurrent theme both in the methodology of the NEDC and in the outcomes of review and consultation. A primary objective of the NEDC project has been to develop an evidence based communications framework to contribute to the promotion, prevention and early intervention of Eating Disorders.

Research and evaluation of on-going communication strategies in other health fields has demonstrated the value of targeted communication to promote health, prevent the development of illness and sustain behaviour change.

A comprehensive and coordinated communication strategy which includes an evaluated and evidence based public health awareness campaign, integrated with the development of other Eating Disorder initiatives, is required.

There is an urgent need to bring about significant cultural change in how society determines self-worth and develops self-esteem in young people. The value currency needs to shift away from dieting and skinniness towards recognition and appreciation of the diversity of body shape and size, and internal values.

A coordinated public health communication strategy that recognises and builds on the work that has been done to date in Australia, particularly in Victoria, should be a high priority. Coordinating the key messages with the anti obesity sector will assist in removing
the confusion and misunderstandings that are prevalent in relation to dieting and healthy lifestyle practices.

Although a key target audience for this communication strategy is young people it needs to reach all segments of society and all communities. Eating Disorders have no age or gender boundaries.

The NEDC has commenced the investigative process that will underpin a comprehensive communication strategy, identifying the target audiences, the essential messages and the most appropriate communication channels to positively influence the thinking and behaviour of those audiences in relation to Eating Disorders. This process has involved identifying the evidence base for promotion and prevention, listening to young people and those with a lived experience of an Eating Disorder, assessing existing information and communication resources, and determining objectives for future communication activities.

To contribute to prevention and early intervention, communication strategies must be capable of influencing the social norms that support unhealthy eating and body dissatisfaction, the resilience and help seeking behaviours of people who are at risk of developing an Eating Disorder and the community environment in which people may seek information or help about Eating Disorders.

Three behavioural goals have been identified as the basis for an Eating Disorders communication strategy:

1. **Recognition** – broad community awareness and understanding of Eating Disorders as a priority mainstream health issue to increase support and reduce stigma
2. **Resilience** – young people being able to resist pressures towards high risk behaviours for Eating Disorders
3. **Help seeking** – Eating Disorders and risk factors being identified at an early stage leading to early intervention and reduction in the impact of the illness

These goals summarize the findings of the Review Forums and align with the vision underpinning the Eating Disorders National Framework and the principles of the Fourth Mental Health Plan. A national Eating Disorders communication strategy should contribute to achievement of priority actions for the Fourth National Mental Health Plan including:

- Improving community and service understanding and attitudes
- Working with schools and communities to deliver programs to improve mental health literacy and enhance resilience
- Implementing targeted prevention and early intervention programs for children and their families through partnerships between mental health, schools and other related organisations
- Supporting young people to develop resilience and coping skills.

An effective communication strategy is one that promotes a dialogue between the communicating agency and their audience. An Eating Disorders communication strategy should focus on the dissemination of evidence based information, implementation of evidence based prevention strategies and the promotion of active collaboration to contribute to a reduction in the stigma associated with Eating Disorders and to help young people build resilience and early help seeking behaviour. It will ensure that stakeholders and the community, including young people, have the opportunity to communicate with the Eating Disorders sector, contributing to the development and dissemination of evidence based messages.

The evidence presented in chapters 2 to 8 of this report demonstrates that a complex, multi-faceted approach, closely integrated with the development of other Eating Disorder initiatives, will be required for an effective Eating Disorders communication strategy.
Several principles for communication have emerged during the NEDC review and consultation processes. Underpinning these principles is the primary vision that Eating Disorders are recognised as a ‘priority mainstream health issue in Australia’. Achieving this recognition will require the development of a clear identity for Eating Disorders.

**Communication Principles**

**First do no harm** – the development and dissemination of messages about Eating Disorders, risk factors and related health promotion issues such as obesity, must be reviewed for ‘risk of harm’

**Evidence based** – all promotion and prevention strategies must be grounded in evidence and evaluated in the Australian context

**Monitored and adapted** – to reduce the risk of harm, all communication strategies should be monitored on an ongoing basis and adapted as issues are identified

**Multiple target audiences** - adopting a broad definition of the target audience, communicating with young people and families plus the communities which influence them including health professionals, media, schools and the broader community

**Multiple communication channels** – to meet the needs of diverse audiences different messages delivered through multiple communication channels will be required

**Consistent** – despite the need for diversity in messaging there is a need for consistent factual messaging to all audiences and clear links between each communication activity

**Participatory** – direct engagement with target audiences, particularly young people, will ensure the most effective messaging, active engagement in the process of change. It will also facilitate monitoring the impact of messages in real-time

**Collaborative** – engaging key stakeholders such as health professionals, schools, the media and other health promotion campaigns in collaborative development of communication strategies is most likely to ensure consistent and effective messaging

**Integrated** – communication is an integral part of the development of consistent and effective national approaches to Eating Disorders. Communication strategies should therefore be developed alongside, and actively promote, other Eating Disorders strategies

**Prevention** - assertive dissemination of evidence based prevention programs through schools, supported by appropriate staff and parent education, is supported by the evidence base as a priority response to the reduction of risk factors for young people

**Long-term** – once started, communicating about Eating Disorders must be a long-term commitment if it is to significantly change social norms and influence successive groups of young people
Towards an Evidence Based Communication Strategy

The following steps have been identified to bring together the themes and recommendations from this report into one comprehensive strategy. These steps outline the priority areas for action to initiate a national communications strategy for Eating Disorders.

1. **Communicate a national commitment** and position Eating Disorders as a broad public health concern with an easily identifiable and accessible national portal for access to evidence-based information on Eating Disorders. A branding identity could be employed to create familiarity and immediate recognition of the issue.

