



Butterfly
Foundation for Eating Disorders

Submission to Mental Health Commission

The Butterfly Foundation

Submission on the Draft Strategic Plan for Mental Health in NSW

THE BUTTERFLY FOUNDATION

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The Butterfly Foundation is Australia's only national charity supporting those affected by eating disorders and negative body image. Services span prevention, early intervention and support, including the provision of the federally funded national support line, staffed by trained counsellors experience in dealing with eating disorders.

Butterfly's philosophy is based on recognizing the need for greater respect for sufferers and carers and involving them in treatment; increased choices and access to effective treatment within the public health sector; greater awareness in the community of the seriousness of negative body image and eating disorders, which have incredibly high mortality rates, and the need to change the culture around 'thin' as a perfect ideal.

Butterfly works in collaboration with a range of partners, believing this is the most effective way to bring about sustainable cultural change. Butterfly has extensive networks among eating disorder professionals, not for profit consumer organisations, researchers and academics, corporate, fashion, and media. Butterfly seeks to bring people together to improve knowledge, awareness and capacity in the sector. Our collaborative approach has seen Butterfly successfully coordinate the National Eating Disorders Collaboration (NEDC) for the Australian Department of Health, as well as manage multiple projects with state health services and other non-government organisations.

1. Response to the Draft Strategic Plan

The Butterfly Foundation endorses all of the key issues and themes that appear in the current strategic planning report.

There are however some differences between eating disorders and other mental illnesses and these need to be highlighted in the context of planning any mental health service response.

The following submission addresses eating disorders in Australia and the best practice information available from the National Eating Disorders Collaboration as well as benefits and barriers in the current NSW health system and opportunities for further development to meet mental health needs in the state using evidence-based approaches.

2. Eating Disorders in Australia

Eating disorders are complex mental illnesses. They involve highly disturbed eating behaviours, weight control measures and a significant distortion of body image and its relationship to the person's self worth.

Eating disorders are becoming increasingly common in Australia. Approximately 9% of the population will have an eating disorder. Over 913,000 Australians suffered from an eating disorder in 2012. While eating disorders can affect anyone of any age and gender, they are particularly prevalent in young people and, increasingly, children.

Eating disorders continue to be largely hidden in the general population. The ego-syntonic nature of eating disorders and socially normative nature of disordered eating behaviours, together with the high level of stigma associated with eating disorders lead to the majority of people with eating disorders avoiding treatment, or seeking treatment for related conditions such as obesity or mood disorders. Many people fail to recognise eating disorders as mental illnesses and this lack of awareness is prevalent in the medical profession as well as in the general population. This inhibits identification, diagnosis, and referral for treatment.

A person with an eating disorder requires treatment that is specific to their disorder, delivered by health professionals who have been trained in the delivery of evidence based approaches. It is essential for safe treatment that medical and nutritional treatment is integrated into psychiatric care. Safe treatment for eating disorders addresses all aspects of the illness including physical, psychological, nutritional, and functional.

Access to evidence based treatments is a higher priority for people with eating disorders than access to social support at this stage in the development of the mental health system. Studies suggest that only 22% of people with eating disorders access specialist treatment for their illness (Swanson, Crow et al, 2011) and identification of people with bulimia nervosa and binge eating disorder may be as low as 10% of actual cases.

The biggest barrier to getting the right treatment for eating disorders is having access to somewhere that is specifically set up to treat eating disorders. The most dangerous experiences of patient's with eating disorders in public health services have occurred because there was nowhere else for them to be referred to. Without skilled, purposeful eating disorders treatment the revolving door of hospital admission is going to continue.

Consultation conducted by the NEDC has identified that lack of knowledge about eating disorders, their identification, assessment and treatment, is prevalent amongst health professionals including general practitioners, emergency department personnel, dietitians, and psychologists. The lack of knowledge and confidence to treat eating disorders represents a significant barrier to gaining access to effective treatment.

Eating disorders have serious physical, social and psychological impairment consequences and medical complications and can ultimately be fatal. Without appropriate intervention as early as possible in the course of illness, eating disorders are likely to persist long term and lead to reduced quality of life and life expectancy.

