Submission to the Draft National Stigma and Discrimination Reduction Strategy

National Mental Health Commission

Butterfly Foundation

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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, 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.

Introduction

Butterfly Foundation (Butterfly) welcomes the opportunity to contribute to the consultation on the Draft National Stigma and Discrimination Reduction Strategy (the Strategy). We acknowledge the significant community consultation and sector engagement that has been undertaken as part of the Strategy's development and thank the National Mental Health Commission (the Commission) for engaging with Butterfly as part of that process.

In this submission we provide a brief overview of eating disorders and body image issues in Australia and information on manifestations of stigma and discrimination which are specific to eating disorders and body image concerns. We have structured our feedback in response to the consultation questions 1,2,3 and 5, providing additional detail as needed in support of recommended additions or changes to priority actions and how best to support their implementation. We also share (with permission) several lived experience perspectives on stigma which we have gathered over the past 18 months and hope that these voices will convey the importance of actions which address the specificity of eating disorder stigma and weight stigma across the Strategy.

Eating disorders are complex mental disorders involving physical as well as psychological harm; in this way they differ from other mental health conditions. While historically eating disorders have been conceptualised as conditions affecting people of low weight, current evidence shows that eating disorders are experienced by people with a range of body types. For example, people in larger bodies[1] make up more than half of all people with an eating disorder in Australia (Da Luz et al, 2017). Despite this, people in larger bodies commonly report experiences of weight stigma and discrimination in accessing treatment and support within the health system and more broadly, for example in accessing employment. For the Strategy to make a measurable difference in the lives of people that Butterfly supports and advocates for, the specific forms of stigma attached to eating disorders and bodies, including the ways it manifests as structural, public and self-stigma, as well as weight stigma, must form part of the Strategy and its implementation and evaluation.

Overall we support the vision, the principles, and the structuring of the Strategy's priorities into the four categories of: mplement foundational actions across settings to address stigma and discrimination; reduce structural stigma and discrimination; reduce public stigma; and reduce self-stigma.

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[1] In line with the language preferred by the majority of the eating disorder and body image lived experience community and the language used by the National Eating Disorders Collaboration, we use the term 'people in larger bodies' or 'people of higher weight' throughout this submission. We use the medical term 'obesity' only where this relates to policies or publications which use this term.

To ensure that the Strategy adequately responds to eating disorder stigma and weight stigma and discrimination, we recommend additional consideration be given eating disorders and body image across several action areas under the four categories. We also recommend that people with lived experience and those working in non-government organisations which work with people with lived experience be afforded a stronger role in responsibility for the delivery of the Strategy, particularly in relation to education and community knowledge, attitudes and behaviours.

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).

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, 2022b). 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.

Impact of Covid-19

The Covid-19 pandemic has had a significant impact on eating disorder presentations (McLean, Utpala & Sharp, 2021). In one study, the number of annual eating disorder presentations among children and adolescents increased by 62 per cent in 2020 compared to the two years prior (Chadi et al., 2021).

Negative body image outcomes due to Covid-19 include increased shape and weight concerns, increased drive for thinness/muscularity, increased body and appearance dissatisfaction, and decreased self-esteem (Schneider et al., 2022). Worsened disordered eating behaviours include binge eating, dietary restriction, and compulsive exercise, along with increases in stress, anxiety and depression among people living with eating disorders (Ibid.)

Studies have also documented disruptions to social support networks and access to treatment and support (Vuillier et al., 2021).

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).

Eating disorder stigma reduction

Stigma and shame are the most frequently identified barriers for accessing treatment (Ibid). Despite this, there has been limited investment in stigma reduction initiatives that focus on eating disorder stigma. While stigmatising attitudes toward mental illnesses such as anxiety and depression have lessened as they have become better understood by the community, the variability, intensity and incidence of stigma surrounding eating disorder diagnoses remains much less understood.

Exposure to stigmatising attitudes predicts a range of negative psychological, social and physical outcomes for people with eating disorders. Stigma increases social isolation, reduces help-seeking, and exacerbates symptoms of eating disorders.

Experiences of public stigma – negative attitudes and beliefs which cause people to fear, reject, avoid, or discriminate against people with mental illness – are strongly tied to experiences of self-stigma and shame, which create barriers to accessing treatment and support.

Butterfly has recently been investigating the evidence in this area under a previous contract with the Commonwealth Department of Health and Aged Care; this work has recently been approved for publication and is available on the Butterfly website (Butterfly Foundation, 2022a).

