Submission to the House of Representatives Standing Committee on Health, Aged Care and Sport Inquiry into Diabetes

Butterfly Foundation

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"Please listen to what people have been through. Weight stigma is so rife in our society that our health research and policies are tainted with it. Shaming a larger person into a smaller body is not a long-term solution to any health problem meanwhile the obsession with body size is contributing to a pandemic of body image issues and eating disorders in our young people. We need to move away from our obsession with 'obesity' and focus more on sustainable lifestyle behaviours such as getting people moving more, sleep and managing stress. These are much more positive ways to influence a person's health than making them smaller." (p 13)

About us

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 operates a National Helpline that that supports between 25,000-30,000 people each year. We also provide a wide range of individual and group-based programs for people in recovery, carers and family members, while our prevention programs address the modifiable risk factors in the development of body image issues and eating disorders.

Acknowledgements

As an organisation which works with people affected by eating disorders and body image issues, including families and carers, we recognise the value of lived experience as a form of knowledge and as a force for positive change. We acknowledge the insights shared with us by lived experience advocates which are reflected within this submission.

Executive summary

Eating disorders affect around 4 per cent of the Australian population in any given year, while lifetime prevalence is 9 per cent. 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.

There is a high prevalence of eating disorders among people in larger bodies. This population group makes up more than half of all people with an eating disorder in Australia, yet eating disorders among people in larger bodies have been consistently under-recognised and under-treated. Weight stigma among health professionals is a major factor in the limited access to treatment for people in larger bodies.

Eating disorders are more common in people with type 1 diabetes than those without type 1 diabetes. Eating disorders are twice as likely to occur in adolescent girls with type 1 diabetes than those without type 1 diabetes. While there is limited research on eating disorders and type 2 diabetes it is estimated that between 12 and 40 per cent of people with type 2 diabetes have an eating disorder.

People with lived experience of both diabetes and eating disorders told us that health care professionals need to acquire greater knowledge regarding the intersection between eating disorders and diabetes and that the management of diabetes should not be focused on food and weight, which can exacerbate weight stigma.

Butterfly recognises the need for preventive health policy, including investment in promoting good nutrition and physical activity to reduce the incidence of diabetes, heart disease and stroke. However, we have concerns in relation to the concepts and language that are often employed in 'anti-obesity' initiatives. Nutrition education and messaging in schools is a particular area of concern for Butterfly. A recent review of young people treated for anorexia nervosa between 2015 to 2020 found that healthy eating education was a trigger for 14 percent of the patients, and that early adolescents were especially vulnerable (Lin et al, 2023). It is critical that preventive public health programs and campaigns align with best practice in eating disorder prevention and avoid weight stigma.

Responses to Butterfly's lived experience engagement in relation to stigma and discrimination demonstrate that people in larger bodies with eating disorders face particular forms of stigma and discrimination in accessing treatment and support. People with lived experience of diabetes and eating disorders shared that they had experienced stigma from health professionals and had not received compassionate and adequate care. Often other health issues that were experienced were overlooked as medical professionals had a bias toward indicating that a person's weight or 'obesity' was the core concern.

Butterfly makes the following recommendations for policy and practice change in relation to the Inquiry's Terms of Reference:

1. **Preventive health policy must align with eating disorder prevention policy**

Butterfly recommends that all healthy eating and physical activity strategies and campaigns be developed in alignment with best practice in the prevention and treatment of eating disorders and body image issues. Any new healthy eating and physical activity strategies developed to address diabetes should invest in the development of awareness, knowledge and skills in relation to weight stigma.

2. **Invest in addressing the economic and social determinants of eating disorders, including food insecurity and the health and wellbeing needs of priority populations**

Policies and programs that address individual and familial level factors in relation to nutrition and exercise can only go so far. The food security needs of families and priority populations such as Aboriginal and Torres Strait Islander communities must be addressed in order to prevent poor physical and mental health.

3. **Educate diabetes treatment providers on screening tools and treatment options for people with diabetes who are at risk of developing eating disorders**

In line with the NICE guideline on the treatment of people with an eating disorders and diabetes, a multi-disciplinary approach should be adopted by diabetes and eating disorder care teams. Screening for disordered eating among people with diabetes should begin in pre-adolescence and continue through early adulthood in order to obtain detect and treat eating disorders as early as possible (Hanlan et al, 2013).

4. **Diabetes education materials for families, carers and supports should include information about eating disorder warning signs**

Health promotion for those who support family and friends with diabetes management should include information about the signs and symptoms of eating disorders and how to seek further advice and support (such as the Butterfly Foundation's National Helpline).

Introduction

Butterfly Foundation (Butterfly) welcomes the opportunity to contribute to the House of Representatives Standing Committee on Health, Aged Care and Sport's Inquiry into Diabetes (the Inquiry).