The cost of an eating disorder to the community is significant. The total socio economic cost of eating disorders in 2012 was estimated at \$69.7 billion. Anorexia Nervosa and Bulimia Nervosa are the 10th and 8th leading causes, respectively, of burden of disease and injury measured in disability adjusted life years of young women in Australia aged 15-24 years. The cost of untreated or inappropriately treated long term eating disorders is much greater for everyone involved than the cost of adequate provision of treatment.

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

2.1 National standards for best practice with eating disorders

The National Eating Disorders Collaboration (NEDC) is an initiative of the federal Department of Health (previously Health and Ageing). It is a collaboration of people and organisations with an expertise and / or interest in eating disorders. Its purpose is to develop a nationally consistent, evidence based approach to the prevention and management of eating disorders in Australia.

The NEDC has developed a National Eating Disorders Framework standards schema, which includes seven core principles and four implementation principles which, if implemented together, provide the foundation for an effective and consistent system to address eating disorders.

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

Practice Principles

- Person and family centred care that addresses the needs of individuals
- Prioritization of prevention, early identification and early intervention Prevention, early
- Safety and flexibility in treatment options
- Partnering to deliver multi-disciplinary treatment in a continuum of care
- Equity of access and entry
- Tertiary consultation accessible at all levels of treatment
- Support for families and carers as integral members of the team

Implementation Principles

- Evidence informed and evidence-generating approaches
- A skilled workforce
- Communication to ensure an informed and responsive community
- Systems support integration, collaboration and on-going development

Safe treatment for eating disorders addresses all of the aspects of illness: physical, behavioural and psychological. People have access to a range of safe treatment options which meet different needs at each stage of risk, illness and recovery. Flexible and appropriately supported entry, exit and transition between services supports individually tailored care planning.

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

An effective system is founded on a skilled and supported workforce. All health professionals who work with people at risk of eating disorders should receive training in eating disorders to raise their awareness of the serious nature of eating disorders and to enable them to identify, assess and contribute to the treatment of eating disorders. Training includes attitudes and practices that support early identification, intervention, recognition of the ambivalence and fear that is prevalent in this population and a recovery oriented approach.

Putting these principles into practice, a service providing treatment specifically for eating disorders should be able to demonstrate that:

- All staff delivering treatment are trained in the delivery of that treatment for people with eating disorders
- Patients collaborate in the development of individual treatment and recovery plans
- Assessment and decisions about the type and level of treatment are based on the patient's physical condition, psychology, eating disorder behaviours and social circumstances
- Treatment is motivational and non-coercive in approach

- Treatment specifically addresses physical, psychological and nutritional needs, delivered by a multi-disciplinary team
- Treatment duration and dosage is evidence based and sufficient to address the complexity of the disorder
- Family are actively engaged and supported as integral members of the treatment team unless contraindicated
- There are formal links and coordination between inpatient, outpatient and primary care services with effective transition strategies to ensure coordinated long term care
- Treatment and support strategies are evidence informed and/or evidence generating including systematic evaluation of patient outcomes and satisfaction

Continuum of Care

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

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

1. Primary, secondary and tertiary prevention
2. General outpatient support provided in both hospital and community settings with flexible access to a range of services delivered with variable frequency of access, with particular emphasis on relapse prevention / early intervention
3. Intensive outpatient support for people living with their family or other support structures who require intensive clinical support
4. Day programs, providing a more structured program, including group therapy
5. Residential programs, providing 24 hour support ideally located in the community. This level of care provides a step down or step up level following or before hospitalisation and is imperative for those who may not have a significant support structure in their homes
6. Inpatient services for medical intervention and stabilisation; intensive, structured inpatient programs to address severity and co-morbidity.

(National Eating Disorders Framework, NEDC, 2012)

3. The Current NSW mental health system and eating disorders

The Butterfly foundation congratulates the NSW government on the recently announced NSW Service Plan for People with Eating Disorders. Implementation of this plan will improve access to intensive treatment, including inpatient and day programs, for the most severely ill, particularly those living within the Sydney metropolitan area.

The Service Plan notes the importance of developing community based care options and clinical networks for earlier and more effective treatment of eating disorders and the Butterfly Foundation strongly supports these goals.