2. **Establish a strong web presence** to:
   a. Provide access to the research, resources and review outputs from the NEDC project
   b. Provide a means of ongoing contribution to the information and knowledge base
   c. Promote the existence and purpose of the website through peak health professional bodies, youth websites (e.g. Reach Out) and other relevant professional peak bodies

3. **Establish an online clearinghouse** to ensure that the information on the website continues to represent the current best quality information on Eating Disorders

4. **Develop the evidence base** to support effective, innovative communication; working with target audiences to identify their information needs and preferences and the effectiveness of Eating Disorder key messages, including:
   a. A national youth survey and youth consultation
   b. Investigation of prevention and early intervention strategies in the Australian context
   c. Innovation group to explore digital approaches to message dissemination including e-health and social media

5. **Establish a strong ongoing dialogue with key stakeholders** outside the Eating Disorders sector to identify their information and communication needs
   a. Engage with key stakeholders through the website, working groups and regional, state and national networking activities
   b. Develop appropriate communication campaigns targeting different professional groups
   c. Collaborate to develop a supportive media environment
   d. Coordinate Eating Disorders communications with other health promotion sectors and other mental health initiatives
   e. Develop information and professional development resources to extend and support the impact of such campaigns
   f. Conduct annual national workshops combining professional development with opportunities to contribute to the work of the NEDC

6. **Assertively disseminate and implement evidence based programs and resources**
   a. Prevention approaches for schools and young adults
   b. Training and skill building resources for teachers, parents and others engaged with children and young people
   c. Professional development resources for health professionals

7. **Integrate communication with other development strategies** ensuring that changes in behaviour are supported by:
   a. Referral pathways to appropriate Eating Disorder services
   b. E-health strategies
   c. National data collection
8. **Review emerging evidence** including evidence of audience information and communication needs, and integrate into one comprehensive strategy. Review the benefits and risks of a mass media approach to disseminating key messages.

9. **Ensure program sustainability.** Strategic communication is not something that is done once. A good strategy continues over time as it reaches new audience members and adapts to changes in the environment. Continuity must be in place at the organisational level, among leaders, and in policy and funding, to ensure that strategic communication efforts achieve long-term impact.

This approach will enable immediate action to be taken, through the development of a strong web presence disseminating information resources developed by the NEDC, while the more complex approaches to target specific audiences are developed collaboratively with key stakeholders and audiences. Together these actions form the basis for a future communication strategy for Eating Disorders that is comprehensive, integrated, sustainable and responsive to social change.

The full communication framework is available in a separate publication: *Eating Disorders: The Way Forward - A Strategic Communication Framework.*

### 3. National Collaboration

The need for national coordination and collaboration continues to be clearly articulated by members and supporters of the NEDC. The Eating Disorders sector’s capacity to communicate and develop the evidence base and the continuum of care will require the development of infrastructure to support collaboration and coordination. There is a strong desire for cost efficiency, non duplication of effort and a collective voice. Bringing together people with diverse expertise and experience requires the catalyst of effective leadership and administrative support.

The Eating Disorders National Framework has been developed to achieve the sector’s vision through the implementation of a collaborative, coordinated and evidenced based approach to the research, prevention and treatment of Eating Disorders to reduce the incidence, and impact of the illness.

**Eating Disorders are a priority mainstream health issue in Australia**

A healthy, diverse and inclusive Australian society acts to prevent Eating Disorders

Every Australian at risk has access to an effective continuum of Eating Disorders prevention, treatment, care and recovery support.
Conclusion

As a society, Australia is developing an awareness of the incidence, severity and impact of Eating Disorders but there is still a long way to go. Eating Disorders can remain hidden from sight resulting not only in years of silent suffering for many people, but also the added complication of long-term physical and social consequences.

A National Framework that embodies a commitment to raising awareness of Eating Disorders so as to reduce the stigma attached to them is essential if our society is to reach a level of awareness that acknowledges they are not a lifestyle choice.

Eating Disorders need to be prioritised as a mainstream health issue for Australia with the research and resource development concomitant with such a serious illness.

Effective, targeted prevention and intervention strategies will reduce the incidence and duration of the illnesses. Public health awareness campaigns to change our culture will develop resilience in our young people and reduce the risk factors for developing an Eating Disorder.

While the short term consequence of reducing stigma and raising awareness of the reality of Eating Disorders may be to increase the reported incidence of Eating Disorders in our community, as was the case when depression was targeted in a like fashion, the longer term goal is the effective immunisation of the next generations of young Australians against the risk of an Eating Disorder and the sustained recovery of those who are affected.

The international Academy of Eating Disorders has published a Worldwide Charter for Action on Eating Disorders. The recommendations in that charter resonate with the Australian National Framework. It defines the rights of people with Eating Disorders and carers as being:

1. The right to communication / partnership with health professionals
2. The right to comprehensive assessment and treatment planning
3. The right to accessible, high quality, fully funded, specialised care
4. The right to respectful, fully informed, age appropriate, safe levels of care
5. The right of carers to be informed, valued and respected as a treatment resource
6. The right of carers to accessible, appropriate support and education resources.

Australia has a proud history of leading the way. Let us launch our Australian National Framework by coming together and in a powerful and public signal of commitment formally adopt the Charter and commence The Way Forward.
Eating Disorders
National Framework: The Way Forward

The following tables identify the priority actions and principles identified by the NEDC and discussed in this report for the development of effective, evidence based approaches to the prevention and treatment of Eating Disorders in Australia.

All priorities identified by the NEDC are founded on the principle that people with Eating Disorders and those with risk factors for Eating Disorders have a right to receive appropriate support and treatment.

People with a lived experience and their carers deserve the same rights as other health care users; the right to an accessible, informed, well-educated, competent health care system that can respond to their specific needs across a spectrum of care:

- In a variety of treatment and non-clinical settings
- In a coordinated and planned way
- Engaging them in individualised and needs-specific treatment plans
- Without stigma and prejudice.
Given their complexity, the key to unlocking a cure for Eating Disorders and effective prevention strategies is likely to be found in a multidisciplinary approach.

