Butterfly
Foundation for Eating Disorders

24 July 2018

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir / Madam

RE: INQUIRY INTO ACCESSIBILITY AND QUALITY OF MENTAL HEALTH SERVICES IN RURAL AND REMOTE AUSTRALIA

We welcome the opportunity afforded at the public hearing on 19 July 2018 to make written submissions to the Committee on the accessibility and quality of mental health services in rural and remote Australia.

As the peak 'voice' for those with a lived experience of an eating disorder, and as a leading provider of prevention, clinical and support services for eating disorders and negative body image across Australia, Butterfly Foundation engages regularly with rural and remote communities and the professionals who serve them. We have drawn on this expertise and used the evidence base developed by the National Eating Disorders Collaboration on best practice in addressing eating disorders in developing this submission.

Thank you for your work in reviewing the accessibility and quality of rural and remote mental health services and your consideration of our testimony and submission.

Yours sincerely

Christine Morgan
CEO / Director

Frances Cook
National Manager
Knowledge, Research & Policy

EATING DISORDERS AND RURAL AND REMOTE MENTAL HEALTH

A SUBMISSION TO SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE
INQUIRY INTO ACCESSIBILITY AND QUALITY OF MENTAL HEALTH SERVICES IN RURAL AND REMOTE AUSTRALIA.

Butterfly
Foundation for Eating Disorders

Contact
Frances Cook
National Manager Knowledge, Research & Policy
The Butterfly Foundation
103 Alexander Street Crows Nest NSW 2065
Ph: (02) 9412 4499

1 Table of Contents

2 Executive Summary

The Butterfly Foundation welcomes the opportunity to present to the Committee on the accessibility and quality of mental health services in rural and remote Australia. As a leading provider of prevention, clinical and support services for eating disorders and negative body image across Australia, Butterfly Foundation engages regularly with rural and remote communities and the professionals who serve them. We have drawn on this expertise and the work of the National Eating Disorders Collaboration (NEDC) in developing this information.

Eating Disorders are serious mental illnesses. They result in significant psychological distress, physical health complications and increased risk of mortality. Eating disorders frequently start in childhood and youth (median age of onset is 18) consequently impacting on education, identity formation and physical growth. With a high risk of recurrence and chronicity, eating disorders can also impact on health and quality of life for the whole life span. The average length of treatment is 5-7 years, although early identification and intervention can significantly reduce this duration.

Eating disorders are not low-prevalence illnesses; approximately 9% of the Australian population will be affected by an eating disorder. They occur regardless of culture, age, socio-economic background or geographic location.

The key issues for people with eating disorders seeking mental health treatment in rural and remote communities are:

- A general lack of awareness of eating disorders. This results in increased stigma, a decreased ability to identify or intervene early, social isolation for people with a lived experience and their families, and a reluctance to access treatment or support.
- Eating Disorders are rarely considered core business for general mental health services. For some, this goes as far as experiencing discrimination or encountering unhelpful believes from mental health and primary health professionals. More often, this may mean that people with eating disorders are excluded entirely, that inclusion or exclusion criteria make it difficult for people with eating disorders to access treatment, that they receive treatment that is not specific or evidence-based, or they have to travel vast distances on a regular basis to access care from an urban centre incurring significant costs

- A lack of connection and coordination. This means that people are often not aware of any services that may be available to them, they struggle to coordinate their mental health care with physical health care and nutritional support, they fall through gaps between services, and do not receive support if they return from receiving intensive treatment in an urban centre.
- Workforce development is difficult to sustain. With a frequently changing workforce who have multiple competing priorities, training programs may not result in sustained improvements to expertise in treating eating disorders among mental health services in rural or remote areas.

There are mental health treatments for eating disorders that are proven to be effective, particularly when provided within the first three years of illness. These modalities require specialised training and support but can be implemented by a wide range of mental health and allied health professionals. There is also a significant role for a well-supported and formalised peer workforce providing recovery support.