In this submission we provide a brief overview of eating disorders and body image concerns in Australia, some research on the relationship between eating disorders and diabetes, and share feedback from our lived experience network, the Butterfly Collective. Our submission is relevant to all of the Inquiry's Terms of Reference, but specifically to Terms of Reference 2, 4 and 5. We focus on:

1. The relationship between diabetes and eating disorders, including evidence that Type 1 and Type 2 diabetes are risk factors for the development of eating disorders.
2. The problematic nature of the 'anti-obesity'[1] movement, including how 'obesity' prevention, diagnosis and treatment can harm people with eating disorders by perpetuating weight stigma, reducing help-seeking and contributing to poor quality health care (including refusal of care).

[1] We use the terms 'obesity' and 'anti-obesity' with caution in this submission, using quotation marks. We do so in recognition that obesity is medical term applied to people in larger bodies. For people who experience weight stigma and discrimination due to the pathologising of larger bodies, the term 'obesity' may be triggering. This is especially the case for people who are experiencing or recovering from eating disorders where overvaluation of weight and/or shape is a factor.

Butterfly would welcome the opportunity to provide oral evidence to the Inquiry in relation to any of the matters raised in this Submission.

Overview of eating disorders and body image concerns in Australia

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.

Types of eating disorders include: Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder, Other Specified Feeding and Eating Disorders (OSFED), Avoidant/Restrictive Food Intake Disorder (ARFID), Unspecified Feeding or Eating Disorder (UFED), Rumination Disorder, and Pica.

Prevalence

At any one time, approximately 4 per cent of the Australian population – or more than one million people – is experiencing an eating disorder, while lifetime prevalence is 9 per cent (Deloitte, 2015). Of those with eating disorders: 47 per cent have Binge Eating Disorder, 12 per cent have Bulimia Nervosa, 3 per cent have Anorexia Nervosa and 38 per cent have other eating disorders – such as Other Specified Feeding and Eating Disorders (OSFED) (Paxton et al, 2012). When 'disordered eating' behaviours are included (that is, sub-clinical behaviours), using a 3-month prevalence point, a large-scale community survey found that 16.3 per cent of people in Australia have experienced an eating disorder (Hay, Girosi & Mond, 2015).

The actual prevalence of eating disorders and disordered eating behaviour in the community may be much higher. Research recently conducted for Butterfly shows that from a representative national sample of 3,030 people, 17 per cent of the population – almost one in five – either have an eating disorder or have greater than three symptoms of disordered eating (Butterfly Foundation, 2021b). The Covid-19 pandemic has had a significant impact on eating disorder presentations (McLean, Utpala & Sharp, 2021) and Butterfly's National Helpline has experienced a significant per cent increase (pre-Covid) in contacts from the 2019 to the 2020 and 2021 financial years.

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 (Volpe et al,2016; Hart et al, 2011). While comprehensive data on prevalence at a state and territory level is not available it is estimated that prevalence is similar across different regions of Australia (Deloitte, 2019). For the ACT, the estimated number of people experiencing an eating disorder in any given year (as estimated in 2019) is 17,900, or 4.18 per cent of the Territory's population (Deloitte, 2019).

The prevalence of eating disorders is similar to substance use disorders, and higher than bipolar disorder and autism spectrum disorder (Santomauro et al., 2019).

Comorbidities

Eating disorders are frequently associated with other psychological and physical disorders such as depression, anxiety disorders, substance abuse and personality disorders (Hudson et al, 2007).

Mortality rate and suicidality

Eating disorders carry an increased risk of premature death due to long term medical complications and increased rate of suicide. With the exception of some substance abuse disorders, eating disorders have the highest mortality rate of any mental illness (Chesney, Goodwin & Fazel, 2014). The mortality rate for

eating disorders is between one and half times to twelve times higher than the general population (Arcelus et al, 2011).

Gender differences

Eating disorders can affect women and men, however the highest prevalence rates in Australia occur in women and girls aged 15 to 29 years, with a prevalence rate of 13.6 per cent in the 20-24 age group (Deloitte, 2019: 3). In any given year, the majority of contacts to Butterfly Foundation's National Helpline are from girls and women under 25, with numbers of contacts particularly elevated during the height of the Covid-19 pandemic – overall contacts to Butterfly's Helpline in 2020-21 increased by 63 per cent from the year prior to the start of the pandemic (Butterfly Foundation, 2022). According to a large UK study, by mid-life 15 per cent of women have experienced an eating disorder, including through new onset and chronic disorders (Micali et al, 2017). According to a nationally representative study of 100,000 people in the USA, 1 in 5 women (19.7 per cent) will have had an eating disorder by the age of 40 (compared with 1 in 7, or 14.3 per cent of men) (Ward et al, 2019).

While approximately 90 per cent of people diagnosed with Anorexia Nervosa and Bulimia Nervosa in Australia are women or girls, there are significant numbers of men and boys affected by eating disorders and body dissatisfaction. National estimates produced in 2012 for Butterfly Foundation found that 36 per cent of those experiencing eating disorders identify as male. Instances of binge eating disorder are evenly represented across both women and men in Australia (Paxton et al, 2012), while body dissatisfaction (a risk factor for the onset of eating disorders) is a significant issue for younger men and boys. A 2017 Butterfly Foundation survey found that 40 per cent of respondents identifying as male were dissatisfied or very dissatisfied with their appearance (compared with 46 per cent of respondents identifying as female). Men and boys are subjected to specific 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' (Griffiths, Murray, & Touyz, 2015). Eating disorders among boys and men may present differently than in girls and women, particularly with muscularity-oriented disordered eating (Nagata, Ganson & Murray, 2020). These features can mean that eating disorders among men and boys are overlooked or misdiagnosed by health care professionals.