NSW Health is fortunate to have a number of resources which it can draw on to support the implementation of improved eating disorders treatment services.

The CEDD online training modules and the guidelines for the treatment of adolescents with eating disorders (EATING DISORDER TOOLKIT: A practice based guide to the Inpatient management of adolescents with Eating Disorders with special reference to regional and rural areas; Hunter New England NSW Health, 2008.) provide a foundation for future action.

We also note the innovative approaches to treatment currently in place in Sydney Children's Hospital Network Westmead which have the potential to be replicated in other child and adolescent mental health services.

For people with eating disorders access to treatment has been such a significant barrier that it is difficult to identify strengths in the current system. In the Service Plan, Minister Humphries on behalf of the NSW government notes that *“For too long there has not been enough focus on prevention and early intervention to help support young people before eating disorders become long term problems. In addition, local clinicians have often lacked the confidence to treat people with an eating disorder, creating additional pressures on specialist services”*. (Media Release, 14 September 2013)

A lack of options for referral to eating disorders specific treatment is a fundamental barrier to improved health outcomes and to reduction in unplanned admissions to hospital. Providing access to clinicians with expertise in the treatment of eating disorders and providing protocols that support staff to access these clinicians is an essential step towards an effective response to eating disorders.

4. Models for integrated community responses to eating disorders and the mental health system

Butterfly supports the evidence-based models developed by the NEDC and believes that to be effective in preventing, identifying and treating eating disorders these models should be considered in the development of future mental health systems in NSW.

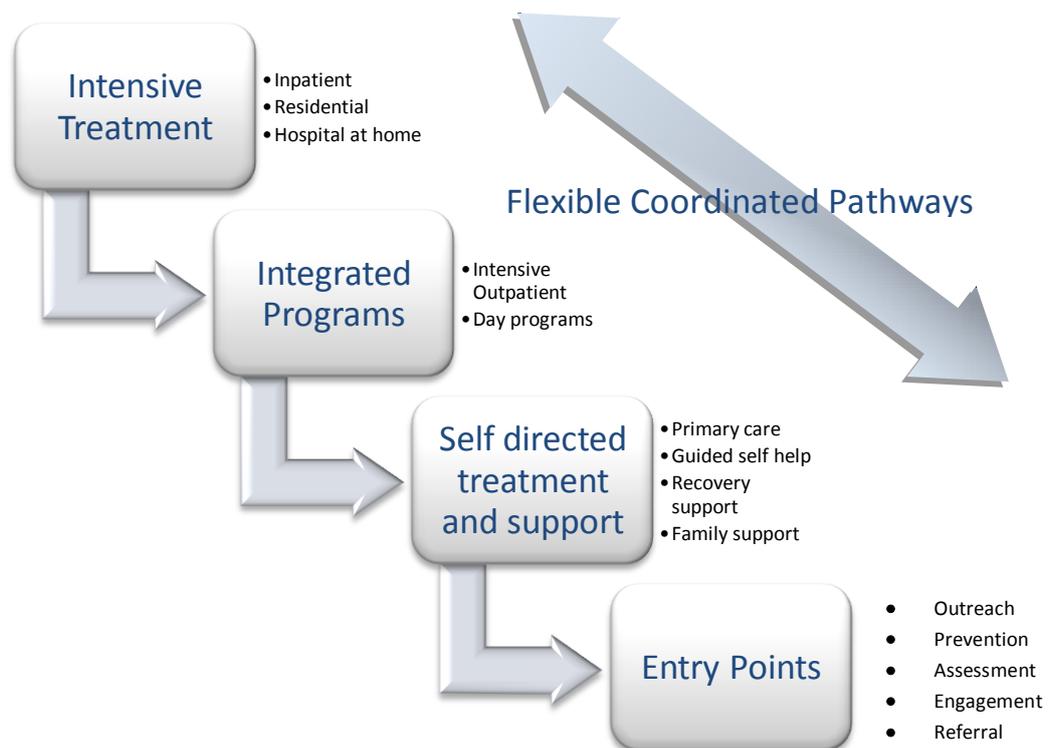
4.1 Essential service system elements

The essential elements of an eating disorders service system include:

1. **Entry points** – services located in or accessible from the local community that support prevention, early identification, assessment, motivational enhancement to engage with treatment and access to defined referral pathways. Entry points are essential for people with all types and levels of severity of eating disorders and at all stages of illness. They provide essential support for families and other supporters including health and other professionals who work with people at high risk.
2. **Self-directed treatment and support options** - services located in or accessible from the local community that provide primary care treatment, support for self-help, support for

recovery and support for families. These services meet the needs of people requiring early intervention, treatment of mild disorders or long term support as a step down from more intensive treatment.