There are new services being piloted in delivering aspects of these programs using online platforms. This appears to be a significant potential for eating disorders but further work is needed to explore the unique aspects of an eating disorder and how they interact with online therapy.

Finally there is a significant need for further public awareness, and a focus on prevention and early intervention within these communities, to reduce stigma, encourage help-seeking and reduce the need for intensive tertiary care.

At a national level, one of the most significant contributions that could be made to advancing these key issues is the mandated engagement of Primary Health Networks in eating disorders prevention, identification, treatment and management. In particular, Primary Health Networks should, in line with National Eating Disorders Collaboration National Practice Standards; address eating disorders in data collection, needs analysis and strategic planning; provide ongoing professional training in eating disorders as part of workforce development, ensure that commissioned mental health services are addressing eating disorders as core business and that their treatments and interventions are evidence based, maintain collaborative partnerships with local , state-based and national eating disorders services as part of their networking.

3   Submission Methodology

In putting together information for this briefing, the following information collection was conducted:

- Consultation survey with National Eating Disorder Collaboration members who provide or access mental health services in rural and remote communities.
    - All states and territories excluding the ACT were represented
    - 62% providers of mental health services and 42% had a lived experience as a consumer or carer (some respondents had experienced both).
    - Professionals who responded included psychologist, counsellors, psychiatrists, social workers, mental health nurses, and a group of allied health providers. Most commonly they provided service in a public health setting (community or hospital) but also represented private practice and non-profit organisations.
- Review of data for services provided by Butterfly Foundation to those in rural and remote communities.
- Discussion with those with a lived experience of accessing care from a rural or remote community
- Review of published NEDC documentation on best practice nationally consistent approach to eating disorders (2012 to 2017).

This submission should be read in conjunction with other key documents produced for the eating disorders sector on best practice in the delivery of evidence-based treatment in a stepped care, community-based model:
- National Eating Disorders Agenda 2017-2022 (2017), The Butterfly Foundation
- National Practice Standards for Eating Disorders (2018), National Eating Disorders Collaboration
- Stepped Care Model (2016), National Eating Disorders Collaboration
- National Framework for Eating Disorders, National Eating Disorders Collaboration (2012).

4   Background

4.1   The Butterfly Foundation

The Butterfly Foundation represents all people affected by eating disorders and negative body image – a person with the illness, their family and their friends.

As a leading national voice in supporting their needs, Butterfly highlights the realities of seeking treatment for recovery, and advocates for improved services from both government and independent sources.

Eating disorders are serious psychiatric disorders with significantly distorted eating behaviours and high risk of physical as well as psychological harm. Left unaddressed, the medical, psychological and social consequences can be serious and long term. Once entrenched eating disorders can impact on every aspect of an individual's life and for many, can be life threatening.

Butterfly operates a National Eating Disorders Helpline ED HOPE that includes information about eating disorders and treatment options, treatment referrals, counselling and support, online support

groups over the phone, via email and online. The Helpline is staffed by trained counsellors experienced in assisting with eating disorders. It also provides a wide range of programs for service providers and recovery groups.

Because Butterfly recognises that eating disorders often arise from poor body image, it delivers a range of Positive Body Image workshops to schools and workplaces through its education program. It has a strong media presence to raise awareness of Butterfly's perspective in community debates about body image and eating disorders.

Throughout its work Butterfly emphasises the critical importance of prevention and early intervention strategies in limiting the development of, and suffering from, negative body image and eating disorders. To expand knowledge in this field The Butterfly Research Institute commissions academic research projects and funds PhD research scholarships.

In the 2016-17 financial year Butterfly Foundation reached:
- 85,000 young people through prevention services
- 9,000 contacts through the National Helpline
- 2.4 million impressions on social media.