### Development: Research & Evaluation

#### Priorities for all Domains

- A collaborative national research community — a research institute ‘without walls’ — to encourage inter discipline and cross discipline research that will target and address the complexity of the illnesses and accelerate the identification of causes and treatment options.
- Establish a National Research Agenda to provide validation of evidence based approaches in the Australian context.
- Identify and implement diverse evaluation strategies for all Eating Disorder activities.
- Provide research funding through NHMRC and other grants to be prioritized as it is for other mainstream health issues.
- Develop infrastructure that profiles the significance, importance and urgency of this research.
- Support succession paths for young graduates to encourage them to join the research in this sector.
- Collect national data to monitor the incidence and progression of Eating Disorders and ensure that this is included in service planning and evaluation.
- Research focussed on the gaps in knowledge and the areas where evidence-based treatments are still needed.
- Consistent national dissemination of evidence based approaches.
- Increase consumer and carer engagement in research.

#### Specific Sector Priorities

- **Promotion & Prevention**
  - Further research identifying risk factors for disordered eating and Eating Disorders that can inform development of future promotion and prevention approaches.
  - All promotion and prevention initiatives require thorough piloting and evaluation to ensure that they are safe.
  - There is a need for further evaluation, including randomised controlled trials and quasi controlled trials, of:
    - the most promising school-based indicated prevention programs
    - community-based and targeted health-care professional, health literacy programs
    - cost-efficient and effective therapies that can be delivered in non-specialist settings and to remote communities.

- **Identification & Early Intervention**
  - Randomised controlled trials to investigate the effectiveness of psychological treatments in adult patients with Anorexia Nervosa.
  - Define an efficient pathway from existing evidence to pilots to practice experience and to RCTs.

- **Treatment Strategies**
  - Increase consumer and carer engagement in research with strategies that support consumers to:
    - conduct research
    - be informed participants in research
    - contribute to research questions, priorities, study design and funding / ethics decisions.
## Development: Accessible Continuum of Care

The quality and availability of care should not be an accident of the person’s physical location, age or ethnicity

<table>
<thead>
<tr>
<th>Priorities for all Domains</th>
<th>Specific Sector Priorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Accessible services for all levels of care: inpatient, day-patient, outpatient and outreach, located in all states and territories</td>
<td>Identifying safe and effective evidence based prevention initiatives that target relevant social and environment factors, including peers, teachers, parents, and the wider school community</td>
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<tr>
<td>- Access to services for people in regional, rural and remote areas supported by innovative technology</td>
<td>Develop clear pathways into care addressing barriers to help-seeking</td>
</tr>
<tr>
<td>- Service approaches to meet the needs of Aboriginal people and people from culturally diverse backgrounds</td>
<td>Adopt more lenient criteria for referral that do not exclude any Eating Disorder diagnosis; remove diagnostic criteria as a point of access to services</td>
</tr>
<tr>
<td>- Diverse evidence based treatment options available on a continuum of care with step-up and step-down options, and the ability to opt in at different life stages.</td>
<td>Utilise technology in the delivery of care such as email, telephone, video conferencing, whilst retaining the opportunity for face to face services</td>
</tr>
<tr>
<td>- National Treatment Standards to address the current lack of consistency across states and regions</td>
<td>Specialised facilities and appropriate environments for the care of people with Eating Disorders that attend to the whole person and address relevant issues across all domains of a person in addition to food and weight focused interventions</td>
</tr>
<tr>
<td>- Review of health fund practices 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.</td>
<td>Establish a “hub and spoke” model of clinical care and training</td>
</tr>
<tr>
<td>- A culture in the field that is person-centred, recovery oriented and reduces the barriers to consumer and carer involvement, accepting and valuing their perspective as having equal status</td>
<td>Resourcing and supporting families and carers through a range of interventions including information, therapy groups, financial support. Include consumers, families and carers in the development of treatment approaches and the provision of assessment and treatment.</td>
</tr>
<tr>
<td>- Ongoing support to prevent relapse provided as an integral part of treatment.</td>
<td>Implement individualised and family sensitive interventions e.g. family treatment, family therapy and family based therapy (FBT) models that adopt individual, not blanket, approaches to family involvement</td>
</tr>
<tr>
<td>- Access to case managers to provide stable consistent oversight and coordination of treatment and support for the duration of the illness.</td>
<td>Family interventions should be based on a wide definition of families to include significant others and communities</td>
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<tr>
<td>- Prioritisation of trusting therapeutic relationships between clinician and patient at all stages of care; maintain therapeutic relationships during transitions in care</td>
<td>Implementation and evaluation of peer support and peer mentoring programs</td>
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<td>- Strong workable partnerships between public and private health.</td>
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<tr>
<td>- Early identification and coordinated targeted treatment strategies offered without time limitations (based on funding rebates) to increase the rates of recovery, reduce relapse and minimise the longer term consequences of the illness</td>
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**Workforce Development**

A continuum of care from prevention to early intervention, treatment and recovery support is predicated on the availability of a skilled workforce appropriately trained in evidence based approaches to Eating Disorders.

<table>
<thead>
<tr>
<th>Priorities for all Domains</th>
<th>Specific Sector Priorities</th>
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<tbody>
<tr>
<td>- Eating Disorders workforce recognised as including Eating Disorder specialists, other physical, mental and allied health professionals, teachers and other educators, counsellors, youth workers and other relevant fields such as the fitness and weight loss industries.</td>
<td>Training for teachers and other community groups in both the conduct and content of effective prevention approaches.</td>
</tr>
<tr>
<td>- Every professional involved in primary care requires a strong foundation in Eating Disorders knowledge delivered as part of their mandatory professional training.</td>
<td>Appropriate training and support for general practitioners to enable them to assess whether there is a risk of an Eating Disorder. Develop professional attitudes and values appropriate to building a therapeutic relationship with people affected by Eating Disorders which respects their individuality and state of change.</td>
</tr>
<tr>
<td>- Professional development training delivered collaboratively across professions; innovative technology to support individual and remote learning</td>
<td>There is a need to foster a culture in the field that is person-centred, recovery oriented and reduces the barriers to consumer and carer involvement, accepting and valuing their perspective as having equal status.</td>
</tr>
<tr>
<td>- Courses on Eating Disorders should be assessed for quality, consistency and rigour</td>
<td>Education and skills training for parents / carers and families Developing training and support for consumers and carers in participation strategies (e.g. training in peer mentoring)</td>
</tr>
<tr>
<td>- Develop and implement accreditation for the Eating Disorder sector</td>
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</table>
There is an urgent need to bring about significant cultural change in how our society determines self worth and develops self-esteem in our young people.