3. **Integrated programs** – services located in or accessible from the local community that provide structured multi-modal and multi-disciplinary programs with an intermediate level of treatment and support. These services meet the needs of people with mild to moderate levels of illness who have sufficient motivation, self-direction and social support to engage in the program and implement new behaviours in their daily life but who require a higher level of support than the typical weekly level of service provided for self-directed treatment. Integrated programs typically include intensive outpatient programs and day programs. Integrated community based programs may provide an entry level of treatment, a step down from intensive treatment or a step up from self-directed treatment and support.
4. **Intensive treatment** – residential services providing 24 hour treatment and support in a hospital or specific residential setting or as a hospital at home program. Intensive treatment may provide medical treatment and re-feeding as well as the multi-modal mental health elements of integrated programs. These services meet the needs of people with severe illness, a low level of motivation for change and potential risks to safety. They may also be required when no lower level of service is available within the community.
5. **Flexible coordinated pathways** – case coordination, treatment and discharge planning, and collaboration between service providers both within the health and NGO systems to ensure that people have an integrated and consistent experience of treatment and support and flexible movement between services in response to their individual needs.



4.2 A continuum of care

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

Systems are required to support integration of services provided at different levels of care, in different settings from community services to tertiary services, and potentially in different health regions or even different states.

4.3 Safe treatment practices

The National Eating Disorders Collaboration definition of safe treatment includes:

“Safe treatment for eating disorders addresses all of the aspects of illness: physical, behavioural and psychological. People have to have a range of safe treatment options which meet different needs at each stage of risk, illness and recover. It is unsafe to treat one dimension without the others. Flexible and appropriately supported entry, exit and transition between services supports individually tailored care planning. When transitioning from child and adolescent services to adult services appropriate support is provided to the individual and their family.” (NEDC National Framework, 2012)

Consumers and carers have made the following comments on their experience of safe treatment in NSW health system:

All the hospital wanted was to re-feed and weight restore and then get her out of there. Some hospitals punish you for not eating. It's frightening and degrading and all you want to do is get out of there.

My daughter was terrified of the treatment she received and terrified of re-admission which made her anxiety worse and so made the eating disorder behaviour worse as well

Current treatment for eating disorders often focuses on weight restoration rather than addressing the full spectrum of the disorder.

A patient with an eating disorder needs much more than re-feeding or re-hydrating. They need staff to respond safely to their immediate presenting health problem and also to the full spectrum of the eating disorder.

All they did was rehydrate me and then they sent me home. I wasn't properly assessed. They didn't contact my psychiatrist. They just sent me home. I was back in Emergency the next week.

While medical stabilisation and weight restoration are sometimes required, the next step on from this treatment must be an eating disorders assessment and a referral or transfer to an eating disorders specialist program or an eating disorder specialist clinician. Discharging a patient after weight restoration or medical stabilisation without such an assessment can only result in a cycle of re-admissions to hospital.

There is a need to link inpatient and outpatient programs so that there is an ongoing treatment plan not just isolated incidents of treatment. Consultation is required between hospitals, for example, tertiary consultation for general mental health services and medical wards. Protocols should provide information on where to seek tertiary consultation and how to request this support.

There is a need to break down the barriers in the health system to collaborative care.

All the clinicians and support agencies and the carer, everyone needs to be involved if you want the person to have a chance of getting well.

The pattern should be that you are medically stabilized, then go through a full eating disorders assessment with both medical and psychiatric staff then transferred to an ongoing eating disorders program either as an inpatient or an outpatient. And then you need follow up after discharge, maybe a home visit, to make sure that the plan has worked and that you are OK.