Butterfly is committed to collaboration across the sector, and presently co-ordinates the National Eating Disorders Collaboration (NEDC) for the Australian Department of Health. The NEDC has over 2,800 members drawn from every state and territory within Australia and 4,000 subscribers to monthly e-bulletin communications. The NEDC website averages above 60,000 visitors per month. Since 2015 more than 3,000 people trained in introductory training for eating disorders, with a specific focus on delivery in regional locations.

1.1   Eating Disorders in Australia

Eating disorders are serious and complex mental illnesses associated with high levels of psychological distress and significant physical health complications. Eating disorders are a group of serious psychiatric illnesses which includes anorexia nervosa, bulimia nervosa, binge eating disorder, and other eating and feeding disorders. Each of these disorders involves distinct behaviours and beliefs specific to the diagnosis and treatment varies depending on the diagnosis. However, people with all types of eating disorders share disturbed eating behaviours and distorted beliefs, with extreme concerns about weight, shape, eating and body image.

Most people with an eating disorder present with binge eating disorder or other eating and feeding disorders[i]. These disorders are as clinically severe as anorexia nervosa and bulimia nervosa[ii], with an elevated mortality rate and increased risk of suicide comparable to that of anorexia nervosa[iii].

Eating disorders have been shown to have one of the highest impacts on health related quality of life of all psychiatric disorders[iv].

Eating disorders frequently start in childhood and youth (median age of onset is 18) consequently impacting on education, identity formation and physical growth.

Eating disorders have a significant prevalence, with approximately 1 in 20 Australians currently having an eating disorder[v].

Eating disorders are often accompanied by significant physical complications and impairment including chronic heart and kidney disease, osteoporosis and diabetes and diseases associated with obesity. Chronic physical complications can occur early in the course of illness[vi]. These disorders have been shown to have one of the highest impacts on health-related quality of life of all psychiatric disorders. They carry the highest mortality rate of all psychiatric illnesses, including a high risk of suicide. The overall mortality rate for eating disorders is up to 20%[vii].

With a high risk of recurrence and chronicity, eating disorders can impact on health and quality of life for the whole life span. Recovery from an eating disorder is a long-term process, lasting on average for seven years but affecting up to 25% of people as a severe and enduring illness. Eating disorders are not self-limiting illnesses and early intervention is required to reduce the severity, duration and impact of illness. When people are unable to access the right treatment when it is needed, early in illness, they are put at risk of a longer duration and greater severity of illness, with potential chronicity and a high suicide risk.

Eating disorders represent the 12th leading cause of mental health hospitalisation costs within Australia[viii]. The economic cost in Australia is conservatively estimated at $69.7 billion per year, of which $19.9 billion is the cost of health services. The burden of disease costs for eating disorders, estimated to be $ $52.6 billion in 2012, are comparable to the estimates for anxiety and depression ($41.2 billion), and for obesity ($52.9 billion)[ix]. A number of evidence-based treatment approaches are available and full recovery from an eating disorder is achievable. The positive side to the story of eating disorders is often lost in the complexity of these illnesses. Person-centred care, tailored to suit the person's illness, situation and needs, is the most effective way to treat someone with an eating disorder[x].

Since 2009 when the Commonwealth Government first engaged the National Eating Disorders Collaboration (NEDC) to map the eating disorders services and resources available in Australia, there have been a number of initiatives in various States that have started to prioritize the development of health system responses for people with eating disorders and their families. In particular, New South Wales, Queensland and South Australia have joined Victoria in implementing eating disorder service plans. There has also been development of professional training resources, delivered by state-based eating disorder organisations. However, there continue to be significant gaps in the continuum of care for people with eating disorders, and variability in the quality and accessibility of services for people living in different areas of Australia. There continue to be areas where eating disorders are not yet on the agenda for health service planning, and mental health services which exclude eating disorders from their service provision; this is particularly true for regional and rural locations across Australia.