Stigmatising attitudes and low mental health literacy

Lack of knowledge and stigmatising views about eating disorders are common within the community. Recently published research conducted by Butterfly with a large, representative community sample (n = 3,030 people) shows that one in four people in Australia believe that if people with eating disorders 'were stronger people, they wouldn't be doing this to themselves', while three in five people believe that 'most people think that bingeing/purging is disgusting' (Butterfly Foundation, 2021b).

Existing research on eating disorder stigma in community samples – largely from the USA – shows that eating disorder stigma differs from other types of mental health stigma. Studies have also shown that eating disorders commonly induce less empathy in comparison to other physical and mental health disorders. For example, in one study people with anorexia nervosa were viewed as 'most to blame for his/her condition', were best able to 'pull him/herself together if he/she wanted to', and were 'acting this way for attention' compared to people with other conditions (Stewart, Keel, & Schiavo, 2006). Another study found that attitudes toward people with eating disorders are significantly more stigmatising than attitudes toward people with depression (Roehrig & McLean, 2010).

Related to stigma, community knowledge about eating disorders is another area that requires attention. While community understanding of conditions such as depression and anxiety has improved markedly in recent decades thanks to the efforts of organisations such as Beyond Blue, knowledge of eating disorders remains very low. Only one in ten people in Australia can recognise the signs and symptoms of eating disorders (Butterfly Foundation, 2021b).

Stigma and discrimination

Stigma often leads to discrimination, which can be classified as structural form of stigma. In a survey report that we released in 2020, Butterfly found that experiences of discrimination were common, with nearly a third of survey respondents saying they had experienced discrimination in accessing services. When elaborating, one respondent said: 'I was told that my ethnic background doesn't get eating disorders and that I would grow out of it'. Another respondent referred to: 'Being called the wrong name and pronouns consistently. Accessing some of the health care systems made me worse instead of better' (Butterfly Foundation, 2020a).

There is considerable variability in the type of self, public and structural stigma experienced depending on eating disorder diagnosis (Brelet et al., 2021).

Eating disorder diagnoses can be associated with weight stigma, which is a form of stigma defined by negative attitudes and stereotypes attached to larger bodies (Hunger et al., 2020). For example, people with Binge Eating Disorder are likely to experience weight discrimination when seeking treatment (Brelet et al, 2021; McLean et al., 2014).

The evidence outlined above points to the need for greater community awareness activity, targeted education about eating disorders for health professionals, and eating disorder-specific anti-stigma initiatives to reduce structural discrimination. The National Stigma and Discrimination Reduction Strategy provides an opportunity to ensure that the particular forms of stigma attached to eating disorders are adequately considered and reflected in the priority actions, their implementation and their review.

Responses to consultation questions

1. Feasibility: Are the actions achievable in the recommended timeframe and allocated to the correct responsible party/parties? Is there a readiness for change?

The feasibility of implementing the actions within the suggested timeframes will be largely dependent on the amount of funding allocated to the roll-out of the strategy, including the level of human resources at agencies and organisations with overall administration of and accountability for each action. Butterfly recommends that proposed budgets be prepared by the Commission and submitted to the Department of Health and Aged Care and relevant Health portfolio Ministers as part of finalising the Strategy. There is appetite in the mental health sector for a sustained focus on the reduction of stigma and discrimination, however without sufficient resourcing sector goodwill and willingness to participate in co-design and co-delivery will be limited.

In relation to the allocation of responsibility for leading the actions, Butterfly recommends a de-centering of Commonwealth Government and the Commission in the implementation of the Strategy. The Strategy should be co-owned by people with lived experience and non-government organisations (NGOs) who work with and provide services and support to those communities. People with lived experience and NGOs should be tasked with development and implementation of several aspects of the Strategy (such as community campaigns and targeted initiatives for priority populations (e.g. for people with eating disorders, Aboriginal and Torres Strait Islander Communities and multicultural communities), with appropriate funding. Doing so will ensure that initiatives have the greatest chance of succeeding in their objectives. Tendering for specific elements of work by NGOs should prioritise collaboration (both inside and outside of the mental health system) and have an outcomes (as opposed to outputs) focus to ensure value for money and the achievement of multiple intersecting aims and objectives in support of the Strategy’s vision. All funded organisations should be required to specify how they are addressing stigma and discrimination at the organisational level as part of eligibility criteria.