The use of liaison officers to provide eating disorder information and support in the hospital setting before discharge is a strategy that has worked in other states, (e.g. Eating Disorders Outreach Service in Queensland). The role is described by consumers as “Someone who can advocate on your behalf to get you into the treatment you need and make sure all the parts of treatment come together”.

Carers require information on what needs to happen after discharge; on the options for treatment, the services to contact and the symptoms that would indicate deteriorating health and therefore readmission to hospital. This is as true for parents of young adults who are living at home as it is for adolescents. Both consumers and carers agree that the treatment that a young person needs at 17 is still the treatment they need at 18 or 20 years. The nature of the illness and the treatment that works doesn't change because the person ages one or two years. Consideration should be given to modifying the age of adolescents to more consistently match community-based services for young people and integrated pathways be developed for older adolescents to access adult services. Standards in adolescent health services for patients with eating disorders should also be the standards for adult patients with eating disorders.

It is important for people with eating disorders to have someone to provide support and family and carers play a critical role in the treatment of eating disorders. Eating disorders are very stressful for families and the role of carer is highly demanding. It is essential that medical staff work with the family or carer rather than excluding them.

If the family isn't supported it affects the patient and how they respond to treatment

The carer needs to be identified as a person who can receive confidential health information. A person under the BMI threshold is not fully able to make their own decisions and needs someone else to act on their behalf.

Nobody tells you a lot. There is a lack of information. I know this is probably a systemic problem but dealing with an eating disorder seems to make it worse. As a carer I am the one who is responsible when she is discharged. I really need to know what is going on and what I need to do.

4.3 Community based services

Most people with eating disorders may be treated successfully by appropriately trained health professionals in community settings. Management of eating disorders on an outpatient basis in a community location enables the patient to remain close to family and social relationships, continue engagement in work or education where possible, and generalize new behaviours into everyday situations.

Intermediate levels of treatment, provided through outpatient programs, intensive outpatient programs and day programs, are essential to ensure the continuum supports the essential step up and step down access to treatment during the course of illness. Without these intermediary levels of treatment, more people will require hospitalization.

Hospitalization is essential in the most severe cases. The complexity of eating disorders and the potential for rapid deterioration in physical health mean that close links must be maintained between community service providers and more intensive levels of specialist treatment including access to tertiary consultation and treatment services.

4.4 Long term access to support

Recovery from mental illness does not mean that the person no longer needs support. Continued supports are often critical to the process of recovery.

The National Eating Disorders Framework includes recovery support as a separate element on the continuum of care with the provision of “*access to ongoing support including individual professional support, group support, peer support and self-help education*” as a standard for the optimal model of care for people with eating disorders. Where long term treatment is referred to in NEDC publications it means a combination of treatment and support services that are delivered in a coordinated and consistent way over an extended period of time to meet the changing needs of the patient.

Establishing a pattern of regular eating, a healthy relationship with food and the ability to self-monitor behaviours and thinking are fundamental to successful eating disorders treatment. These issues are addressed in evidence based treatment for eating disorders however there is a need to sustain these patterns of thinking and behaviour for the long term and in the context of daily life. During and after treatment, people with eating disorders need to learn how to respond to their normal living environments, particularly in relation to food, without the eating disorder. This takes

time, education, encouragement and support. It must be carried out as close to home as possible to enable people to continue or resume their normal life activities and relationships.

People with disordered eating and eating disorders require access to community based programs that provide prevention, relapse prevention, rehabilitation, recovery support and family support services. Access to these services should be included in long term recovery oriented treatment plans. Eating disorders recovery occurs at all stages from prevention through treatment and is an integral part of eating disorder treatment programs therefore it is not necessarily an individual service but rather a framework of key interventions that can be accessed as and when people need them:

- Early intervention (and early re-intervention)
- Case coordination post treatment discharge
- Rehabilitation
- Recovery support
- Relapse prevention
- Family support
- Consumer and carer participation

4.5 Consumer informed care

The Butterfly Foundation received a request from NSW Health to submit a consumer informed opinion on appropriate protocols for the treatment of people with eating disorders in general public hospitals in NSW. In response Butterfly consulted with people who had experience as patients in the NSW public health system in March 2013.