1.2   Evidence-based Treatment of Eating Disorders

Eating disorders are a significant public health problem, not only because they are associated with substantial psychological and medical comorbidity, functional impairment, and high medical costs, but because they are often poorly recognised and undertreated. In order to address this issue, eating disorders must be recognised as a mainstream health priority in Australia. Action is required to prevent eating disorders and to support identification, early intervention, and readily accessible, evidence-based treatment throughout all stages of the illness process.

Good outcomes are achieved by people who receive this type of treatment early in illness and early in subsequent episodes of illness[xi]. Evidence-based treatment approaches are available and full, sustainable recovery from an eating disorder is achievable.

Early detection and intervention is critical to successful outcomes. People who have had an eating disorder for less than 2 years are likely to respond more quickly to treatment and experience a shorter duration of illness with fewer physical health consequences. When delivered early in illness by health professionals with appropriate knowledge and skill in eating disorders, this treatment can lead to full clinical recovery and improved quality of life for about 75% of people with eating disorders. Despite this it is estimated that only one in ten people with eating disorders receive appropriate treatment[xii] and even fewer receive early intervention.

The provision of a stepped continuum of care for people with eating disorders is supported by expert consensus as the ideal approach where the continuum includes a full spectrum of levels of intensity with skilled assessment of need and coordinated transition between services as the person's needs change. The National Framework for Eating Disorders (NEDC, 2012) and Australian clinical guidelines for eating disorders[xiii] identify that a stepped suite of treatment options should be available for people with eating disorders with services at different levels of intensity, including outpatient, intensive outpatient with meal support, day program, and inpatient treatment.

There is strong evidence for types of psychological intervention in the treatment and management of eating disorders. In particular:
- Family-based treatment (also sometimes called Maudsley family therapy), which was supported by a substantial evidence base and had substantial positive effects, was the most validated approach for treating young people with anorexia nervosa.
- Multidisciplinary specialised outpatient treatment (combining CBT, parental counselling and dietary therapy) had a moderate evidence base and moderate magnitude of effect, with improvements occurring up to five years after treatment completion.
- Amongst adults with bulimia nervosa, cognitive behavioural therapy, delivered as guided self-help, individually or in group formats, is strongly supported by a substantial evidence base and substantial and persistent improvements in primary and secondary symptoms. Amongst adults with anorexia nervosa, cognitive behavioural therapy was the most validated intervention (although outcomes are not consistently greater than comparison therapies). Cognitive behavioural therapy was supported by a substantial evidence base and had a moderate magnitude of effect.
- Exposure therapy, which aims to reduce conditioned responses to specific problematic environmental cues using graded exposures, was also well validated for this group. Exposure therapy was supported by a substantial body of evidence and produced moderate treatment outcomes.
- Among adults with binge eating disorder, cognitive behavioural therapy was found to be the most validated intervention. Cognitive behavioural therapy was supported by a substantial evidence base and led to substantial treatment effects, including improvements in eating disorder psychopathology, depressive symptoms, self-esteem and weight.
- Dialectical behavioural therapy had a substantial degree of evaluation with moderate outcomes, while interpersonal psychotherapy and virtual reality-based therapies had a moderate degree of evaluation and effect. Short-term treatment with the central nervous system stimulant lisdexamfetamine had a moderate degree of evaluation and produced

substantial therapeutic effects and effect sizes, while anticonvulsant medications had a moderate degree of evaluation and effect.

Further information on evidence-based treatment for eating disorders can be found in the National Eating Disorders Collaboration Evidence Review (2017).

5   Rural and remote Australians access to eating disorder mental health services

Eating disorders and related risk factors such as poor body esteem and obesity, occur in rural and remote locations. All respondents to NEDC consultation said that eating disorders were a concern in the communities they lived or worked in. This is supported by National Helpline data; where data on location is available, it appears that those residing in outer regional to very remote postcodes contact the service at a rate/proportion broadly reflective of population distribution.

When NEDC members were consulted, 63% of respondents said that in general rural and remote communities were aware of eating disorders but they were not well understood, 11% said in general people were not aware of eating disorders, and 22% said there was some awareness. No respondents felt that eating disorders were well understood in their community.

