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FOR THE AUSTRALIAN CAPITAL TERRITORY

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STANDING COMMITTEE ON EDUCATION, EMPLOYMENT AND YOUTH AFFAIRS  
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## Submission Cover Sheet

### Inquiry into Youth Mental Health in the ACT

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# Submission to the Affairs Inquiry into Youth Mental Health in the ACT

## ACT Legislative Assembly's Standing Committee on Education, Employment and Youth

The Butterfly Foundation

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## About us

The Butterfly Foundation is the national charity for all Australians impacted by eating disorders and body image issues, and for the families, friends and communities who support them. Butterfly changes lives by providing innovative, evidence-based support services, treatment and resources, delivering prevention and early intervention programs and advocating for the needs of our community.

Butterfly highlights the realities for those seeking treatment for recovery, and advocates for improved access to effective, affordable care. Throughout its work Butterfly also emphasises the critical importance of prevention and early intervention strategies in limiting the development of, and suffering from, negative body image and eating disorders.

Butterfly operates a National Helpline that includes support over the phone, via email and online, reaching 20,000 people each year. The Helpline is staffed by trained counsellors experienced in assisting with eating disorders and body image issues. We also provide a wide range of programs for service providers and recovery groups.

Because Butterfly recognises that eating disorders often arise from poor body image, we deliver a range of prevention programs including Positive Body Image workshops to schools and workplaces. We use our strong social media presence to raise awareness, reduce stigma and increase help-seeking in relation to eating disorders and negative body image.

Butterfly coordinates the National Eating Disorders Collaboration (NEDC) for the Commonwealth Government Department of Health, and we are committed to collaboration across the sector.

## Our vision

To live in a world that celebrates health, wellbeing and diversity.

## Our mission

To bring about change to the culture, policy and practice in the prevention, treatment and support of those affected by eating disorders and body image issues.

## Acknowledgements

As the national voice of lived experience Butterfly seeks to empower and amplify the voices of people around Australia who have lived experience of an eating disorder or care for someone affected, and are willing to share their stories. We acknowledge the insights shared with us by lived experience advocates within this submission.

## Executive summary

Eating disorders currently affect around 4 per cent of the Australian population – approximately one million people in any given year. Left unaddressed, the medical, psychological and social consequences can be serious and long term.

A key challenge in the identification and treatment of eating disorders is lack of awareness, high levels of stigma and the marginalisation of eating disorders within the health service system. Eating disorders are rarely considered core business for primary health professionals and general mental health services, which can result in exclusion, limited access to evidence-based treatment, and a lack of coordination.

Listening to the voices of people affected by eating disorders is essential to the development, implementation and review of policy and programs. The eating disorder peer workforce is developing by drawing on this form of knowledge to meet the need for communities of recovery in the transition from treatment to self-directed recovery.

Children and young people repeatedly rank body dissatisfaction as one of their top issues, with body dissatisfaction reported by approximately 50 per cent of pre-adolescent girls, while pre-adolescent boys are increasingly reporting a desire for a more muscular body. Greater investment in primary prevention and early intervention are required to prevent eating disorders from developing, including within primary school settings. This is an area of current focus for Butterfly, with the development of a whole of primary school body image program which we aim to implement across all Australian primary schools.

Despite clear evidence of the economic benefits of improving access to quality care and support across the mental health care continuum – and notwithstanding significant recent investment from the Commonwealth Government in this areas – several service gaps and barriers to treatment remain.

## Introduction

The Butterfly Foundation welcomes the opportunity to provide a submission to this Inquiry.

Our submission addresses Terms of References i, ii, iii, xxx, xxx, xxx and xxx, with a focus on the voices of those affected by eating disorders and negative body image and areas for service improvement across the domains of prevention, early intervention, treatment and recovery.

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.

While eating disorders can affect anyone at any age, they remain more prevalent among adolescents and young people, with the average onset for eating disorders occurring during adolescence and young adulthood.

While data on prevalence at a state and territory level is not available it is thought that prevalence is similar across different regions of Australia, and across several demographic cohorts.