### Communication

<table>
<thead>
<tr>
<th>Priorities for all Domains</th>
<th>Specific Sector Priorities</th>
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<tr>
<td>- A complex, multi-faceted approach to communication that is closely integrated with the development of other Eating Disorder initiatives</td>
<td>Assertive dissemination and implementation of effective prevention approaches to schools, service providers and community groups, accompanied by appropriate training and support, over an extended time period so as to maximise reach and effectiveness</td>
</tr>
<tr>
<td>- Evaluated and evidence based public health awareness campaign that recognises and builds on the work that has been done to date in Australia, particularly in Victoria</td>
<td>Reducing exposure to negative media coverage of Eating Disorders and related issues, promotion of negative body issues and health messaging, through media regulation and voluntary codes of conduct</td>
</tr>
<tr>
<td>- Coordinated key messages with the anti obesity sector to assist in removing the confusion and misunderstandings that are prevalent in relation to dieting and healthy lifestyle practices.</td>
<td>Inclusion of an Eating Disorders focus in obesity prevention programs</td>
</tr>
<tr>
<td>- Broad definition of target audience to include all segments of society; Eating Disorders have no age or gender boundaries.</td>
<td>Dissemination of clear and accessible information on referral pathways and treatment choices</td>
</tr>
<tr>
<td>- Three behavioural goals for an Eating Disorders communication strategy:</td>
<td>Assertive dissemination and implementation of effective indicated prevention programs together with evidence to support their efficacy.</td>
</tr>
<tr>
<td>• Recognition – broad community awareness and understanding of Eating Disorders as a priority mainstream health issue increases support and reduces stigma</td>
<td></td>
</tr>
<tr>
<td>• Resilience – young people are able to resist pressures towards high risk behaviours for Eating Disorders</td>
<td>Improve the quality and accessibility of evidence based information and training resources delivered through a central clearing house as well as through a range of other channels such as professional development workshops, and web-based resources.</td>
</tr>
<tr>
<td>• Help seeking – Eating Disorders and risk factors are identified at an early stage leading to early intervention and reduction in the impact of the illness</td>
<td>Increased public awareness of Eating Disorders in the general community using a ‘no blame’ model to address misconceptions and myths, eliminate stigma and promote support and help seeking behaviour</td>
</tr>
<tr>
<td>- Dialogue between the Eating Disorder sector and target audiences to ensure that stakeholders contribute to the development and dissemination of evidence based messages</td>
<td>Development of consumer produced and influenced resources.</td>
</tr>
<tr>
<td>- Dissemination of evidence based information and resources</td>
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</table>
Collaboration

Bringing together people with diverse expertise and experience requires the catalyst of effective leadership and administrative support

<table>
<thead>
<tr>
<th>Priorities for all Domains</th>
<th>Specific Sector Priorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ The Eating Disorders sector’s capacity to communicate and develop the evidence base, workforce and continuum of care will require the development of infrastructure to support collaboration and coordination.</td>
<td>Establish working strategies with related health promotion fields to ensure that health promotion interventions, especially those targeting obesity, contribute in a positive way to the reduction in risk factors for Eating Disorders. This will require better cooperation between public health researchers, eating disorder researchers and obesity researchers. Collaboration with the media to develop a positive media landscape that will influence social norms related to eating, weight, appearance and self worth</td>
</tr>
<tr>
<td>■ National coordination that supports collaboration for the ongoing development and implementation of the National Framework, national research agenda, national treatment standards and coordinated national communication strategy</td>
<td>Collaboration with the public and private health sectors, education (primary, secondary, tertiary), fitness and weight loss sectors in the provision of healthy and accurate messages about weight, fitness and Eating Disorders.</td>
</tr>
<tr>
<td>■ Support for and national coordination of the existing NGO community Eating Disorder associations</td>
<td>Integration between care providers and settings — including public and private health and community providers — to deliver seamless care, especially during transitions between services</td>
</tr>
<tr>
<td></td>
<td>Develop structures and processes that enable representation and participation of consumers, carers and families in the design and implementation of all knowledge, policy, services, training, prevention and research consumer participation. To ensure effective, safe and equitable participation, this would encompass training for consumer and carer representatives, and ongoing financial support and personal support</td>
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<tr>
<td></td>
<td>Improve networking and reciprocal communication between consumers, carers and researchers</td>
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</tbody>
</table>

Development Collaboration

Promotion & Prevention

Identification & Early Intervention

Treatment Standards & Strategies

Consumer & Carer Participation
Appendices

A. References
B. NEDC Members and Supporters
C. Australian National Workshop
D. Worldwide Charter for Action on Eating Disorders
Appendix A References


Marks, P., & Maguire, S. (2005, May). *Full submission to the Select Committee on Mental Health – Eating Disorders – Core Business for Mental Health (focus on service needs for New South Wales).* Sydney: Centre for Eating and Dieting Disorders.