It is the experience of Butterfly Foundation when engaging with communities across Australia that awareness of eating disorders often relates to anorexia nervosa only, and that there is significantly less awareness or understanding of binging disorders including bulimia nervosa and binge eating disorder, or atypical presentations.

Respondents to consultation indicated that the three most significant impacts on people accessing mental health services in rural and remote Australia were:
- Local mental health services do not treat eating disorders (28%)
- Lack of awareness of available services in our outside community (21%)
- Not meeting inclusion or exclusion criteria for available services (10%).

The barriers and needs experienced by anyone accessing mental health care are exacerbated by the unique presentation and treatment needs of eating disorders. One in four consultation respondents said that general mental health services in rural and remote Australia were good to very good, but only 4% said the same of eating disorders services in rural and remote Australia.

When looking across consultations and NEDC documentation, the following issues present as recurrent themes:

- **Availability of appropriate medical and mental health services for Eating Disorders**
    - Lack of available services specifically addressing eating disorders
    - People with eating disorders often do not meet inclusion, or meet exclusion criteria, for mental health services
    - Long waiting lists or limited hours particularly where services are on a 'first in first out' basis

- o Geographic barriers including access to services within a community, but also access to family and support when using services in regional or metropolitan areas

- **Stigma/ Medical and Community Attitudes**
  - o Having generalist primary or mental health care professionals declining to treat eating disorders or feeling unable to provide appropriate care
  - o Pervasive myth beliefs among professionals as well as community (e.g. eating disorders are behavioural, a lifestyle choice or reflect poor character).

- **Poor systems, communications and knowledge**
  - o Lack of case coordination or engagement, particularly between primary medical care and mental health services
  - o Lack of awareness of eating disorders services that are available either within a community or at a state/territory or national level
  - o People with eating disorders are frequently treated for co-morbid conditions or physical health consequences (e.g. obesity) without knowledge of the eating disorder as underlying cause or condition, and without evidence-based treatment for the eating disorder.

- **Cost of services**
  - o Specialist eating disorders services available to these communities are frequently private and full evidence-based dosage may be poorly covered by Medicare or private insurance
  - o Living in rural or remote locations compounds affordability issues as it increases additional costs (e.g. travel and accommodation, additional lost work hours, accessing specialist food or medicines)

- **Social Isolation**
  - o There are often no connection points, particularly for families and carers, to others who have experienced eating disorders, or ready access to peer support or advice
  - o Less engagement points within the community for early identification of concerns for children and young people.
  - o Lack of ongoing recovery support services which increases the risk of relapse.

6   The mental health workforce service delivery in rural and remote locations

42% of NEDC consultation participants indicated that in their area services are provided to people with eating disorders but this is not specific treatment for their eating disorder. A further 22% said services are not provided to people with eating disorders.

Both child and adolescent and adult mental health services in regional and rural locations experience difficulties maintaining staff teams that are skilled in the treatment of eating disorders. The relatively small number of patients with eating disorders requiring treatment at any one time does not support the development of extensive clinical expertise in every health service.

The delivery of safe, quality treatment at any level in the service continuum is dependent on the availability of a workforce that is knowledgeable and skilled in eating disorders. 97% of the health workforce has not received sufficient training in eating disorders to feel confident to provide treatment (NEDC, 2012).

All health professionals working with high-risk populations, and all professionals required to work in the multi-disciplinary team require 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.

Consultation showed the most significant challenges to delivering mental health services in rural and remote locations were
- Shortage of specialist eating disorders clinicians (91%)
- Lack of training and support for general mental health clinicians (73%)
- Geographic distance from services (73%)
- Cost of available services (64%)
- Shortage of prevention services (64%)
- Lack of awareness of services available locally or remotely (64%)
- Community attitudes or lack of awareness (56%)
- Shortage of emergency or inpatient services (53%)
- Social isolation (51%).