2. Enablers: What might support the actions and/or assist the work needed to implement the change?

As noted above, joint responsibility for carriage of various priority areas with NGOs and lived experience advocates, and adequate funding is required to bring about the desired changes. Of particular importance from an administrative and governance perspective within government agencies is cross-agency communication and coordination, noting that several actions range across areas outside of the mental health system.

Butterfly also suggests the following changes and additions to enable meaningful positive change for people with eating disorders and body image issues, and their families and support people.

Greater knowledge and tracking of eating disorder stigma is needed to adequately respond to the nature and changing patterns eating disorder stigma and related forms of stigma

Butterfly recommends that the Strategy include investment in research on eating disorder stigma, including weight stigma and appearance-based discrimination. This should include include tracking over time to help understand the prevalence and patterns of eating disorder stigma as it manifests within the Australian context. This is required because of the nature and complexity of eating disorder stigma and discrimination.

In conducting population level research on experiences of structural stigma, public stigma and self-stigma, factors related to stigma of various eating disorder diagnoses must be included such as weight stigma, blame-based stigma, and appearance-based discrimination. Current mental health research and generic mental health campaigns do not sufficiently address eating disorders, which are a set of complex mental health conditions with physiological features and distinct manifestations of stigma (Stewart, Keel, & Schiavo, 2006; Roehrig & McLean, 2010). Further research is also needed to understand why stigmatising attitudes on eating disorders by mental health professionals prevail and what factors contribute to stigmatising behaviour. From this research stigma intervention programs should be developed to address stigma and discrimination within the field, as currently there is limited research and evidence base on health professional attitudes towards eating disorders in the Australian context.

Butterfly has collected significant information on attitudes, behaviours, stigma and experiences of discrimination among people with eating disorders and body image issues our community insights research (Butterfly, 2021) and social media campaigns. Butterfly could work with both the the Commission and SANE Australia to develop a component of the National Stigma Report Card that can collect data on public eating disorder stigma. Data insights could be used to conduct research and drive a campaign encouraging members of the community blow the whistle on eating disorder stigma when it is observed in the public domain (similar to SANE Australia's long running Stigma Watch initiative).

Include appearance-based discrimination as a focus area for human rights and anti-discrimination reform

With regard to actions under Priority 1: Implement foundational actions to address stigma and discrimination (1A, 1B and 1C), Butterfly welcomes the focus on human rights and recommends that appearance-related discrimination be considered as part of scoping and review processes. Considering this form of discrimination is critical to the development of a National Stigma and Discrimination Reduction Strategy as weight stigma and discrimination is an issue that is consistency raised with Butterfly by members of the lived experience community. Experiences of weight stigma and discrimination in accessing health care for eating disorders is the most common form raised with us in consultations (more detail on this topic is provided in the sections below). Within Australia currently only two jurisdictions proscribe discrimination on the basis of appearance; in the Australian Capital Territory and Victoria this is referred to in the legislation as "physical features". In Victoria, for example, this form of discrimination refers to: height; weight; size; shape; facial features; hair; and birthmarks . A recent news story underscores the importance of this form of legal protection from unfair treatment in various domains of public life; a man was fired from a job for allegedly being 'too fat' was reportedly exploring whether he can access discrimination law as a means of redress (Schnitzerling & Waterson, 2022). Given the prevalence of eating disorders among people living in larger bodies, appearance-based discrimination is a key concern for Butterfly. We would welcome the opportunity to be involved in this element of the Strategy's Priority 1 actions.

Work alongside medical associations, peak bodies for mental health and eating disorder professionals, and complaints bodies to provide education on eating disorders and body image, and common eating disorder myths and misconceptions

Butterfly recommends that the priority actions address eating disorder, weight stigma and appearance-based discrimination more clearly, given that our surveys and lived experience consultations have revealed these manifestations of stigma within medical bodies, associations and among health professionals assessing and treating eating disorders.

In our stigma research paper (2022a), 68 per cent of respondents said they had experienced structural stigma, and experiences of stigma in health care settings including from GPs and hospital staff when seeking an assessment, support, or treatment for an eating disorder. These forms of stigma appear to be due in large part to low levels of eating disorder mental health literacy among GPs and other health care professionals. Appearance-based judgments, stigmatising diagnostic metrics such as BMI measurements, and stereotypes of eating disorders by health care professionals all contribute to poor experiences of health care. Weight stigma is particularly harmful and reduces an individual's ability to receive an eating disorder assessment, diagnosis, care, and appropriate treatment, as the following lived experience perspectives indicate:

> "I went to a GP and didn't have a BMI considered 'underweight' so she said she couldn't help me and refused to see me again" (Butterfly Foundation, 2022a).
>
> "On one occasion I was told by my GP I couldn't have an eating disorder because I was actually "overweight" and "fat". I really feel like GPs should have some sort of general training on how to support people living with eating disorders" (Butterfly Foundation, 2022a).
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> "I stopped seeing doctors in the middle of my illness, I couldn't bear to go in weekly or fortnightly for necessary medical monitoring because they were just so triggering and dismissive. It consequently made me get sicker to the point of being nearly hospitalized" (Butterfly Foundation, 2022a).