As set out in the National Agenda for Eating Disorders 2017-2022 (Butterfly Foundation, 2017a) key challenges in addressing eating disorders include: the availability of a skilled workforce; access to affordable, integrated physical and mental health care; the need for early identification; gaps in the continuum of care; and enabling sustainable recovery.

In this submission we provide an overview of areas with particular relevance to children, young people and their families and carers.

We would welcome the opportunity to provide oral evidence in relation to any of the matters raised in this submission.

## Eating disorders in Australia

Eating disorders are a set of mental health conditions associated with high levels of psychological distress and significant physical health complications. Eating disorders are complex psychiatric disorders which involve a combination of biological, psychological and sociocultural factors. 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.

Types of eating disorders include: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Other Specified Feeding and Eating Disorders (OSFED) and Unspecified Feeding or Eating Disorder (UFED). In addition to these clinical disorders, 'disordered eating' refers to unhealthy eating patterns that can include restrictive dieting, compulsive eating or skipping meals. Disordered eating can include behaviours which reflect many but not all of the symptoms of other feeding and eating disorders, and along with dieting are the most common indicators of the development of an eating disorder.

### Prevalence

There is a lack of consistent data on prevalence of eating disorders in Australia, however according to analysis commissioned by Butterfly using Australian Institute of Health and Welfare data, it is estimated to affect approximately 4 per cent of people – or almost 1 million people – in any given year (Deloitte Access Economics, 2015).

We do not have an estimate of the number of people experiencing eating disorders in the ACT.

### Gender differences

Women and girls are more likely to be affected by eating disorders, with a prevalence rate of 5.11 per cent, while prevalence in boys and men is estimated at 2.94 per cent (Paxton et al., 2012). Around 15 per cent of women will experience an eating disorder in their lifetime (Butterfly Foundation, 2017b)

Women and girls are more likely to experience all types of eating disorders likely than men and boys, with the exception of Binge Eating Disorder where there is almost equal prevalence (Hay, Girosi, & Mond, 2015).

Several sociocultural factors contribute to the development of poor body image and eating disorders in women and girls, including diet culture and weight stigma (Squire, 2020), and body-policing and self-objectification norms (Jovanovski, 2017).

Men and boys are subjected to different cultural messages about appearance that can increase their vulnerability to eating disorders. These include an idealised physical body shape that is lean and muscular, and social norms that frame masculinity as about control and taking charge 'take charge' and be 'in control' (National Eating Disorders Collaboration, n.d.). Between 15-20 per cent of people experiencing anorexia nervosa and bulimia nervosa are male (Hay et al., 2008). The actual percentage of men among people with eating disorders may be much higher as their experiences may be overlooked or misdiagnosed by clinicians (Strother et al., 2012). Men

also may be less likely to seek treatment for the eating disorder due to the stereotype that the disorders only affect women.

*"I felt that changing my body was the only thing I could do-to fit in, to belong, to be good enough. And so I started dieting and excessively exercising. And the obsession had begun, and then ED took over my life. I lost a significant amount of weight, but I was still unhappy with my body. And I was still being body shamed, this time for being too thin! So my attention turned to 'bulking up' and putting on more muscle. As I put on weight, my motive was not health, all of my behaviours were still being driven by ED and my negative body image." (Dan, Share Your Story)*

## Children and adolescents

While eating disorders can affect anyone at any age, they remain more prevalent among adolescents and young people, with the average onset for eating disorders between the ages of 12 and 25 years (Volpe et al., 2016).

The significance of eating disorders and body image concerns for this group is evidenced in the contacts to our Helpline – 57 per cent of contacts in the last financial year were from young people aged up to 25 years. There were 19,962 contacts to the service in 2018-19, an increase of 56 per cent on the previous year.

Children and adolescents with eating disorders can experience interrupted physical, educational and social development and are at risk of significant medical complications in the long-term, along with other mental health issues. The earlier the onset of an eating disorder the more likely it is to restrict social development and educational and employment outcomes.