While research into eating disorders among transgender and gender non-conforming people is limited, existing studies suggest that transgender people are more likely than cisgender people to have been diagnosed with an eating disorder, or to engage in disordered eating behaviours (Diemer et al., 2018; Parker & Harriger, 2020). Experiences of disordered eating are particularly high among young trans people. An Australian study found that two out of three young trans people have limited their eating in relation to gender dysphoria during puberty, while 23 per cent have a current or previous diagnosis of an eating disorder (Strauss et al, 2017).

Other demographic characteristics

Contrary to common stereotypes, large scale surveys show that eating disorders do not discriminate by income or education (Hay, Girosi, & Mond, 2015), while 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). People who are LGBTIQA+ are at greater risk for disordered eating behaviours (Calzo et al, 2017). Neurodiverse people have an increased risk of developing eating disorders (Biederman et al., 2007; Solmi et. al, 2021).

Economic costs

The total social and economic cost of eating disorders in Australia in 2012 was estimated at $69.7 billion (Paxton et al, 2012). In today's figures, this number is $80.1 billion per year. This number includes health system costs, productivity cost and carer costs. In 2012, direct financial costs were estimated at $17.1 million, and the burden of disease costs were $52.6 million.

The estimated cost of eating disorders (in terms of disability-adjusted life years) is higher than that of depression and anxiety combined (ibid).

If the social and economic costs of body dissatisfaction in Australia were to be included these figures would likely be much higher. Economic analysis recently conducted in the United States has found that each year body dissatisfaction incurs $84 billion in financial costs, with an additional $221 billion in loss of wellbeing (ears of life lost and years lived with a disability) (Dove with Deloitte Access Economics, 2022). Prepared with input from researchers at the Harvard T.H. Chan School of Public Health and Boston Children's Hospital, this analysis found that one-third (32 per cent) of the financial costs of body dissatisfaction are borne by individuals and families, with government incurring 29 per cent of costs and employers incurring 14 per cent of costs. Estimates of appearance-based discrimination include $269 billion in financial costs, with an additional $233 billion in wellbeing losses.

The range of influences on body image and eating disorders

Body image and eating disorder thoughts and behaviours are influenced by a range of factors including individual characteristics such as personality traits, with higher levels of neuroticism and lower levels of extraversion associated with poor body image (Allen & Walter, 2016; Roberts & Good, 2010; Swami et al., 2013). Psychological risk factors include low mood or depression, low self-esteem and perfectionism (Sharpe et al., 2018; Murray, Rieger, & Byrne, 2013; Nichols et al., 2018). Another individual-level factor is subscription to hegemonic appearance ideals (such as leanness or muscularity), with upwards social comparison a contributing factor to poor body image (Fardouly, Pinkus, & Vartanian, 2017). Biological life events such as puberty and menopause have also been found to influence body image (Slater & Tiggemann, 2012; de Guzman & Nishina, 2014; Deeks & McCabe, 2001; and Erbil, 2018).

Sociocultural factors affecting body image include the influence of social media and traditional media. Butterfly is alerted to harmful trends on social media platforms and other online spaces by our community on a regular basis. Examples of harmful content include videos portraying young people engaging in dangerous restrictive dieting behaviours to lose excessive amounts of weight, which in theory could be demonstrative of an eating disorder. While this in itself is an issue, what is more concerning is that these behaviours are being shared with other users who may then engage in the same behaviours or make body, weight, shape, or appearance comparisons to the person in the original post (who may have or be at risk of experiencing an eating disorder). This type of content could encourage risky eating and exercise behaviours which are a known trigger for eating disorders. In addition, targeted advertising and machine learning can mean that people who are interested in appearance-related content (including those searching for help) may be exposed to such content at a higher rate, thereby increasing their risk for eating disorders (Rodgers et al, 2019). For someone at risk of, experiencing or recovering from an eating disorder, repeated exposure to this content can significantly stall recovery progress or reignite eating disorder thoughts and/or behaviours. However, the exact nature of the harm caused by such content is difficult to quantity.

While there is little that state and territory governments can to do alter online environments (given that online safety is regulated by the Commonwealth), there is much that can be done to develop alternative sources of information to educate and empower children, young people, and their families and carers.

This includes campaigns and programs that can influence the modifiable risk and protectives factors involved in the development of body dissatisfaction, disordered eating and eating disorders.

Appearance-related teasing and weight stigma among children and young people

Sociocultural factors that influence the development of body image include appearance-related teasing or bullying (Menzel et al., 2010; Valois et al., 2019; Webb & Zimmer-Gembeck, 2014) and weight stigma.

Weight stigma refers to social devaluation of higher weight, which can lead to people in larger bodies experiencing prejudice and discrimination in the public sphere (including health care settings).