These key issues also translate to challenges for the workforce delivering mental health services:
- Competing demands for time with generalist mental health workers providing a significant number of services to all types of mental illness
- Many workers are not aware of or not provided with training needed to provide eating disorders treatment as part of their core business.
- High turnover of staff means training programs in eating disorders often not resulting in sustained expertise in rural or remote locations.

7   Attitudes towards mental health services

In general, consultations conducted by NEDC and Butterfly and a number of lived experience based research projects conducted since 2015 have highlighted a view from those with an eating disorder that the most significant concerns regarding mental health services are in fact the negative attitudes and myth beliefs of clinical professionals.

People with eating disorders are greatly concerned that they will experience shame, blaming, fear and inappropriate treatment if they present to mental health services. This is not a unique experience to rural and remote communities, but is compounded by the lack of service options available.

8   Opportunities for improvement

Most important needs for improvement in mental health services identified by consultation respondents were:

- Early identification and intervention (96%)
- Training for professionals in mental health care (96%)
- Increased services available within community (95%)
- Improved financial access to treatment (87%)
- Community awareness and acceptance (87%)
- Tertiary consultation and supervision from eating disorders experts (80%)
- Manualised programs able to be replicated (60%)
- Technology based solutions (e.g. online treatment, Apps) (56%)

Consultation with those working or living in rural and remote locations identified the following as key opportunities or needs for development to improve the mental health care of people with eating disorders:

- **Specialist services and coordinated approaches**
  o More specialist services aimed specifically at people who have an eating disorder
  o More staffing hours dedicated to eating disorders management
  o More experts in eating disorders, at all levels of the multi-disciplinary team
  o Coordinated approach between public and private practitioners
  o More treatment centres, community support
  o Implementation of early intervention programmes and wrap around services
  o Multidisciplinary communication and support.

- **Professional development and eating disorders training**
  o Ongoing support and training for local clinicians, including within hospital context
  o Clinician support networks which could include case conferencing using digital platforms
  o Carer support networks/ Community support
  o Specialist support and ongoing training for GPs
  o More health promotion in community

- **Other pathways – Professionals, carers, consumers**
  o Better access and availability of quality public services within the general settings
  o Assistance for lengthy travel expenditures for those residing in rural or remote locations
  o Inclusion of psychological supports and counselling for change and life skills along with medical and nutritional interventions
  o Information about how and where to access appropriate help for community and professionals
  o More use of teleconference for treatment and support.

There is little evidence about the application of eating disorder interventions in rural and remote settings and indeed whether the effectiveness of interventions is affected by being in an urban or rural environment. It will be important to develop data and research to further understand the needs of rural and remote communities with respect to eating disorders and mental health service provision.

8.1 Models for Services Delivery proposed by National Eating Disorders Collaboration

A 'hub and spoke' approach was suggested in the National Eating Disorders Framework (2012) to promote integrated, coordinated treatment options across health regions. Fragmentation of services across primary, community and secondary care and the challenges of providing health care in rural and remote areas has led to the adoption of hub and spoke approaches in most states. The concept of an eating disorder hub and spoke model fits well with these existing approaches. There are positive examples in NSW and Queensland of the implementation of these types of programs. The NSW Service Plan, mandating public health responses to eating disorders, was reference by those in rural areas as starting to have a positive impact on availability of care.

An outreach approach enables trained eating disorder clinicians working from a central hub location to visit and work directly with treatment teams in regional locations.

An outreach approach contributes to:
- Direct provision of patient assessment and treatment planning
- Ensuring quality standards of treatment provided through all hospital and community level treatment services
- Building workforce capacity through mentoring and experiential learning
- Facilitation of referrals and transitions to other services as required

An outpost approach also enables health professionals trained in eating disorders to work with local treatment teams. In an outpost approach staff are embedded in local services on a long term basis and provide a direct service to patients and local clinicians.