Body dissatisfaction is common among children under 12. Nearly 50 per cent of girls aged 9 to 12 years old reported feeling dissatisfied with their body according to one study (Clark & Tiggemann, 2008). Another study found that 54.8 per cent of boys ages 12 to 18 expressed a desire to alter their body in some way (Lawler and Nixon, 2011). More detail on body image concerns for children is provided in the section on prevention and early intervention below.

## Other social and demographic characteristics

Most people with eating disorders have similar incomes and education levels as the general population (Hay, Girosi, & Mond, 2015).

While people with eating disorders were generally younger than others, one study of population data showed that the mean age was in the fourth decade for anorexia nervosa and bulimia nervosa and in the fourth or fifth decade for all other disorders (Hay, Girosi, & Mond, 2015). Close to 5 per cent of women aged over 45 are currently living with an eating disorder, many of whom experienced the onset of symptoms in their childhood or adolescence.

There is little research on the experiences of Aboriginal and Torres Strait Islander people and eating disorders. However, emerging research suggests Aboriginal and Torres Strait Islander people experience eating disorders and body image issues at a similar or higher rate than non-Indigenous people (Burt et al., 2020). A recent study found that eating disorders are common amongst Aboriginal and Torres Strait Islander adolescents and are associated with poor psychosocial quality of life (ibid.).

Research suggests that LGBTIQ+ communities are generally at higher risk for developing eating disorders which can be associated with the likelihood of past trauma and difficulties of coming out (Lyons, 2017). Within this internally diverse group, transgender people having a much higher risk of developing eating disorders (ibid.). One

study found that gay and bisexual men had significantly higher prevalence estimates of eating disorders than heterosexual men, but that there were no differences in eating disorder prevalence between lesbian and bisexual women and heterosexual women, or across gender or racial groups (Feldman & Meyer, 2007).

*“My eating disorder came about from hating the way I looked. I am 15. You see I was born female but I don’t recognise that. I am transitioning as best as I can within the legal limitations of this country to identify as male as that is who I truly feel I have always been. In order to redirect certain fat displacements on certain parts of my female body I began dieting... I know those around me who loved me were seeing the red flags and warning signs and I know they couldn’t reach me. The ED had completely taken over my rational thought patterns. But the professionals were focused on other reasons for this and I know at the time my mum was tearing her hair out for help and support and I know she found it hard to get it... I am in recovery now and doing ok...I wish we had known about this much earlier. They say eating disorders within the transgender community is very high. Why do law makers make it so difficult for people to try to be who they want to be?” (Marshall, Share Your Story)*

## **Mortality**

Eating disorders carry an increased risk of premature death due to long term medical complications and increased rate of suicide. The mortality rate for eating disorders is between one and half times to twelve times higher than the general population (Butterfly Foundation, 2017b).

Mortality in eating disorders is higher than most other psychiatric disorders (Chesney, Goodwin, & Fazel, 2014). Mortality rates are almost twice as high for people with eating disorders than in the general population – according to estimates commissioned by Butterfly, there were up to 1,828 deaths from eating disorders in 2012 (515 males and 1,313 females) (Paxton et al., 2012).

## **Comorbidities**

Eating disorders are frequently associated with other psychological and physical disorders such as depression, anxiety disorders, substance abuse and personality disorders (Butterfly Foundation, 2017b).

People with bulimia nervosa, binge eating disorder and sub-threshold bulimia nervosa are more likely to be obese than people without an eating disorder (Hay, Girosi, & Mond, 2015).

## **Suicidality**

Deliberate self-harm is associated with eating disorders and suicide (Butterfly Foundation, 2017b). Suicidal ideation and attempts have been examined in relation to extreme and unhealthy weight control behaviours among male and female adolescents. Findings from this study showed that suicidal ideation and attempts were reported by: 22 and 9 per cent of females respectively; and 15 and 4 per cent of males respectively (Shankman et al, 2008).

Suicidality differs according across different types of eating disorders. Suicide is the second leading cause of death among people with anorexia nervosa, while suicidal behaviour is elevated in bulimia nervosa and binge eating disorder relative to the general population (Smith, Zuromski, & Dodd, 2018). One-quarter to one-third of people with anorexia nervosa, bulimia nervosa or binge eating have thought about suicide, and one-quarter to one-third of people with anorexia nervosa bulimia nervosa have attempted suicide (ibid.).