Weight stigma starts developing early in childhood, with children as young as 3 years old attributing negative qualities (such as 'lazy' and 'mean') to images of children with larger bodies and attributing positive qualities (such as 'nice' and 'clever') to images of children with thinner bodies (Musher-Eizenman et al., 2003; Damiano et al., 2015a; Spiel et al., 2012).

At age 5, 90 per cent of boys and 92 per cent of girls have indicated a preference for not inviting children in a larger body to their birthday party, and perceiving thin-to-average sized children as 'good' (Children's Body Image Development Study, cited in Butterfly Foundation, n.d.).[i]

Intersecting experiences of gender, race, ethnicity, age and sexuality also have an impact on body image (for an overview of this literature, see Centre for Appearance Research, 2020). Poor body image is, in turn, a risk factor for a range of mental health conditions including – but not limited to – eating disorders. Butterfly's Body Kind Youth Survey Report (2023a) documents impacts on several domains of life, including schooling, social activities and participation in sport and physical activity.

Body dissatisfaction and dieting among children and young people

Body image concerns are consistently ranked within the top 3-5 personal concerns of young people aged 15-19 (Mission Australia, 2022). In 2021, 33 per cent of those surveyed were 'extremely' or 'very concerned' about their body image. A national survey of 12–18-year-olds was recently conducted by Butterfly; results show widespread prevalence of body concerns and several significant impacts of body dissatisfaction among Australian young people (2023a).

Body dissatisfaction can begin early in life and is common among children under 12. As part of the development of our primary school program, Butterfly Body Bright, Butterfly conducted a survey with 165 Australian adults, ranging in age from 19-65, who developed body image and/or eating concerns during primary school. This survey found that:

- 93 per cent of respondents indicated that their primary school body concerns worsened in adolescence
- A range of serious and unhealthy behaviours developed during primary school:
    - 64 per cent started restrictive dieting (most frequently at ages 10-12)
    - 77 per cent engaged in disordered eating behaviours (with ages 8, 10-12 most frequent ages of onset)
    - 33 per cent engaged in excessive exercise (most frequently at ages 10-12
- 43 per cent of respondents reported developing an undiagnosed eating disorder between the ages of 5 and 12 (highlighting the need to make more primary schools aware of these serious issues in childhood).

Stigmatising weight attitudes form very early in childhood, and are related to appearance-based teasing, which are linked to the development of body dissatisfaction and unhealthy behaviours (Spiel et al, 2012; Damiano et al, 2015a; Puhl et al, 2021; Damiano et al, 2015b; Rancano et al. 2021). 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, 2017). In one study, nearly 50 per cent of girls aged 9 to 12 years old reported feeling dissatisfied with their body (Clark & Tiggemann, 2008). Another study found that found that 54.8 per cent of boys aged 12 to 18 expressed a desire to alter their body in some way (Lawler and Nixon, 2011).

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 (Field et al, 2003).

This research underscores the importance of working to address the social determinants of negative body image and disordered eating – such as weight stigma and the negative impacts of social media usage – with children and adolescents before thoughts and behaviours become entrenched. Without preventative strategies and early intervention, interrupted physical, educational and social development can pose risk of significant medical complications in the long-term, along with other mental health issues.

Low help-seeking among people with eating disorders

Less than one in four people (23.2 per cent) with eating disorders seek professional help (Hart et al, 2011). Barriers to help-seeking include: stigma; feelings of shame; denial of and failure to perceive the severity of the illness; practical barriers such as cost of treatment; low motivation to change; negative attitudes towards seeking help; lack of encouragement from others to seek help; and lack of knowledge about help resources (Ali et al, 2017).

Access to care among people of higher weight

There is a high prevalence of eating disorders among people in larger bodies; this population makes up more than half of all people with an eating disorder in Australia (Da Luz et al., 2017). Despite this, eating disorders among people in larger bodies have been consistently under-recognised and under-treated:

> People with a lived experience of an eating disorder who are of higher weight report being misdiagnosed, dismissed by health professionals and sidelined or excluded from eating disorder treatment services (Ralph et al., 2022)

Weight stigma among health professionals is a major factor in the limited access to treatment for people in larger bodies; this concept is discussed further on pages 11-13.

Diabetes and eating disorders

Eating disorders are more common in people with type 1 diabetes than those without type 1 diabetes (NEDC, n.d.). Eating disorders are twice as likely to occur in adolescent girls with type 1 diabetes than those without type 1 diabetes (ibid). While there is limited research on eating disorders and type 2 diabetes it is estimated that between 12 and 40 per cent of people with type 2 diabetes have an eating disorder (García-Mayor & García-Soidán, (2017).

The relationship between eating disorders and diabetes is complex. For type 1, diabetes is a risk factor for the development of disorders eating and eating disorders (NEDC, n.d.). This is perhaps not surprising given that the management of type 1 diabetes involves a focus on diet, meal planning and monitoring of carbohydrate intake. Restriction and precise monitoring of food intake are risk factors for the development of eating disorders. Insulin restriction has been reported in studies as a weight control behaviour (for both type 1 and type 2 diabetes) (Rodin et al, 2002).