A more detailed reference list and annotated bibliography on Eating Disorders may be found in the NEDC publication - Eating Disorders Prevention, Treatment and Management: An Evidence Review

References for recommendations on communications strategy, including external consultant reports, form part of the NEDC publication - Eating Disorders: The Way Forward - Strategic Communication Framework
## Appendix B
### NEDC Partners and Supporters

#### Formal Partners

<table>
<thead>
<tr>
<th>Organisation / Program or Faculty</th>
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<tbody>
<tr>
<td>Alfred Child and Adolescent Mental Health Service</td>
<td>If Not Dieting</td>
</tr>
<tr>
<td>Australian and New Zealand Academy for Eating Disorders</td>
<td>Inner West General Practice</td>
</tr>
<tr>
<td>Australian Association of Social Workers</td>
<td>Inspire Foundation</td>
</tr>
<tr>
<td>Australian College of Mental Health Nurses</td>
<td>Institute of Health and Biochemical Innovation, QUT</td>
</tr>
<tr>
<td>Australian Counselling Association</td>
<td>Isis - The Eating Issues Centre Inc</td>
</tr>
<tr>
<td>Australian Nurses Federation</td>
<td>Latrobe Regional Hospital</td>
</tr>
<tr>
<td>Australian Scientific Research Consulting</td>
<td>La Trobe University: School of Psychological Science</td>
</tr>
<tr>
<td>Australasian Mens Health Forum</td>
<td>Lisa Cox Presents</td>
</tr>
<tr>
<td>Brain and Mind Research Institute</td>
<td>Mater Child and Youth Mental Health Service</td>
</tr>
<tr>
<td>Bridges Association Incorporated</td>
<td>Medical-Legal Network for Children</td>
</tr>
<tr>
<td>Carers Australia</td>
<td>Meridian Clinic</td>
</tr>
<tr>
<td>Centre for Clinical Interventions</td>
<td>Monash University: School of Primary Health Care</td>
</tr>
<tr>
<td>Centre for Eating and Dieting Disorders, NSW</td>
<td>Monash-Alfred Psychiatry Research Centre</td>
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<tr>
<td>Charles Sturt University</td>
<td>Murdoch Children’s Research Institute</td>
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<tr>
<td>Curriculum Corporation</td>
<td>Northern Rivers Eating Disorders Service</td>
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<tr>
<td>Department of Adolescent Medicine: Eating Disorder Family based Treatment Team</td>
<td>Northside Clinic Greenwich</td>
</tr>
<tr>
<td>Dietitians Association of Australia</td>
<td>Orygen Youth Health Research Centre</td>
</tr>
<tr>
<td>Eating Disorders Association Inc (QLD) Resource Centre</td>
<td>Pharmaceutical Society of Australia</td>
</tr>
<tr>
<td>Eating Disorders Association of SA Inc</td>
<td>Princess Margaret Hospital: Eating Disorders Unit</td>
</tr>
<tr>
<td>Eating Disorders Foundation of Victoria</td>
<td>Princess Margaret Hospital: Psychological Medicine</td>
</tr>
<tr>
<td>FEAST ED</td>
<td>Princess Margaret Hospital for Children</td>
</tr>
<tr>
<td>Flinders University</td>
<td>Pulse Health Ltd</td>
</tr>
<tr>
<td>Headspace</td>
<td>Queensland University of Technology</td>
</tr>
<tr>
<td>Home Economics Institute of Australia</td>
<td>RIPE</td>
</tr>
<tr>
<td>Hospital School Services</td>
<td>Royal Australasian College of Physicians</td>
</tr>
<tr>
<td>Hunter Institute of Mental Health</td>
<td></td>
</tr>
</tbody>
</table>
## Supporters

<table>
<thead>
<tr>
<th>Organisation / Program or Faculty</th>
</tr>
</thead>
</table>
| Royal Brisbane and Women’s Hospital:  
The Eating Disorder Outreach Service |
| Royal Children’s Hospital:  
Centre for Adolescent Health |
| Royal Prince Alfred Hospital |
| South Australia Health: Mental Health Unit |
| Southern Health: Mental Health Program |
| Swinburne University of Technology |
| Tasmanian Eating Disorders Support Service (TESS) |
| Telethon Institute for Child Health Research |
| The Acorn Support Group |
| The Children’s Hospital at Westmead:  
Eating Disorders Service |
| The Garvan Institute of Medical Research |
| The Jean Hailes Foundation for Women’s Health |
| The Oak House |
| The Psychotherapy and Counselling Federation of Australia |
| The Royal Australian and New Zealand College of Psychiatrists |
| University of Melbourne:  
Faculty of Medicine, Dentistry and Health Sciences |
| University of Sydney: School of Psychology |
| University of Western Australia |
| University of Western Sydney:  
Centre for Educational Research |
| Victorian Centre for Excellence in Eating Disorders |
| Women’s Forum Australia |
| Women’s Healthworks: Body Esteem Program |
| Hollywood Private Hospital:  
The Hollywood Clinic |
| Mission Australia |
| SANE Australia |
| Carers WA |
| The Black Dog Project |
| Princess Margaret Hospital: Eating Disorders Programme, Child & Adolescent Health Service |
| Australian General Practice Network |
| The Royal Australian College of General Practitioners |
| University of Western Sydney:  
School of Medicine |
| South Pacific Private |
| Child and Family Welfare Association of Australia Inc (CFA) |
| School Health (State-wide):  
Child and Adolescent Community Health Policy |
| St Vincent’s Hospital |
Appendix C
National Eating Disorders Workshop

In October 2009, approximately 200 individuals attended the National Eating Disorders Workshop in Canberra to spend a day in collaborative discussion, sharing knowledge and experience, reviewing evidence and identifying priorities for the development of effective approaches to Eating Disorders in Australia. This was the first event of its kind in Australia and provided an opportunity for participants to contribute to the development of the National Framework.

The Workshop was attended by people with an experience, interest or expertise in Eating Disorders including representatives from public and private health services, the mental health sector, allied health services, education, the fitness industry and media and fashion industries. All states and territories were represented.

In the introduction to the workshop, the NEDC Chair, Claire Vickery, noted that the National Workshop was an opportunity to make a very real difference in how Eating Disorders are understood, talked about and treated in Australia:

“We are in the unique position of being able to frame goals and strategies that will define the way forward for Eating Disorders in Australia.”