In response to priority actions 1A, 1B, and 1C, discrimination complaints and actions in response to these complaints need to be reviewed. An external review body involving people with a lived experience of eating disorders needs to review state and territory healthcare provider complaints bodies such as the Health Care Complaints Commission, Office of the Health Ombudsman, and complaints made through the Australian Government Department of Health and Aged Care.

Butterfly is aware of instances where people with eating disorders have experienced discrimination and abuse from health care workers and where they have faced further harm when pursuing complaints through the Health Care Complaints Commission. As one of our lived experience community said: "What are my rights when it comes to interacting with GP or reporting malpractice by a GP?".

In response to priority action1f, greater support and guidance is needed to help people who have experienced stigma while seeking support for an eating disorder or body image distress. This action should also include helping carers and supporters of people with lived experience to navigate complaints, particularly the supporters of children and young people who have experienced discrimination, and carers themselves who have experienced discrimination while seeking support. Funded complaints services should be reviewed in the time it takes for complaints to be processed, and current support for people with mental ill-health who make complaints. Lived experience workers, including the peer workforce, should be trained in supporting consumers to navigate the system of care, including making complaints.

In response to priority action 3.1D, Butterfly would like to see educational programs and continuing professional development modules (CPD) provided by medical associations to include anti-stigma interventions addressing common stigmatising beliefs on eating disorders and weight stigma and discrimination among health professionals. Stigma interventions for health professionals need to involve contact-based strategies and lived experience input (Doley et al., 2017). Interventions need to be further tailored toward the specific eating disorder diagnosis, and content should be designed to educate target groups who are statistically more likely to stigmatise eating disorders such as male professionals (Brelet et al., 2021).

> “Ongoing awareness and training for clinicians, educators, staff, and management that encourages support and focuses on ending stigma” (Butterfly Foundation, 2022a).

In response to priorities under 2.1 and in response to 3.1b contact-based training and education of mental health professionals, including psychiatrists and psychologists needs to focus on eating disorders and their many presentations. Education about eating disorders is lightly covered in university and other education settings and does not adequately prepare mental health clinicians, nurses, and other mental health professionals.

In Butterfly’s research on eating disorder stigma, people with lived experience reported psychologists having stereotypical views of eating disorders or refusing to provide support to a person on the basis that they were not sufficiently trained on eating disorders.

> “When I was searching for a psychologist, I talked on the phone with a few to see if they were a good fit. Unfortunately a few of them had ‘never heard’ of my diagnosed eating disorder, which made me feel uncomfortable proceeding with treatment ….” (Butterfly Collective, 2022a).

In response to 2.2b, 2.2c, these action priorities also need to ensure that there are minimum standards/clinical guidelines are in place for the care of co-occurring eating disorders, disordered eating, and body image concerns among people with lived experience within general practice, emergency departments, and inpatient units. This includes education for GPs on creating an effective eating disorder plan for people seeking help for an eating disorder.

> “I wish we could advocate for all psychiatric units and all psychiatrists to treat eating disorders. It is a psychiatric illness, after all, and the deadliest one at that. So, I would say, advocate for equality of service, rights of patients. No one should not be turned away from any mental health service or psychiatric facility” (Butterfly Foundation, 2022a).

In response to priority action 2.1a, harmful use of discriminative and abusive language towards a mental health consumer by professional staff also needs to be included. This should involve having policies within health systems, co-designed by people with lived experience, that eliminate all unsafe, harmful, discriminative, and abusive language towards a person seeking support and help. Policies should also involve inclusive and culturally safe language. Training needs to be provided to professionals in health care settings as part of a strategy to reduce stereotyping and stigma. In Butterfly’s recent stigma research paper (2022) many people with lived experience mentioned negative and harmful communication from a GP, nurse, or emergency worker. Stigmatising language was particularly used against people experiencing an eating disorder in the system of care who were culturally and linguistically diverse, neurodiverse, or living in larger bodies.