For people with type 2 diabetes, eating disorders may develop post-diagnosis as a result of pursuing weight loss through restrictive diets. Conversely, eating disorders may lead to increases in body weight that in turn increase the risk of developing type 2 diabetes (NEDC, n.d.).

In recognition of the relationship between eating disorders and diabetes, Butterfly is currently a partner in a research project to support the mental health of young adults with diabetes (particularly type 1). The APHLID project: Apps and Peer support for a Healthy future and Living Well with Diabetes study is being led by Professor David Simmons of Western Sydney University.[2] The APHLID project seeks to create and test a technology-enabled model of care leveraging peer support, using a clinically validated digital platform. The model combines (i) apps to address common mental health issues including anxiety, depression and eating disorders, (ii) linkage to digital tools to self-manage type 1 diabetes, (iii) a proven digital platform for day to day lifestyle and type 2 diabetes self-management, (iv) digital linkage with the healthcare team and (v) access to an online peer support network.

This model will be evaluated and translated to the real world across seven hospitals and two regional Aboriginal Medical Services. A 6-month randomised controlled trial of the model will compare the impact of the approach on distress, wellbeing, healthcare costs, glucose and weight management among 142 young adults living with diabetes and mental health conditions. A parallel cohort study among those without a mental health condition will study the effect of the approach on maintenance of good mental health.

Lived experience insights from people with diabetes and eating disorders

In preparing this Submission, Butterfly consulted with members of our online community reference group, the Butterfly Collective, about their experiences of diabetes and eating disorders. With over 800 members form across Australia, Butterfly engages with this group to co-produce and consult on a range of research, policy, program, and promotional projects and activities. We asked about experiences in relation to type 1 diabetes, type 2 diabetes and gestational diabetes, with a focus on experiences in the health care system.

People with lived experience of both diabetes and eating disorders told us that health care professionals need to acquire greater knowledge regarding the intersection between eating disorders and diabetes and that the management of diabetes should not be focused on food and weight, which can exacerbate weight stigma. A key theme was that a strong focus on weight in diabetes management may potentially lead someone to disordered eating behaviours, having negative consequences for a person's mental and physical health in the long run.

> "Diagnosis was shaming as I had been 0.01 under the diagnosis for type 2 and could receive no assistance to reduce weight due to a medication and then it was all thrown my way and Duromine/Trulicity/Ozempic and still shamed into believing it was my diet and my lack of control which caused my weight increase. I was told I needed to eat once a day/restrict intake and still blamed when weight loss was slow." (Triona, 47, WA).

> "The only thing I would like to say about this is that being management of gestational diabetes worsened my eating disorders, specifically the intense focus on food and weight. The strict diet and exercise routine I was put on and being told not to gain weight even though I was pregnant set me back hugely which ultimately resulted in worse mental and physical health in the long run. I also gained weighed rapidly after having my baby as I had been so restricted during my pregnancy so therefore had the opposite effect and what they were hoping." (Nina, 41, WA)

[2] More detail on the study is available here: https://www.westernsydney.edu.au/newscentre/news_centre/more_news_stories/first-of-its-kind_health_app_to_be_trialled_for_young_people_managing_diabetes_and_mental_health

When asked about how experiences of health care could have been improved, we received the following responses:

> "Easier access to a diabetic-specific dietitian, that was also a bad experience which ended in me just using Google for self-help. More understanding from medical professionals who understand some medications cause weight increase. I would have loved to have been linked in with a face-to-face peer type of group focusing on supporting each other" (Triona, 47, WA).

> "As I am now a health professional myself I know there are better, more intuitive ways, of managing diabetes. There are ways that are more sustainable in the long run and don't require unmanageable food and weight restrictions that people cannot maintain." (Nina, 41, WA)

People with lived experience indicated that current messaging, language, and methods used in diabetes management are harmful and can negatively impact persons eating disorder recovery, particularly methods that require a restriction of foods or methods aiming to change a person's weight. Responses urged health professionals to understand that certain medications and interventions for diabetes could have negative long-term implications and may not be sustainable. Overall diabetes management was perceived as lacking understanding in relation to eating disorders and disordered eating.

> "What is out there currently is dangerous! Online platforms talk a lot about needing to starve yourself while also on medications for type 2 . . . Getting earlier intervention is blocked for those sitting under the required number to be classified as type 2 and that's not ok for people to have to struggle with decreased mental wellness and increased physical illnesses or risks of future medical emergencies with heart/blood pressure. I am lucky to be recovered from 13-year journey with bulimia to have had enough knowledge to recognise triggers and understand healthy DOES NOT mean skinny and obtaining healthy should be accessible in an early intervention model for all with proper connected supports. I found it so hard to explain what my Doctor told me was dangerous to my teen daughter currently experiencing an eating disorder." (Triona, 47, WA).

> "More research needs to be done on the link between disordered eating behaviours and diabetes such as restricting and bingeing. Higher weight in diabetes is a correlation NOT a cause and should therefore be treated as one. Focusing on people's weight to treat diabetes does more harm than good in the long run to a person's mental and physical health." (Nina, 41, WA).