National Workshop Program

<table>
<thead>
<tr>
<th>Time</th>
<th>Program</th>
<th>Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.00</td>
<td>Welcome</td>
<td>Claire Vickery, Chair</td>
</tr>
<tr>
<td>9.20</td>
<td>The Lived Experience</td>
<td>Claire Vickery &amp; Rachael Walker</td>
</tr>
<tr>
<td>9.40</td>
<td>Introduction to the National Collaboration</td>
<td>Christine Morgan, National Director</td>
</tr>
<tr>
<td>10.00</td>
<td>The story so far</td>
<td>Review Forum &amp; Youth Forum Leaders</td>
</tr>
<tr>
<td>10.50</td>
<td>Spreading the Word</td>
<td>Jenny Muir, Primary Communication</td>
</tr>
<tr>
<td>11.30</td>
<td>Coffee break — Your feedback on Key Messages</td>
<td></td>
</tr>
<tr>
<td>11.35</td>
<td>Workshop Sessions</td>
<td>Review Forum Leaders</td>
</tr>
<tr>
<td>3.00</td>
<td>Staying Connected – networking opportunity</td>
<td>Plenary Session</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Jenny Muir</td>
</tr>
<tr>
<td>3.30</td>
<td>Emerging Themes: Building on What We Have</td>
<td>Christine Morgan</td>
</tr>
<tr>
<td></td>
<td>Live wiki</td>
<td>Jane Burns</td>
</tr>
<tr>
<td>4.15</td>
<td>The Way Forward: Next Steps after the National Workshop</td>
<td>Claire Vickery</td>
</tr>
</tbody>
</table>
Emerging Vision and Principles

Participants were provided with a workshop information pack which included a draft vision and draft list of principles which had emerged during previous Review Forum and Steering Committee deliberations.

Vision: An effective continuum of Eating Disorders prevention and care is accessible for every Australian at risk.

This vision encompasses effective support for people living with an Eating Disorder and a collaborative approach to prevent the development of Eating Disorders. These two distinct areas of action are represented by two complementary statements below:

1. Eating Disorders are a priority mainstream health issue in Australia
   People with or at risk of Eating Disorders have access to a coordinated continuum of quality, evidence based support – from information, early identification and care, to treatment interventions, and long-term support for recovery

   - **Access** – appropriate, affordable and culturally accessible services are located in all States and Territories
   - **Coordinated Continuum** – collaborative service planning and development leading to integrated services that ensure effective transitions between services and over the lifetime of the consumer
   - **Quality** – the consistent application of standards across services, resources and locations; delivery of all forms of support by appropriately trained personnel; strategies informed and supported by people with a lived experience of Eating Disorders

2. Evidence Based – research and evaluation activities demonstrate the effectiveness of strategies and inform the development of new approaches, services and practitioner training

   Promotions of consistent positive messages about nutrition, weight and body image

   Universal health promotion campaigns and strategies for nutrition, weight and body image take into consideration appropriate prevention of Eating Disorders

   Collaboration to develop and evaluate effective Eating Disorder prevention campaigns

The NEDC is currently working from the perspective that these visions can be achieved by the development of: A collaborative, coordinated and evidenced based approach to the research, prevention and treatment of Eating Disorders to reduce the incidence, and impact of the illness
Principles

The following underpinning principles were listed for consideration by participants:

- Eating Disorders require the same quality, breadth and accessibility of care as other serious physical or mental illnesses.
- Services take a consumer-oriented approach:
  - Person centred care is the most responsive way of assisting people with Eating Disorders. People with Eating Disorders, their families and carers are central to making choices about care. Their rights and interests will be protected.
  - Services adopt a strengths-based approach and are guided by the aim of supporting each service user toward long-term recovery.
  - Services are built around those elements that have been shown to be valued by service users: autonomy, respect, confidentiality, a supportive and empathetic atmosphere, being recognised and treated as an individual.
  - The significant role of families and carers is recognised and supported.
- People with or at risk of an Eating Disorder, their families and carers should receive appropriate services, where and when they need them, regardless of social, cultural or economic background or location.
- Services work together to deliver a seamless, coordinated continuity of care:
  - Multidisciplinary approaches, and multi-skilled staff, are essential to address the range of needs of people with Eating Disorders.
  - Services are coordinated and integrated to facilitate easy transitions between services.
  - Consultation with families, carers, health professionals and advocates is essential to develop and deliver effective care for people with Eating Disorders.
- Services are based on research evidence. When research evidence is not available, services are based on the potential of the action items, judged on the basis of current knowledge and experience, to prevent or treat Eating Disorders.
- The development of evidence based approaches to the prevention, early identification, and management of Eating Disorders is a priority which requires collaboration between research, practitioners and people with a lived experience of Eating Disorders.

Workshop Sessions

Workshop sessions were aligned to the four Review Forums. These sessions provided an opportunity for participants to:

- Identify priority areas for action to achieve the Collaboration’s vision.
- Contribute supporting opinion and evidence for proposed actions based on their experience.
- Identify issues for further consideration that may fall outside the immediate scope of the National Framework.

Each workshop considered the priority issues and actions for their particular area, with specific questions posed to initiate discussion (see below). The questions posed were developed from previous Review Forum meetings, together with the outcomes of other Collaboration activities such as the Evidence Review, Information and Resource Review, and Steering Committee deliberations.

The feedback was collected from the summaries recorded by workshop leaders, the written responses made during the Workshop Sessions and a live Wiki conducted during the closing plenary session.
Workshop Session Questions

Promotion and Prevention Workshop Discussion Questions

<table>
<thead>
<tr>
<th>Actions and Challenges</th>
<th>Workshop themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are our priorities for selective prevention?</td>
<td></td>
</tr>
<tr>
<td>How do we reach people with prevention messages in all age groups and at major life transitions?</td>
<td></td>
</tr>
<tr>
<td>How do we ensure that prevention strategies are evidence based?</td>
<td></td>
</tr>
<tr>
<td>How do targeted prevention strategies interact with a collaborative continuum of care?</td>
<td></td>
</tr>
<tr>
<td>How do we build on what’s already there?</td>
<td></td>
</tr>
</tbody>
</table>

| What are our priorities for universal prevention? |  |
| How do we overcome the ‘thin ideal’? |
| How do we ensure consistency in messaging? |
| How do we ensure that strategies are evidence based? |
| How do universal prevention strategies interact with a collaborative continuum of care? |
| How do we build on what’s already there? |