Early access to effective treatment is the best approach to prevent suicide among people with eating disorders.

## The importance of lived experience

This section is relevant to all of the Committee's Terms of Reference, but is addressed specifically to the first Term of Reference – Hearing the voices of the ACT community.

Butterfly is committed to listening to, learning from, responding to and amplifying the voice of people with eating disorders and their families and carers.

*"There is still to this day stigma around eating disorders as they aren't commonly spoken about and most people do not understand the complexity of an eating disorder. This can make recovery difficult, but recovery is not impossible." (Jasmine, Share Your Story)*

Best practice program development requires genuine engagement and co-design with people who have experienced an eating disorders, their families and their carers. Since early 2019 we have employed a Lived Experience Engagement Coordinator to work with lived experience advocates to inform our work and the work of others in the mental health sector. The Coordinator helped design and now manages Butterfly's first ever speakers' bureau – Empowered Voices.

### Empowered Voices

Empowered Voices is made up of a community of people around Australia who have lived experience of an eating disorder or care for someone affected, and are willing to share their stories. Our speakers are dedicated volunteers who are willing to share their experience across a range of platforms with the objectives of reducing stigma and encouraging help-seeking. From media opportunities, to research input, community fundraising events, health professional seminars and internal Butterfly staff events, stories of a lived experience are continually regarded as a powerful addition to education, research and advocacy.

Not only does storytelling provide a personal insight into the world of someone who has experienced an eating disorder, it sends a clear message of hope to those in the community that recovery is very much possible. Our volunteer speakers are at the forefront of changing the conversation around eating disorders, providing insights which cannot be replicated through other forms of knowledge generation.

Empowered Voices benefits both Butterfly and our speakers. Butterfly dedicates resources to training, mentoring and opportunities to speak. Butterfly screens and vets any speaker opportunities, working collaboratively with speakers and event organisers to create the respect and sensitivity essential to safely sharing experiences.

Butterfly also encourages anyone affected by an eating disorder to share their experience with our online community via the Share Your Story platform on our website.

*"I've battled anorexia and bulimia for nine years of my life. It's not been a linear trajectory, often filled with roller coaster ups and downs. I've had a fair share of experiences with psychologists, psychiatrists, dieticians, cardiologists, GPs through therapy, group programs, hospitalisations—the list goes on... Today, the pesky eating disorder voice occasionally creeps up. But I've learnt to turn up the volume of things in my life that matter most to me, and to notice those thoughts as temporary clouds-in-passing—and to not pay any attention to them... I've learnt that each little step I chip away at, is a win—and as my therapist always said, we aim for progress, not perfection." (Phoebe, Share Your Story)*

Experiencing an eating disorder and navigating the mental health service system can be profoundly disempowering; becoming the author of that narrative through storytelling can form part of ongoing recovery. Using

that story to advocate for others and to inform program development can be an empowering experience for individuals affected by eating disorders. Later this year we will be further developing this aspect of our work through the establishment of a Lived Experience Network which will inform all of Butterfly's program, policy and advocacy work.

*"In society, it seems as though unless we are on our death bed or have hit some tragedy beyond words, we are not worthy of expressing our hardships or problems freely, without being judged or considered selfish. No matter how big or small the issue may be, if it is causing you to doubt your life and jeopardise your body for the sake of feeling better or trying to find an out, you have EVERY right to reach out for support in any way that suits you. Although binge eating disorder hasn't been as commonly known as other disorders, I know I find satisfaction in being the one to step up and bring it into the spotlight and to see people come through stronger from these sufferings is more than inspiring in many ways. Together we can all shine the light on those still in the dark to come and join us."*  
(Gemma, Share Your Story)

## **Families and carers**

This section relates to Area of Focus iii (identifying roles and responsibilities of the family unit in supporting youth facing mental health and addiction challenges, and supporting families in carrying out these roles and responsibilities).