Opportunities exist to embed outpost services within Primary Health Network regions to support the development of local responses to eating disorders, coordinate multidisciplinary care for individuals, support transitions between services, and provide a local point of contact for eating disorder information.

Embedding specifically trained health professionals in local regions will build capacity into the local workforce and provide for:
- Coordination between service providers
- Skilled initial assessment and triage
- Coordination of individual treatment plans in collaboration with service providers and families
- Facilitation of individual case coordination and the development of multidisciplinary teams in primary care
- Development of local system capacity through the development of outpatient service models where eating disorder services do not already exist within the community
- A point of contact for clinicians, people with eating disorders and their families
- Provision of education to individuals and groups
- Transition and recovery support
- Delivery or facilitation of basic professional development sessions for primary care and other professionals.

The outpost model places the emphasis on early intervention, recovery support and tertiary prevention. This model presumes a deficit in local eating disorder service provision and intentionally adds capacity to the workforce. The model is specifically intended for health regions that are not already well served by eating disorder services.

Whether employed by the local region or by the eating disorder hub, outpost staff should be trained, supported and supervised by the tertiary hub in order to ensure appropriate links between the hub and spokes and maintain consistent practice standards.

National coordination is required to reduce the current level of duplication of effort and inequity in access to treatment and support for people in different regions. Without a national response to embed adequate eating disorder training in health qualifications and professional development, priorities for improvement of eating disorders mental health care in rural and remote locations will not be achievable. Workforce development requires the implementation of existing national workforce competencies for eating disorders (NEDC, 2015); coordinated dissemination of existing education; and support for outreach by existing tertiary centres, to enable supervision and consultation support for newly trained health professionals.

8.2   Opportunities for Technology to improve mental health care

Technology provides excellent opportunities for bringing evidence-based treatment and support to those without access to face to face services within their community. There are currently important trials in the delivery of CBT-e in an online context by InsideOut Institute. The Butterfly Foundation National Helpline is also delivering expanded intervention services (support groups, psychoeducation carer programs and brief intervention) using online platforms.

Beyond current eating disorders treatment offerings there is research that supports the concept of online services delivery for certain eating disorder populations. For example there is good evidence for reduction of symptoms using online CBT approaches for specific groups such as women with post - natal depression[xiv].

It is important in addressing technology opportunities to acknowledge the access barriers experienced in rural to very remote locations (e.g. poor mobile phone reception, inconsistent or unavailable internet connection). Options where internet and phone coverage is insufficient should be explored including such as locating connection facilities at the premises of a local service provider.

Beyond providing virtual access to treatment, technology has the opportunity to address the other more highly identified concerns through; online learning platforms for professionals and families, digital connection to tertiary consultation and expertise, and a range of web applications and social media to target community awareness and acceptance.

8.3   Opportunities for engagement of peer workforce

Peer workers draw on their lived experience and knowledge of eating disorders to help others achieve improved recovery outcomes. Peer work has shown to be an effective and supportive component of treatment and ongoing support for a wide range of mental health issues.

Peer workers may:

- Work directly with others with lived experience e.g. to provide support, information, education, coaching, counselling
- Work with health professionals and service providers to ensure that the services delivered are person centred and recovery oriented e.g. through clinician education; service and practice design; research and evaluation.

These roles are not mutually exclusive and peer workers may work directly with their peers and also contribute to service improvement. The service recipient may be the person with an eating disorder, or their family or support group, or their clinical team or their school or employer.

Peer support workers provide a safe, supportive environment in which people are able to openly share and reflect on their experience, creating new ways of engaging with and understanding life.

It is important to note that peer work, particularly in an eating disorders context, is not an alternative to therapy. There are also specific considerations in the development of any peer work models or programs:

- Peer workers in an eating disorders context should be partners in recovery, they must have experienced recovery from an eating disorder for an appropriate, sustained period of time before engaging in providing support to others
- Peer workers require an appropriate structure for providing their professional services including defined roles and responsibilities, adequate training, supervision, support and appropriate remuneration
- Peer work is most effective when integrated into a multidisciplinary treatment team.