> "I was denied proper care based on being autistic. A nurse once said, referring to me, 'Why do we even help people like this?'... A nurse told me that '"this is a place where we treat eating disorders, not autism. Just discharge yourself if you don't want to engage in the program like everyone else'" (Butterfly Foundation, 2022a).

In other research, health care workers and nurses expressed that they viewed patients with anorexia nervosa to be manipulative, disrespectful and non-compliant with treatment. This affected health care workers' ability to treat eating disorders as they related to patients with discomfort, anger, and fear (Anderson, Accursi, Kinasz, & Le Grange, 2016). People with Binge Eating Disorder are more likely to experience weight discrimination when seeking treatment (Brelet et al, 2021). Policies that uphold human rights, respect and agency of people receiving treatment for an eating disorder are therefore needed to reduce eating disorder stigma among health professionals.

In relation to priority actions 2.1i, 2.1j, and 2.2i, people with a lived experience of an eating disorder mentioned experiencing stigma due to not meeting current diagnostic criteria for an eating disorder diagnosis.

> "Unable to access an eating disorder care plan because I had been in recovery for a while and it was not considered 'severe enough' [EDE-Q score not high enough to meet requirements]". (2022a).

With the interconnection between mental health diagnoses and eating disorder diagnoses, stigmatising attitudes of eating disorders within health professional needs to be adequately addressed if stigma related to mental ill-health is to be addressed.

Provide training and education to managers, human resources, and employee assistance programs on eating disorders and weight stigma and discrimination

People experiencing an eating disorder should be supported and protected from discrimination within their place of work and when returning to work. While priority actions 2.3j, 2.3k, and section 2.6 aims to increase employment opportunities and provide flexible employment for people with lived experience more generally, people with an eating disorder are at higher risk of stigma and discrimination based on their disorder, or perceived understandings of their disorder. In the recent National Survey of Mental Health-Related Stigma and Discrimination (2022), 25 per cent of respondents selected that they were unwillingly to work closely with someone who has an eating disorder.

In Butterfly's recent stigma research (2022a), one person with lived experience communicated that they had been treated as an insurance liability:

> "Losing my job being considered an insurance liability in the school I taught in many years ago. I wasn't a person, I was an illness and liability. I had to fight to receive my pay, my job, and my dignity" (2022a).

People with a living and lived experience of an eating disorder should also be able to freely disclose their lived experience and seek support within the workplace without fear of discrimination, bullying, or risk of dismissal from employment. Butterfly would welcome the opportunity to collaboration with the Commission and the Mentally Healthy Workplace Alliance to advocate for policies that support people experiencing an eating disorder to request reasonable adjustments to their work and access support to safely return to work.

> "The policies in my workplace that support mental health and eating disorders are minimal and when returning to work from periods of illness, my life is made really hard. Stigma around the illness particularly affects me as an HPE teacher as the many stereotypes of the illness are out on me" (Butterfly Foundation, 2022a)

In response to priority actions 2.6b, 2,6d, 2.6e, education in relation to lived experience of body image concerns and eating disorders should be included. This should include education for managers, human resources, and staff on avoiding language around weight and size, body shapes, and discussion of food and diet culture. Education should also cover common misconceptions and stigmatising beliefs regarding eating disorders, which could be offered through online digital modules. Butterfly would welcome the opportunity to extend our prevention offerings to workplaces or to collaborate with organisations that provide workplace trainings to large organisations, such as the Black Dog Institute, to ensure that content on eating disorder mental health literacy is included.

It is also critical that counsellors employed within Employee Assistance Programs (EAPs) be trained to understand eating disorders and body image concerns, as many counsellors working within EAP programs have not received education on eating disorders.

Address eating disorder and weight stigma in relation to children and young people within education systems through education of teachers, other school staff and tertiary workforces

In relation to priority actions 2.7a, 2.7b, 2.7d, 2.7e, and 3.1b education on eating disorders and body image – with an anti-stigma focus – should be included within school and educational settings through mental health and eating disorder literacy programs for teachers and students. Stigma reduction through prevention work can help to reduce rates of eating disorders and stigmatising attitudes towards eating disorders. Due to the nature of eating disorders and body image concerns, general mental health educational programs may not effectively reduce stigma and discrimination toward eating disorders. It has been brought to Butterfly's attention that in some school systems, harmful activities and conversations are taking place in the classroom which are placing emphasis on children's weight.