Areas for change identified in this consultation include:

- **Staff knowledge and attitude** – there is an urgent need for training of staff in emergency, medical and psychiatric wards in the assessment and treatment of eating disorders; appropriate engagement of people with eating disorders and in how to implement protocols
- **Existing protocols** – current protocols for emergency departments do not help staff to work with people with severe eating disorders. Current protocols for adolescent services provide a sound basis for the development of protocols for adult services
- **Early access to treatment** - early and timely access to treatment for eating disorders is essential to improve outcomes.
- **Screening** - screening for eating disorders should be routine in emergency departments, psychiatric wards and in some medical wards.
- **Full assessment** – assessment must take all factors into consideration including the person’s history, current eating disorders treatment plan, physical indicators, eating disorder behaviours, high risk conditions such as pregnancy or diabetes, and the social circumstances

that the patient will be discharged to including an assessment of carer capacity to provide support in the current circumstances.

- **Exclusion criteria** – require immediate amendment to enable seriously ill patients to access treatment. It is never appropriate to refuse essential medical treatment to a patient with an eating disorder on the basis that they have a history of mental illness, suicidality, self harm or substance abuse. This was the most disturbing issue to emerge from the discussion.
- **Accessing treatment from the Emergency Department** - the next step on from emergency or medical ward treatment must be a full eating disorders assessment and a referral or transfer to an eating disorders specialist program or an eating disorder specialist clinician.
- **Admission to Inpatient treatment** - the best option for hospital treatment is admission to a general medical ward with staff that are trained in eating disorders and skilled to monitor physical health, behaviour and safety. A general psychiatric ward is not a suitable place for treatment of someone with an eating disorder unless there is a risk of suicide.
- **Safe treatment** – a patient with an eating disorder needs a multi disciplinary response to their immediate presenting health problem and to the full spectrum of the eating disorder. There is a need to link treatment across departments and to link inpatient and outpatient programs so that there is an ongoing treatment plan not just isolated incidents of treatment.
- **Discharge planning** - ongoing treatment post discharge is essential. Plans must ensure that the patient is linked in with key eating disorder clinicians in the community for ongoing treatment and support and have appropriate care or support systems in place at home. Discharge plans should include information to help patients and their families understand the warning signs of relapse, and readmission plans.
- **Case coordination and liaison** – people who present to hospitals for treatment require a case coordinator or liaison officer to advocate on their behalf, coordinate treatment and provide eating disorder information and support to clinical staff.
- **Parents and carers** – it is essential that staff identify the carer from the beginning of treatment and work with the carer rather than excluding them. Carers need information on the treatment plan and on what needs to happen after discharge.

5. The way forward

In an effective eating disorders treatment system, hospitalisation would be rare and would always occur in combination with community responses, preventing it from becoming a separate intervention.

Recognising that while much of the care required is clinical, a significant proportion is also psycho-social rehabilitation, people with eating disorders would have long term access to community based recovery support. Rehabilitation structures would include community based integrated eating

disorders programs at different levels of intensity from day programs at the highest level of intensity, to intensive outpatient programs and recovery support programs.

There are several key ways in which NSW can move towards integrated community responses to eating disorders within future mental health systems.

6.1 Implementation of nationally consistent, evidence-based approaches

Key standards and models required to create positive change in future mental health systems are detailed in sections 2 and 4 of this submission. Future mental health systems should be modelled on the essential service elements identified in these approaches.

In particular, systems need to:

- Promote recognition of eating disorders as significant mental illnesses that require their own specific approach to treatment and support
- Recognise ownership of eating disorders as a mental health issue which requires integration of medical and allied health services
- Secure a position for eating disorders in all future developments of the NSW mental health programs and services
- Ensure that key issues in eating disorders treatment are included in strategic planning:
 - Eating disorders specific treatment
 - Community based programs
 - Facilitated entry points including soft entry
 - Safe, multi-disciplinary treatment
 - Integrated medical and psychiatric care
 - Co-ordinated care between service providers and between episodes of illness\
 - Long term recovery support in the local community
 - Assertive outreach programs, including prevention and early intervention to reach the large number of people who do not currently receive treatment

6.2 Workforce knowledge and attitudes

In NEDC consultation with health professionals working with people with or at risk of eating disorders, less than half received training in eating disorders and an additional 47% receive training they believe is inadequate to equip them to treat eating disorders. Consultation has found limited awareness of the presentation of eating disorders other than extreme weight loss in anorexia nervosa in both health professionals and the general community.