More than two million people in Australia care for someone with an eating disorder (Butterfly Foundation, 2019). Family members and carers play an important role in supporting treatment and recovery, particularly for people with moderate to severe eating disorders. Without this support there is a need for higher intensity of treatment and greater risk of recurrence and chronicity of eating disorders. Rates of relapse range from 22-52 per cent among people recovering from anorexia nervosa and bulimia nervosa (Keel et al., 2005). While recovery can be a long process, these setbacks can be eased by the support of carers who form a crucial part of treatment and support teams.

Family and carer voices are also essential for advocating for person-centred care, for better recognition of their role on the treatment team, and for their own needs for support.

*"The time commitment and impact on the family as a whole and as individuals is enormous and often not mentioned or valued and yet the family is the support mechanism the person needs to support their recovery."* (Carer, cited in the National Agenda for Eating Disorders 2017-2022)

*"Families supporting patients also need support, it is a full-time job supporting someone through recovery often having to break from work, focus has to be on patient but so hard if no support."*  
(Carer, cited in the National Agenda for Eating Disorders 2017-2022)

Butterfly runs carer support groups where carers of loved ones with eating disorders come together to share their experiences, skills and strategies, and to draw on mutual support. The groups are confidential and supportive spaces, run by qualified specialist therapist. Our most recent survey of group members showed that 94 per cent of attendees found them either valuable or extremely valuable.

In 2019 we undertook a survey which showed that more than 40 per cent of carers have never sought support, despite a staggering 83 per cent of respondents highlighting the impact on their mental health. The survey also found that:

- 64 per cent of carers acknowledged that they would benefit from psychological support
- 78 per cent lost work or their ability to study to be able to provide the support needed
- 76 per cent said it impacted on sleep, 76 per cent said it impacted on their relationships, and 71 per cent said it impacted on their social life.

*“This is the hardest thing I have ever done or faced.” (Carer, Butterfly Foundation, 2019)*

*“It affects our family psychologically.... Carers to long term eating disorder sufferers are rarely given any thought at all. We need psychological support and respite.” (Carer, Butterfly Foundation, 2019)*

## Peer support

*“There needs to be a smoother transition between inpatient admissions and going back to living an everyday life. The big change is usually inadequately supported, making relapse rates very high and likely.” (Anonymous, cited in the National Agenda for Eating Disorders 2017-2022)*

Peer support is increasingly recognised as a critical part of the stepped care approach to mental health, particularly in relation to ongoing recovery through delivering positive messages about body image, healthy eating and exercise behaviours within a person’s home community.

Recovery is a long-term process, lasting on average for one to six years, but affecting up to 25 per cent of sufferers as a severe and long term illness (Deloitte Access Economics, 20150)

*“My experience was that once I left inpatient treatment there was not adequate community support to help me stay well” (Anonymous, cited in the National Agenda for Eating Disorders 2017-2022)*

Non-clinical support via peer workers can play a key role in supporting long term recovery, particularly in the transition between treatment and self-management. Peer support and peer mentoring can support self-directed recovery, in addition to life skills education, re-entry to treatment pathways and case coordination for people who require access to multiple services (Butterfly Foundation, 2017a).

The eating disorder peer workforce is developing by drawing on lived experience knowledge to meet the need for communities of recovery in the transition from treatment to long term self-directed recovery. Promising approaches include:

- Eating Disorders Victoria’s Peer Mentoring Program (recovery and discharge), which support adults with an eating disorder upon discharge from a hospital inpatient unit or in transition out of an intensive day program. It provides one-on-one mentoring with an Eating Disorders Victoria employee who has recovered from an eating disorder. Participants and Mentors meet on a fortnightly basis for 13 sessions, each being up-to three hours at a time. The mentor supports the participant by working together to develop a recovery focused ‘Wellness Plan’ and undertaking activities identified to achieve identified goals. Common goals include engaging with community life and developing self-care.
- Eating Disorders Queensland’s Carer Peer Mentoring, which supports people who are recovering from eating issues by partnering mentees with mentors who have recovered from an eating issue. Mentors are trained by Eating Disorders Queensland and commit to regular mentoring contact agreed to by mentor and mentee for a six-month period.