Identification and Early Intervention Workshop Discussion Questions

<table>
<thead>
<tr>
<th>Actions and Challenges</th>
<th>Workshop Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are our priorities for developing and disseminating consistent evidence based resources to support early identification and intervention?</td>
<td></td>
</tr>
<tr>
<td>Where are the gaps in the information and resources that need to be filled?</td>
<td></td>
</tr>
<tr>
<td>How can we extend the evidence base to support early identification and intervention?</td>
<td></td>
</tr>
<tr>
<td>How could a collaborative continuum of care assist identification and early intervention?</td>
<td></td>
</tr>
<tr>
<td>How can we make effective use of what’s already there?</td>
<td></td>
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</tbody>
</table>

How can we engage professionals outside the Eating Disorders sector in knowledge development? |  |
| How do we encourage and enable professions and academic institutions to build their knowledge of Eating Disorders? |
| How do we collaborate with other professions to build knowledge of Eating Disorders? |
| How do we engage other professional groups in the delivery of a coordinated continuum of care? |
| How can we make effective use of what’s already there? |
## Treatment Standards and Strategies Workshop Discussion Questions

<table>
<thead>
<tr>
<th>Actions and Challenges</th>
<th>Workshop Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How can we ensure consistent dissemination and implementation of evidence based standards?</strong></td>
<td>▪  What do we identify as evidence-based standards?</td>
</tr>
<tr>
<td></td>
<td>▪  Where are the gaps in the evidence-based standards that need to be filled?</td>
</tr>
<tr>
<td></td>
<td>▪  How could collaboration enhance the dissemination and implementation of standards?</td>
</tr>
<tr>
<td></td>
<td>▪  How do we ensure that practitioners are engaged with research?</td>
</tr>
<tr>
<td></td>
<td>▪  How can we make effective use of what’s already there?</td>
</tr>
<tr>
<td><strong>How can we work towards providing a continuum of care that offers choice, effective transition and long-term support?</strong></td>
<td>▪  How can we extend the evidence base to support both diversity and consistency in care?</td>
</tr>
<tr>
<td></td>
<td>▪  How could collaboration enhance the development of a continuum of care?</td>
</tr>
<tr>
<td></td>
<td>▪  How do we develop a workforce (for both service delivery and research) that is knowledgeable about Eating Disorders across the continuum of care?</td>
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<tr>
<td></td>
<td>▪  How do we use what’s already there?</td>
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</tbody>
</table>
## Consumers and Carers Workshop Discussion Questions

<table>
<thead>
<tr>
<th>Actions and Challenges</th>
<th>Workshop Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>If we could design the ideal service to ensure that people with Eating Disorders and their families are identified early, treated appropriately, given choices and supported holistically, what would it look like?</td>
<td>What sort of help is needed at the outset, when you discover there is something wrong?</td>
</tr>
<tr>
<td>(Think about the whole service, right through from discovery to recovery and restored quality of life.)</td>
<td>Who should be involved along the journey, and what should be their attitude?</td>
</tr>
<tr>
<td>In this service, what are the priority areas? (From your description you will be asked to highlight the bits you would prioritize if you were starting a service from the beginning.)</td>
<td>Where should the service occur?</td>
</tr>
<tr>
<td></td>
<td>Think about step-up/step-down services, treatment choices</td>
</tr>
<tr>
<td></td>
<td>How are we defining ‘holistic’, ‘choice’ and ‘quality of life’</td>
</tr>
<tr>
<td></td>
<td>Where are the gaps in the current system?</td>
</tr>
<tr>
<td></td>
<td>What are the gaps in the current knowledge and skill base that would need to be addressed to achieve holistic approaches?</td>
</tr>
<tr>
<td></td>
<td>What about ongoing support in the community?</td>
</tr>
<tr>
<td></td>
<td>How do we use what’s already there?</td>
</tr>
</tbody>
</table>

What are the ways that you, or others, can participate in increasing our understanding about Eating Disorders, making treatment practices better, and helping to prevent Eating Disorders?

- How can people with lived experience and families share their knowledge to help others?
- How could engagement with people living with Eating Disorders be included in professional education and workforce development?
- What about inclusion in research?
- Where are the gaps in the current knowledge and skill base that would need to be addressed to achieve holistic approaches?
- How can we use lived experience to assist with prevention of Eating Disorders?
- How do we use what’s already there?
Live Wiki

This activity provided an opportunity to discuss experiences and share knowledge, in small groups of participants from different Review Forum sessions. Three key questions were posed:

1. A major challenge facing the collaboration moving forward is to identify our key messages. Today we have spent a lot of time discussing what they are and being informed by current best practice, the evidence and the lived experience. Take the next ten minutes to identify your top three, four or five.

2. We have been excited and amazed at the collective involvement and shared vision of the collaboration members. What does the future look like for NEDC?

3. This is your chance to have your voice heard – if something is bugging you, has not been resolved or you have just felt too shy or nervous to speak up – put it on paper and send it to the front

Publication of Feedback

Feedback from each workshop session was summarised by the workshop leaders and presented during the closing plenary session. Raw feedback from the workshop sessions, live Wiki and from evaluation forms was made available to workshop participants and other NEDC members on the NEDC website.

The feedback has provided one of the essential building blocks for the National Framework and some of the direct comments made by participants have been included in the text of the Framework to illustrate salient points.
Appendix D:

Worldwide Charter for Action on Eating Disorders

Rights and expectations for people with eating disorders and their families
Preamble

In recognition that eating disorders—anorexia nervosa, bulimia nervosa, binge eating disorder, and related disorders—are serious mental disorders that devastate the physical, psychological, and social well-being of millions of people of all ages and their families and loved ones, and that eating disorders have one of the highest mortality rates (in the case of anorexia nervosa) of any psychiatric disorder.