Consumers experience widespread misunderstanding of eating disorders amongst health professionals and an unacceptable level of derogatory communication:

They seem to think that we can just stop it if we want to. They don't understand that someone with an eating disorder doesn't have control

Well, you should eat. Go home and have a slice of bread.

I could lose a couple of kilos if I had your self control

For early intervention and timely treatment to occur it is essential that people who work with those at high risk of eating disorders proactively identify eating disorders symptoms and engage people in help seeking. It is essential that there are then appropriate treatments for those people to be referred to. Without an active response from health professionals, supported by a knowledgeable community, early intervention will not happen.

Ensuring a skilled and knowledgeable workforce is a priority for the provision of effective treatment for eating disorders. The NEDC has concluded that training in eating disorders is an essential part of professional development for all health professionals, particularly those working in General Practice, Emergency Departments, on general medical and psychiatric wards and in specialist units which may be expected to treat people with eating disorders such as cardiac, renal, gastroenterology. The existing online training modules from CEDD would be an appropriate starting place for this training.

6.3 Understanding the impact of eating disorders on specific communities

Butterfly and the National Eating Disorders Collaboration have recently commenced visiting regional and rural centres across Australia to support the implementation of best practice in eating disorders in each community and identify opportunities and barriers to implement the evidence-base in locally relevant ways. Feedback from regional and rural services highlights the difficulties in accessing specialist treatment options and integrating these in a locally accessible continuum of care. They have noted that many services available in NSW, as well as other states, are centric to metropolitan and capital city areas. Communities have identified the need for systems to include access pathways for individuals living outside of these areas. The development of systems needs to include further consideration of the access and integration needs of regional and rural communities.

Consultation undertaken by Butterfly and NEDC has shown that the mental health needs of culturally and linguistically diverse communities are generally not well understood and this is particularly true for eating disorders. Treatment programs for eating disorders need to consider the role of family and cultural practices around food preparation and consumption. Prevention models also need to further explore issues relating to healthy eating, obesity, dieting and body image for a wide range of cultures.

In addition to this it is particularly important to further explore the needs of indigenous individuals and communities in prevention and treatment options. There is a lack of research evidence on eating disorders in Aboriginal and Torres Strait Islander communities; however these groups are known to have higher risk for a range of disorders that relate to risk factors for eating disorders including poor nutrition, obesity and higher rates of admissions for mental health problems and self harm.

The findings of a study by Hay and Carriage (BMC Public Health, 2012) found binge eating to be at least as common if not more common in Indigenous peoples and concluded that for Aboriginal and

Torres Strait Islanders eating disorder symptoms are at least as frequent as for non-indigenous Australians. The core cognitive feature of an eating disorder, namely weight and/or shape concern, was found to be as high or higher in Indigenous participants in the study and levels of restrictive dieting and other compensatory weight control behaviours were similar to non-indigenous participants.

Based on these findings it is surmised that eating disorders are likely to be at least as much a problem for Aboriginal and Torres Strait Islander people as for non-indigenous Australians. This finding is important as there are relationships between eating disorders and other health conditions of significance in Aboriginal and Torres Strait Islander communities, including obesity, substance abuse and mood disorders.

6.3 Identifying further information

Eating disorders have not been included in health data collection in any meaningful way. No data has been collected on eating disorders by the Australian Bureau of Statistics. No data has been available on eating disorders to guide the development of mental health initiatives.

On the basis of current data it is not possible to accurately establish benchmarks for the capacity of eating disorders services or estimate the level of future need for eating disorders specialist services. A priority area for action is therefore more detailed data collection to support decision making. Inclusion of all diagnoses of eating disorders in health and welfare data collection and mental health surveys as a first step towards developing a detailed profile of eating disorders in Australia.