Butterfly conducted research which gathered insights from people with lived experience in 2016. The *Insights in Recovery* report found that peer contact had been useful to participants in the following ways:

- Instilling hope and motivation
- Instilling a belief that recovery is possible
- Providing a realistic picture of recovery and validation of own experience
- Learning practical coping skills and strategies
- General social connection - feeling less alone (Butterfly Foundation, 2016).

Recently the National Eating Disorders Collaboration (NEDC) released a Peer Work Guide to promote and facilitate the implementation of evidence-based peer work in treatment and support services for people with eating disorders.

## Primary prevention and early intervention

This section relates to Terms of Reference ii and iii, and Area of Focus iv.

Primary prevention is a critical part of the Butterfly Foundation's work which supports our Strategic Goal 2: Prevent eating disorders from developing.

Our Prevention Services operate across several school and community settings to change beliefs and behaviours at the individual and population level. Our programs with young people, parents, teachers and community professionals delivering education, strategies and tools have now reached over 880,000 young people and over 7,600 professionals and parents Australia-wide. Our aim is twofold: increase the proportion of students who report that they have positive body esteem or a healthy relationship with food or exercise; and bring about an increase in weight-neutral health policies and an integration of the no-diet approach into health policy.

*"I walked around most of primary school years with my head held down because I wanted to be invisible and avoid the pain from the body shaming and teasing from the other school kids. By the time I was 20, I had used food as a coping mechanism for so long and continued to put on weight that my negative feelings towards my body had continued to become worse and worse. I would get told "oh, you'll do something about your weight when you are ready". But really, all I wanted, all I needed to hear was 'you are enough, just as you are'." (Dan, Share Your Story)*

The evidence base for investing in programs for children and adolescents is clear. Research highlights that body dissatisfaction is an important risk factor for negative physical, mental and social outcomes including unhealthy dieting and muscle building behaviours, depression, anxiety, higher weight and eating disorders (Paxton & Damiano, 2016). Body dissatisfaction is repeatedly one of the top ranked issues for young Australians with body dissatisfaction reported by approximately 50 per cent of pre-adolescent girls, while pre-adolescent boys are increasingly reporting a desire for a more muscular body (Carlisle et al, 2019). Stigmatising weight attitudes are forming from very early in childhood, and are related to appearance-based teasing, which are linked to the development of body dissatisfaction and unhealthy behaviours. Importantly, greater body concerns from ages 5 and 7 have been shown to predict dieting by age 9 (Evans et al., 2013; Dohnt & Tiggemann, 2006). By the time they reach adolescence, 1 in 6 girls have already employed at least one potentially dangerous method of weight reduction.

An example of one of our programs is 'RESET – a conversation about boys' body image'. This program is Australia's first digital body image program for adolescent boys, providing the opportunity to talk about pressures and concerns relating to body image. This program helps educators raise awareness, reduce stigma and encourage help-seeking in boys and young men, and is available to all schools to download.

## **Butterfly Body Bright**

To address these challenges we are developing a program for Australian primary schools. Butterfly Body Bright is a new whole of school approach to consistent and long-term promotion of positive body image and healthy behaviours for Australian primary schools, including healthy attitudes and behaviours towards the body, food, and physical activity within in an appearance-inclusive environment. It is a strengths-based, evidence-informed universal prevention program to foster a positive foundation for children's developing body image by equipping students with skills to be confident in their body. It also aims to build resilience to socio-cultural risk factors that underpin the development of body dissatisfaction and disordered eating. The program is being developed with the input of an Expert Advisory Group, and Educator Reference Group and a Parent Advisory Group.

Once an evaluation of the pilot is completed we will be seeking to roll out the program throughout primary schools across Australia. Butterfly would welcome involvement from the ACT Government in the pilot phase of the program and in funding the implementation of the program throughout the ACT.

## **Access to evidence-based care**

This section relates to Term of Reference iv and several Areas of Focus.

As with prevalence data, information on access to care is inconsistent, with estimates of people with eating disorders accessing specialist treatment ranging from 10-25 per cent (Butterfly Foundation, 2017a and 2017b);

Access to treatment also varies by type of disorder. For example for those with binge eating disorder access may be as low as 10 per cent (Deloitte Access Economics, 2015, 16).