Health promotion and prevention

Butterfly recognises the need for preventive health policy, including investment in promoting good nutrition and physical activity to reduce the incidence of diabetes, heart disease and stroke. However, we have concerns in relation to the concepts and language that are often employed in 'anti-obesity' initiatives. We frequently observe public health promotion activity in this area which: shows insufficient understanding of eating disorders; employs weight stigmatising language; shows a lack of understanding of weight science (presenting weight as a personal choice which is easily controlled); uses ambiguous definitions of 'healthy'; and features an over-reliance on population health measures such as Body Mass Index.

Our concerns are borne out in a recent review of young people treated for anorexia nervosa between 2015 to 2020 found that healthy eating education was a trigger for 14 percent of the patients, and that early adolescents were especially vulnerable (Lin et al, 2023). Other triggers identified in this study included environmental stressors (reported by 30 per cent), external pressures of the thin/fit ideal (29 per cent), internalised thin/fit ideal (29 per cent), weight-related teasing (19 per cent) (ibid).

Nutrition education and messaging in schools is a particular area of concern for Butterfly. A recent Australian study has found that children's discourses of health and nutrition are heavily influenced by

biophysical and 'obesity' discourses, and are potentially problematic given their focus on 'avoidance of fatness' and negative judgement in relation to overweight (Verlardo & Drummond, 2019). A small study conducted with participants either currently or previously diagnosed with an eating disorder found that 'anti-obesity' campaigns had the potential to confirm eating disorder thoughts and behaviours, and could act as potential triggers (Bristow et al, 2022).

As part of developing the any new preventive health strategies to reduce the prevalence of diabetes a review of nutrition education within school and sporting environments should be conducted with regard to how they may be contributing to dichotomous thinking. If food is being framed as 'healthy/unhealthy' or 'good/bad' it may be contributing to disordered attitudes and behaviours around eating. There may also be broader wellbeing initiatives in schools that impact body image and eating disorder risk and protective factors (e.g., self-esteem and resilience programs). Evaluations of such programs should include body image, disordered eating and eating disorders in their outcome measures.

The damaging impact of weight stigma

Weight stigma refers to negative beliefs, attitudes and behaviours towards people based on their body weight, size and shape. Weight stigma typically occurs in relation to people living in larger bodies.

Weight stigma and discrimination can have serious negative impacts on peoples' health and wellbeing. This was recognised recently by the ACT Auditor-General's Performance Audit Report of the ACT Childhood Healthy Eating and Active Living Programs (2022). The report provides a review of literature in this area and notes that:

> "Pervasive cultural and social beliefs that body size and shape are within an individual's control and hence people with larger bodies are 'ignorant', 'lacking willpower' or 'lazy' causes people who are labelled or perceived as 'overweight' or 'obese' to experience bias, blame, discrimination and stigma." (ibid, p 120)

The Auditor-General's Performance Audit Report also noted the intersectional nature of weight stigma, given that people of different ethnic and racial backgrounds tend to have different body sizes and shapes.

The NEDC website provides a summary of the impacts of weight stigma and discrimination in relation to people with higher weight, who are more likely to:

- avoid seeking and engaging in medical care, leading to delays in diagnosis and treatment
- engage in disordered eating, contributing to the onset of eating disorders and increasing disordered eating in people experiencing eating disorders
- experience higher levels of body dissatisfaction
- experience higher levels of psychological distress, including stress, anxiety, depression, feelings of worthlessness and loneliness, and suicidal ideation
- experience poorer quality of life
- face discrimination in healthcare, affecting the quality of care they receive, leading to poorer health outcomes and increasing risk of mortality
- face discrimination in employment and education
- avoid physical activity and leisure pursuits.[3]

The management of eating disorders for people with higher weight: clinical practice guideline (Ralph et al, 2022) notes that weight stigma is a major factor in the under-recognition and under-treatment of people with eating disorders in larger bodies. In response, the guideline promotes weight-inclusive practice and

[3] See https://nedc.com.au/eating-disorders/eating-disorders-explained/weight-stigma/

provides 21 clinical recommendations to improve care for people with eating disorders who are of higher weight.

In response to the Auditor-General's Performance Audit Report, Butterfly's Submission to the ACT Legislative Assembly's Standing Committee on Public Accounts Inquiry into the Auditor-General's Performance Audit Report of the ACT Childhood Healthy Eating and Active Living Programs (2023b) recommended that the new preventive strategies include actions directed towards addressing weight stigma and discrimination, noting evidence cited above in relation to its impact on children, adolescents and adults.

At the federal level, it is critical that preventive public health programs and campaigns align with best practice in eating disorder prevention and avoid weight stigma. Strengthening practice guidance and professional development in this area would build the knowledge and capacity of the health workforce to approach issues of healthy eating and physical activity in ways which address diabetes without inadvertently cause harm to the body image of children, young people and adults.

Lived experience insights into weight stigma and discrimination

Responses to Butterfly's previous lived experience engagement in relation to stigma and discrimination demonstrated that people in larger bodies with eating disorders face particular forms of stigma and discrimination in accessing treatment and support. This was the same when we consulted with our Butterfly Collective members on experiences of people with diabetes in relation to the 'anti-obesity' movement. We asked how obesity prevention, diagnosis and treatment affects people with eating disorders, and whether weight stigma had contributed to reduced or delayed help-seeking or to poor quality health care (including refusal of care).