In recognition that the highest quality of treatment involves a partnership among the treatment providers, the person with an eating disorder, and their family or loved ones.

In recognition that people with eating disorders and their families have a right to be involved in treatment decisions and to be involved in respectful ongoing communication with the treatment providers regarding important treatment-related information and developments.

In recognition that people with eating disorders have the right to high quality, evidence-based care delivered by competent practitioners at an appropriate intensity and duration.

In recognition that people with eating disorders have the right to fully funded (by insurance or government), specialised eating disorder treatment provided at the earliest possible time.

In recognition that this charter advocates universal ideals and standards of care which the government, the providers of healthcare, and the public should strive to achieve.

The parties hereto adopt this charter and call upon its observance by all concerned.

Charter History

This charter provides people with eating disorders, and their families and loved ones, with a list of their basic rights and reasonable expectations regarding eating disorder treatment and services. It was produced through collaboration between the Academy for Eating Disorders (AED) and other professional and patient/carer organisations around the world. The content is drawn from the results of a large web-based survey of key stakeholders (people with eating disorders, their families and other carers, and eating disorder health professionals) undertaken between February and May 2016.

This document was written in full knowledge that the quality and accessibility of eating disorder programs and services is not equal around the world. It is hoped that the Charter will serve as a tool to assist people with eating disorders and their loved ones in identifying high quality, appropriate services and practices, and to guide them in challenging unhelpful, out-dated, and anti-therapeutic practices. It is also our hope that this Charter will provide service planners and providers with the basic building blocks for quality program and service development.

The core value underlying this document is that a partnership among people with eating disorders, their families, and the treating team, with rights and responsibilities for all sides, is imperative for any quality eating disorder service or individual healthcare encounter.

The Rights of People with Eating Disorders and Carers

I. Right to Communication/partnership with Health Professionals

II. Right to Comprehensive Assessment and Treatment Planning

III. Right to Accessible, High Quality, Fully Funded, Specialised Care

IV. Right to Respectful, Fully-informed, Age-appropriate, Safe Levels of Care

V. Right of Carers to be Informed, Valued and Respected as a Treatment Resource

VI. Right of Carers to Accessible, Appropriate Support and Education Resources
I Right to Communication/partnership with Health Professionals

- People with eating disorders have a right to have their condition taken seriously, just like people with other physical or mental disorders.
- People with eating disorders have a right to be treated with empathy and respect.
- People with eating disorders have a right to have their illness, its antecedents, maintaining factors, health risks, prognosis, and treatment options fully explained to them in user-friendly terms, and to be given the opportunity to ask questions and discuss any concerns they have about their illness or its treatment.
- People with eating disorders have a right to a full explanation and rationale for hospital/treatment program rules and regulations.
- People with eating disorders have a right to be actively involved in decisions about their care.

In regard to service evaluation and planning:
- The input of people with eating disorders and carers should be integrated into the planning and setting up of new eating disorder services.
- Satisfaction for people with eating disorders and carers should be routine outcomes included in the evaluation of services.

II Right to Comprehensive Assessment and Treatment Planning

- People with eating disorders have a right to a comprehensive assessment of their physical, emotional, and social needs.
- People with eating disorders have the right to a Care Plan.

III Right to Accessible, High Quality, Fully Funded, Specialised Care

- People with eating disorders should expect to be treated by a healthcare practitioner who is competent in the assessment and treatment of the physical and psychological aspects of their disorder.
- People with eating disorders have a right to the availability of accessible, specialised local treatment services.
- People with eating disorders should have the right to equal access to fully funded, specialised treatment and care.

IV Right to Respectful, Fully-informed, Age-appropriate, Safe Levels of Care

- People with eating disorders should be informed about the evidence-base for any treatments they are being offered including its harms and benefits, and alternative treatments.
- Where appropriate, people with eating disorders have a right to be informed about the treatment outcomes achieved in a particular treatment facility and how they compare to published outcome figures.
- People with eating disorders should be alerted to any health risks as they arise and to have these monitored and taken into account in any treatment decisions.
- People with eating disorders should expect that their treatment will address both their nutritional and physical health and safety, and their psychological health and quality of life.
- People with eating disorders should expect that their treatment will include a focus on relapse prevention.
- People with eating disorders should expect that the duration of treatment matches the nature and severity of their illness.
RIGHT OF CARERS TO BE INFORMED, VALUED AND RESPECTED AS A TREATMENT RESOURCE

We use the term ‘carer’ here to denote any family member, partner, or close other of a person with an eating disorder.

- Carers have a right to be treated with empathy and respect.
- Carers have a right to be seen as a resource and a valued partner in the treatment of their loved one.
- Where appropriate, carers should be involved in the assessment and treatment of a person with an eating disorder. The precise nature and degree of carer involvement should be based on the wishes of the person with the eating disorder and their carers.
- Carers should be informed if the risks associated with their loved one’s eating disorder are high and where the person with the eating disorder is in the community, carers should be given clear instructions on how to act on these risks.

RIGHT OF CARERS TO ACCESSIBLE, APPROPRIATE SUPPORT AND EDUCATION RESOURCES

- Carers should be offered support to facilitate their care-giving role.
- Carers have a right to receive information and education about the illness of their close other.

THIS CHARTER CALLS UPON THOSE RESPONSIBLE FOR POLICY AND PRACTICE TO:

- Educate and inform the community with programs that:
  - De-stigmatise eating disorders by promoting the understanding that an eating disorder is not an illness of choice, and by raising awareness of the causes of eating disorders
  - Increase public awareness of the signs and symptoms of eating disorders
  - Make available comprehensive information about eating disorder services and resources
- Connect with the media to provide accurate information on eating disorders and to help shift the culture’s perspective on body image issues and weight and food issues
- Develop and implement effective prevention programs targeting schools and universities
- Educate and train healthcare practitioners at all levels in the recognition and treatment of eating disorders to improve the quality of care
- Provide sufficient specialist services based on regional need
- Provide people with access to fully funded, specialised treatment and care
- Fund research into eating disorders.