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 states and territories that have started to prioritise the development of health system responses for people with eating disorders and their families (Butterfly Foundation, 2017a).

*"The lack of affordable and accessible public services, lack of awareness, lack of integrated treatment approach, and lack of trained specialised hospital staff is appalling. The wait list for the public outpatient services is at least 6 months." (Anonymous, cited in the National Agenda for Eating Disorders 2017-2022)*

*"Finding a service was a huge struggle. We bounced around psychologists with minimal training in managing eating disorders, then struggled to access a more intense therapeutic service when things became worse." (Anonymous, cited in the National Agenda for Eating Disorders 2017-2022)*

## **Building a consistent system of care**

The NEDC is a collaborative project in the Australian eating disorders sector, funded by the Commonwealth Government and coordinated by the Butterfly Foundation. The NEDC supports and build the system of care for

people with eating disorders, including through promoting a nationally consistent, evidence based approach to the prevention and treatment of eating disorders in Australia.

Most recently, this work includes the development of targeted professional resources on eating disorders. These included five free professional development videos featuring sector leaders and a range of lived experience speakers. The videos cover Introduction, Screening & Assessment, Medical Management, Nutritional Management and Recovery-Focused Psychological Treatment. Other resources include a quick reference guide for use in primary care settings, and the development of professional training resources, delivered by state-based eating disorder organisations.

In the previous financial year the NEDC actively engaged with Primary Health Networks (PHNs) across the country to help them improve provision of evidence based eating disorder treatment in their area. This work included delivery of introductory training sessions to participants in the ACT Capital Health Network – the ACT PHN. The NEDC also contributes to PHN e-bulletins, clinical resources, local referral guides (Health Pathways) and promotes uptake of the NEDC National Practice Standards.

## **New Medicare Benefits Schedule item numbers for eating disorders**

Following many years of advocacy by Butterfly and others in the eating disorders sector, in November 2019 the Commonwealth Government introduced new Medicare Benefits Schedule (MBS) Item Numbers for Eating Disorders, which will greatly increase access to care. We are assisting with uptake of these items by providing information through our website and other communication channels, providing advice to health professionals and community members through our Helpline, and assisting the government with monitoring the impact of these reforms.

Notwithstanding these very welcome changes, 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. Even with the MBS rebate, out of pocket costs are still in the order of \$4,000 per annum, which is prohibitive for people living on low incomes. For people in regional, remote and very remote areas factors such as geographical distance, lack of awareness and training among primary health practitioners, and service fragmentation have a disproportionate impact on those living outside of metropolitan areas.

## **endED Butterfly House**

One of the ways in which Butterfly is addressing gaps in care is through the development of the first residential facility for the treatment of eating disorders, endED Butterfly House on the Sunshine Coast in Queensland. In partnership with endED and with \$1.5 million funding from the Commonwealth Government and the support of business, philanthropy and community, this facility will develop a new Model of Care based on the work of Carolyn Costin in the United States, providing intensive, person-centred treatment in a warm and welcoming environment.

*“I firmly believe the lack of residential treatment options close to home prolonged my battle. I know from my 15 year struggle to find the right treatment for my eating disorder that establishment of endED Butterfly House will be life changing for people with eating disorders.” (Millie Thomas)*

We have also begun the Sunshine Coast Access Trial, working with the local PHN to commence Australia’s first trial of a best practice evidence-based approach to eating disorders treatment in primary health, with promising results so far.

## System change for better outcomes

This section is relevant to all Terms of Reference. It draws on the National Agenda for Eating Disorders 2017-2022 (Butterfly Foundation, 2017a), emerging evidence, and insights in the context of Butterfly's current areas of advocacy.

Key challenges in addressing eating disorders which are widely acknowledged among clinicians, non-government organisations and governments include: the availability of a skilled workforce; access to affordable, integrated physical and mental health care; the need for early identification; gaps in the continuum of care; and enabling sustainable recovery.

The National Agenda for Eating Disorders 2017-2022 sets out an agreed national approach collaborative effort to develop nationally consistent responses to people with eating disorders and their families and carers, and a high level program logic to guide improvement over time (Butterfly Foundation, 2017a).