People with lived experience expressed that they had experienced stigma from health professionals and had not received compassionate and adequate care. Often other health issues that were experienced were overlooked as medical professionals had a bias toward indicating that a person's weight or 'obesity' was the core concern. The stigmatising and negative treatment of people in larger bodies when seeking support for diabetes management or other health issues had detrimental effects on individuals' mental and physical health in the long term. People with lived experience shared that the negative treatment of larger-bodied individuals in the health system could be a significant barrier to people with both an eating disorder and diabetes seeking the support and treatment needed.

> "The anti-obesity movement had been extremely damaging to me. Firstly, by constructing obesity as an 'illness' it has pathologised my body and made me feel like a 'failure' of a person for being obese and made me feel like I am seen as an illness by others. Obesity, in my opinion, is a SYMPTOM - rather than an illness in itself - a symptom of another physical and mental condition or a symptom of a very broken social environment/economic system and structures (e.g., diet culture, food insecurity, poverty, the normalisation of eating fast food/highly processed foods through advertising, etc.)." (Kacey, 31, NSW).

> "My mum used to suffer with obesity. Whilst she is now a healthy weight, at the time when she was suffering it was difficult to witness her struggle with obesity messages, as I could tell this prompted feelings of shame towards her body image and self-esteem." (Anonymous).

> "I was refused assistance when at insulin resistance level and told I was obviously eating too much/the wrong foods and not exercising. I was shamed to believe I was the problem and that I must be lying. I was actually diagnosed with hypothyroidism alongside type 2 diabetes when I was finally listened to and even that was a year of testing before any intervention. I had begun

ACT therapy for myself as my mental health declined and depression rose again and not feeling heard or helped. That was my last shred of holding hope for myself." (Triona, 47, WA).

"I have had many negative experiences in healthcare in which healthcare practitioners have not taken my symptoms seriously. They looked at the size of my body and presumed I had poor diet and lack exercise in my life. Hardly any of them asked me what my diet was like before telling me the best thing I could do is lose weight and giving me dieting advice. It wasn't until I developed anorexic behaviours, in order to get to the weight they wanted me to be, for someone to take me seriously and actually perform some medical tests. While they all congratulated me for the size my body was in order to get there I made myself more sick than I've ever been. Meanwhile the condition I actually had (which had nothing to do with my body size) was going untreated because they were so focused on my weight. This creates a huge barrier for larger people in the healthcare system as they start either avoiding it altogether due to poor treatment they receive, or the treatment they actually need is delayed due to focus on their weight both leading to poorer health outcomes for them. It's time we stopped blaming weight on all poor health outcomes associated with higher weight people and acknowledging the way our healthcare system fails them." (Nina, 41, WA).

When asked about how the health care system could be improved for people experiencing both diabetes and eating disorders, the following insights were shared.

"When I was about 19 years old, I went to a doctor for the very first time to speak about having an eating disorder and wanting to get support to try and help me deal with it. However, the GP told me 'I wouldn't worry so much about that. The real concern for me is your weight, you're obese - and that isn't healthy. This is what we should be talking about.' It was incredibly traumatic for me. I went looking for help for my disorder but was essentially told that I should be more worried about the fact I was fat. It took me another 2-3 years before I tried to get help for my eating disorder again. If I'd been treated earlier - my outcomes may have been very different, much more positive. It was quite disheartening. Since that encounter, I've had more positive experiences. However, it is still quite normal for people to disregard my health concerns because they just think it's my weight and suggest I just need to lose weight. Only to find out that my weight wasn't causing the health problem, but something else was the cause." (Kacey, 31, NSW).

"What a person weighs has nothing to do with the severity of their mental health or eating disorder behaviours. Weight should not be a part of eating disorder diagnosis or treatment." (Nina, 41, WA).

Several suggestions were put forward as ways to improve physical health promotion:

"Health initiatives needs to adopt strengths-based approaches to empower people to take care of themselves through positive behaviours, self-love and care, etc. instead of through anti-obesity/anti-fat rhetoric which fosters shame and stigma. Obesity needs to be seen more often as a symptom. We should be looking at what needs to change in our society for health to improve - regulating fast food advertising, improving nutritional education for parents and children, making healthy food financially accessible for those in poverty, and so on." (Kacey, 31, NSW).

"Reviewing policies on displaying kilojoule/calorie contents on menu – whilst this is an obesity prevention strategy, it may also be quite triggering and promote disordered eating practises/enforce diet culture." (Anonymous).

> "I think there needs to be more defined accountability for medical services with follow up on care plans made to ensure people are getting the treatment and how they are coping with it. . . Age restrictions and regulations around social media and groups created for weight loss using interventions such as Ozempic etc. Training for GPs on trauma informed care and practices in working with patients to understand more clearly the dangers of restrictive calorie intake and how that can lead onto disordered eating/eating disorders." (Triona, 47, WA).