The NEDC is developing guidelines on safe and effective Peer Work in eating disorders treatment and recovery. Estimated date of publication is February 2019 and when this resource is finalised it will be made available online at www.nedc.com.au

8.4   Opportunities for implementation in Primary Health Networks

At a national level, one of the most significant contributions that could be made to advancing these key issues is the mandated engagement of Primary Health Networks in eating disorders prevention, identification, treatment and management.

In particular, Primary Health Networks should, in line with National Eating Disorders Collaboration National Practice Standards, address the following issues in ways that meet local opportunities, barriers and needs:

- address eating disorders in data collection, needs analysis and strategic planning
- provide ongoing professional training in eating disorders as part of workforce development
- ensure that commissioned mental health services are addressing eating disorders as core business and that their treatments and interventions are evidence based
- maintain collaborative partnerships with local , state-based and national eating disorders services as part of their networking.

8.5   Opportunities for community based and low-intensity treatment programs

There is strong evidence that treatments that may be considered low-intensity can be effective for binge eating disorder and bulimia nervosa, including manualised guided self-help programs. Information on these programs is available in section 1.3 of this submission and further at www.nedc.com.au

It is important to acknowledge that for targeted, low intensity treatment to be safe and effective for eating disorders the following is required:

- They need to occur in a stepped continuum of care with opportunities for stepping in to more intensive treatment immediately should this be assessed as required
- Treatment planning
- They require well-established processes for early identification and
- They are not delivered with those who are diagnosed with anorexia nervosa, or those with severe and/or enduring presentations.

9   References

[i] Hay PPJ, Mond J, Buttner P, Darby AM. *Eating disorder behaviors are increasing: Findings from two sequential community surveys in South Australia.* 2008;3(2):1–5

[ii] See ref. i

[iii] Crow SJ, Peterson CB, Swanson SA, Raymond NC, Specker S, Eckert ED, Mitchell JE, *Increased mortality in bulimia nervosa and other eating disorders,* American Journal of Psychiatry 2009 Dec 166(12) 1342:6.

[iv] Australian Institute of Health and Welfare. *Young Australians: Their health and wellbeing*. Canberra; 2007

[v] See ref. i

[vi] Katzman DK, Medical complications in adolescents with anorexia nervosa: a review of the literature, International Journal of Eating Disorders. 2005; 37 Suppl S52-9; discussion S87-9.

[vii] Arcelus J, Mitchell AJ, Wales J, Nielsen S, *Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies*. Arch Gen Psychiatry, 2011 Jul: 68 (7): 724 – 31.

[viii] Mathers, Colin, Vos, Theo and Stevenson, Chris 1999, *The burden of disease and injury in Australia,* Australian Institute of Health and Welfare, Canberra, A. C. T.

[ix] Deloitte Access Economics. Paying the price: The economic and social impact of eating disorders in Australia. 2012. 1-136 p

[x] Hay PPJ, Chinn D, Forbes D, Madden S, Newton R, Sugenor L, Touyz SW, Ward W, McGorry P. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders. 2014;48(11):1–30

[xi] NICE Clinical Guidelines 9, 2004, www.nice.org.uk

[xii] Greta Noordenbos, Anna Oldenhave, Jennifer Muschter & Nynke Terpstra. Characteristics and Treatment of Patients with Chronic Eating Disorders, 2002 Eating Disorders, 10:1, 15-29

[xiii] See ref. X

xiv Andersson G, Bergstrom J, Hollandare F, Carlbring P, Kaldo V, Ekselius L, Internet-babsed self-help for depression: randomised controlled trial, Br J Psychiatry J Mental Scie 187 (2005) pp 456 - 461

Ashford MT, Olander EK, Ayers S, Computer or web-based interventions for perinatal mental health: a systematic review J Affect Disorder 197 (2016) pp 134 – 146.