The National Agenda was developed by drawing on the priorities of people with lived experience, who identified their three most important areas for action as:

- Affordable treatment
- Early diagnosis and access to treatment
- Access to a full stepped continuum of care.

Butterfly advocates across each of these areas, including through promoting the new MBS item numbers for eating disorders, promoting awareness of the out of pocket costs and other barriers that people continue to experience, promoting help-seeking and decreasing stigma through our campaigns and ongoing communications with the general community, and advocating to decision-makers to address service gaps identified by people with lived experience.

We are also exploring innovative ways of meeting the need for stepped care within our own service offerings, including through collaborating with sector colleagues on new models, development on low or no-cost online treatment and support options, and (as noted above) developing a program targeting primary school-aged children to address body image problems when they first emerge.

We have also made the economic case for change with research that measures the economic cost of untreated eating disorders, and the economic benefits of investment in treatment. The economic cost of eating disorders 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) (Paxton, et al., 2012).

The National Agenda provides guidance for the development of a minimum effective level of evidence-based, accessible care all people in Australia who are affected by eating disorders. It is underpinned by a series of documents such as Clinical Practice Guidelines, the National Eating Disorder Framework, Stepped Care Approaches for Eating Disorders – Service Implementation Guide, and Butterfly's Insights in Recovery Guide.

The National Agenda has three broad aims: the right type of treatment, earlier access to treatment, and enabling sustainable recovery. The foundations for the change to meet these aims include:

- Standards
  - Implement existing national standards and workforce competencies

- Develop national guidelines on coordinated stepped care for people with eating disorders
- Systems
  - Identify eating disorders as core business for mental health
  - Establish the enablers for integrated medical and mental health care
  - Align medical benefits and health initiatives with the evidence base for eating disorders treatment
- Workforce
  - Coordinate collaborative dissemination of existing education in eating disorders
  - Support development of tertiary outreach capabilities to enable consultation and supervision
  - Service Development
    - Develop existing eating disorder digital services to include prevention, self-help and recovery assistance
    - Develop models for community-based intermediate levels of care
    - Support development of tertiary outreach capabilities
    - Models of family-inclusive practice are described and promoted
- Accountability
  - Monitor and report on progress against the National Agenda
  - Ensure that collection of data on eating disorders
  - Include people with lived experience and their families and carers in all aspects of service planning, development, delivery and evaluation.

## Conclusion

While many challenges exist in the prevention, early intervention, treatment and support for people affected by eating disorders, particularly for children and young people, we are hopeful that with recent federal investment and the current momentum for change within the mental health sector that our combined efforts will result in considerable improvement over time.

The positive side to the story of eating disorders is often lost in the complexity of these serious – yet treatable – 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 (Hay et al., 2014). With early detection and intervention prospects of recovery are from eating disorders are high; when treatment is delivered by skilled and knowledgeable health professionals full recovery and good quality of life can be achieved for around 72 per cent of people (Butterfly Foundation, 2017a). However, recovery is possible at any age and stage of life. Maintaining hope and resilience is a critical part of our work and for the recovery of the people we serve.

*“I’m 61 years old. I was given the diagnosis of anorexia nervosa when I was 14 years old. That was 1971. So long ago. Things were very different then in the eating disorder world... But I am very lucky. The situation I was in seemed to spur me on to search for alternatives and I was very fortunate to find them by gaining life skills, and then a career.*

*Eventually I was able to connect with others and form meaningful and lasting relationships. My course was beset with relapses and serious health problems.... I avoided conventional medical treatment whenever possible. A choice I now regret. More recently, I have started seeing a wonderful psychologist who has been a great help, and I have found a very supportive GP....*

*I believe my genetics, life experiences and the societal and cultural environment I have grown up in have predisposed me to, and almost encouraged, the development of an eating disorder. But I do not have to be victim to these influences. I have always had choices. I might not have always made the best choices but with support, encouragement, caring and understanding I am having a really rewarding life and love being alive.” (Sue, Share Your Story)*

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