> "Please listen to what people have been through. Weight stigma is so rife in our society that our health research and policies are tainted with it. Shaming a larger person into a smaller body is not a long-term solution to any health problem meanwhile the obsession with body size is contributing to a pandemic of body image issues and eating disorders in our young people. We need to move away from our obsession with 'obesity' and focus more on sustainable lifestyle behaviours such as getting people moving more, sleep and managing stress. These are much more positive ways to influence a person's health than making them smaller." (Nina, 41, WA).

Recommendations

1. **Preventive health policy must align with eating disorder prevention policy**

Butterfly recommends that all healthy eating and physical activity strategies and campaigns be developed in alignment with best practice in the prevention and treatment of eating disorders and body image issues. All public health promotion in the area should be informed by an understanding of eating disorders, including the experiences of eating disorders among people in larger bodies. This recommendation aligns with the recently released National Strategy for Eating Disorders 2023-2033, launched by the Commonwealth Minster for Health on 30 August 2023.

We also recommend that the any new healthy eating and physical activity strategies developed to address diabetes invest in the development of awareness, knowledge and skills in relation to weight stigma. This includes audiences such as parents/caregivers, primary and secondary school staff, and among other professionals who work with children (such as in sport, recreation and wellbeing programs).

2. **Invest in addressing the economic and social determinants of eating disorders, including food insecurity and the health and wellbeing needs of priority populations**

Policies and programs that address individual and familial level factors in relation to nutrition and exercise can only go so far. The ACT Auditor-General's Performance Audit Report of the ACT Childhood Healthy Eating and Active Living Programs (2022) recognised that many childhood healthy eating and active living programs have focused on improving food and activity environments and building child and family skills and knowledge, with limited effort directed to supporting the food security needs of families. As the ACT Performance Audit Report notes, there is a risk that:

> 'significant numbers of children in the ACT cannot access healthy eating and active living because of poverty and food insecurity. These children and their families are unlikely to benefit from childhood healthy eating and active living programs focused on building skills and knowledge.' (3.139)

There is also emerging evidence that food insecurity is cross-sectionally associated with higher levels of overall eating disorder pathology, binge eating, compensatory behaviours, binge-eating disorder, and bulimia nervosa (Hazzard et al., 2020). Weight stigma is also associated with food insecurity (Becker et al., 2017).

At Butterfly we are mindful that Aboriginal and Torres Strait Islander people's experiences of food occur within a context of colonisation. As the authors of a report on Aboriginal and Torres Strait Islander people and nutrition research note:

> 'Today, many Aboriginal peoples associate food, in general, with traumatic colonization practices that are centered around the control of food and food systems which are then passed between generations. This cannot be ignored, and further research is required to explore and document what nutritional colonization looks like, and how it affects Aboriginal and Torres Strait Islander peoples' engagement with food and the food system today.' (Wilson, et al., 2020)

To respond to the needs and priorities of this population group, strategies to encourage healthy eating and active living under any preventive health policy must take into account this foundational difference, and be developed in genuine collaboration with Aboriginal and Torres Strait Islander people, including engagement with community-controlled health organisations.

3. **Educate diabetes treatment providers on screening tools and treatment options for people with diabetes who are at risk of developing eating disorders**

In line with the NICE guideline on the treatment of people with an eating disorders and diabetes, a multi-disciplinary approach should be adopted by diabetes and eating disorder care teams. This includes:

- collaborating to explain the importance of physical health monitoring to the person
- agreeing who has responsibility for monitoring physical health
- collaborating on managing mental and physical health comorbidities
- using a low threshold for monitoring blood glucose and blood ketones
- using outcome measurements to monitor the effectiveness of treatments for each condition and the potential impact they have on each other. (NICE, 2020)

Screening for disordered eating among people with diabetes should begin in pre-adolescence and continue through early adulthood in order to obtain detect and treat eating disorders as early as possible (Hanlan et al, 2013).

4. **Diabetes education materials for families, carers and supports should include information about eating disorder warning signs**

Health promotion for those who support family and friends with diabetes management should include information about the signs and symptoms of eating disorders and how to seek further advice and support (such as the Butterfly Foundation's National Helpline).

The NEDC (n.d.) provides the following list of warning signs for a person with diabetes who may be experiencing an eating disorder:

- Lessening attention to diabetes management
- Increasing secrecy about diabetes management including discomfort testing/injecting in front of others
- Fear of the impact of insulin on body weight
- Unexplained weight loss, gain or fluctuations
- Extreme fluctuations in blood glucose levels
- High to very high Haemoglobin A1c (HbA1c) on a continuous basis
- HbA1c inconsistent with blood glucose meter readings

- Frequent high or low blood glucose levels and/or diabetic ketoacidosis (DKA), possibly resulting in hospital admission
- Misusing insulin doses, or changing doses significantly or frequently
- Restricting certain food or food groups to lower insulin dosages.

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[i] A comprehensive summary of children's body image has been prepared by Butterfly and is available here: https://static1.squarespace.com/static/60a212b84e9cf244cb678799/t/60ee3fe6b1dcdf258da813b3/1626226663346/Butterfly+Body+Bright+Relevant+Research.pdf