Programs in education settings should focus on health, not weight, to reduce weight discrimination and the influence of diet culture within school settings. Appearance-related teasing or bullying (Menzel et al., 2010; Valois et al., 2019; Webb & Zimmer-Gembeck, 2014) and weight stigma, can lead to discrimination of people in larger bodies and body dissatisfaction among young people. 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).

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.

The following perspective is from a person with lived experience:

> "I believe some kind of early intervention in primary schools, an educational program about how to foster a positive body image, how to navigate the mind field of social media, how to respond to negative comments people make about their/your body. I think that focusing on what your body can do for you, not what it looks like, and your personal strengths that are not related to physicality can be so beneficial. I also think that educating parents about the impact their words and actions have on their children could be powerful too. Most parents have the purest of intentions but comments about their child's diet and weight and shape can be so detrimental in later life" (2022a).

Furthermore, alternative sources of information to educate and empower children, and young people, their families, and carers outside of a school setting, need to be made available. This includes campaigns and programs that can influence the modifiable risk and protective factors involved in the development of body dissatisfaction, disordered eating and eating disorders. Programs such as Butterfly's Body Bright, a whole of school program to support primary school children's developing body image, supports healthy eating and physical activity attitudes and behaviours, helping to reduce stigma through increasing body image resilience in young people, and in educating teachers and staff about their role in supporting young people to develop positive body image. The Body Bright program addresses:

1) School culture guidelines to build a positive body image community.
2) Online staff training that educates staff about body image in children and how to effectively implement the program in their school.
3) Age-appropriate lesson plans for Foundation to Year 6 students that align with the Health and Physical Education curriculum.
4) Information and resources for families.

In response to priority action 2.7f embedding concepts of body image resilience and body image confidence could be included in the school educational curriculum, including helping young people to understand and respond to weight stigma.

In response to priority action 2.7g eating disorder literacy and training needs to be included for educators, school teachers, and university lecturers who are teaching students studying psychology, social work, counselling, health promotion, education and medicine.

> "This is not just by GPs, psychologists, and inpatient care units but in educational institutions where 2 lecturers at a university said they wouldn't manage an ED as people with eating disorders were too hard to deal with" (Butterfly Foundation, 2022a).

Embedding stigma resistance into anti-stigma digital offerings to reduce self-stigma of eating disorders and mental ill-health

Butterfly welcomes the focus on developing stigma resistance within priority 4 of the Strategy. Within priority 4 of the NMHC strategy, reducing self-stigma of eating disorders and anticipated weight stigma should be addressed alongside that of mental health-related self-stigma.

Individuals experiencing certain disorders can experience weight discrimination related to self-stigma and anticipated weight stigma (Hunger et al., 2020). Anticipated weight stigma – the fear and anticipation of experiencing discrimination in the future – can become psychologically rooted and create negative mental and physical health outcomes. Self-stigma may also become a barrier to help-seeking where a person holds internal stereotypical beliefs about what an eating disorder should look like (Griffiths et al., 2018).

We recommend that to address self-stigma, stigma resistance approaches that support individuals to deflect or challenge stigmatising beliefs that can worsen symptoms and impair recovery and life outcomes, be embedded in braoder anti-stigma interventions. 'Stigma resistance' is an important concept discussed in mental health literature as a way of reducing self-stigma, and has been explored in relation to eating disorders by Griffiths et al (2015). Stigma resistance refers to the capacity to resist, counteract or otherwise remain unaffected by mental illness stigmatisation (Ritsher et al., 2003). Studies have identified that it can play a beneficial role in fighting against the internalisation process and facilitating recovery. Improving self-esteem and learning coping mechanisms to deal with public and structural eating stigma could be features of a trial intervention.

Greater research is needed to understand self-stigma when it comes to eating disorders and anticipated weight stigma, and research is needed to understand whether stigma resistance is an effective intervention. This could be done as part of a research partnership with a university research group, with effects measured using the Stigma Resistance subscale of the Internalized Stigma of Mental Illness Scale and other measures. Informed by such research, self-stigma resources such as website materials and tools to identify self-stigma and use stigma resistance tactics, including self-compassion, could be developed.

3. Barriers: What might slow down or prevent the gaining of support for the actions, or their implementation?

Conflicting objectives between the Strategy and other government policies, for example in the areas of employment, social security and housing, may function to dilute the impact of the priority actions. Of particular concern to Butterfly is the area of public health and population health campaigns in the area of anti-obesity and physical movement policy (we discuss this area in detail in section 5).

Two other potential barriers are discussed below.

Lack of consensus regarding the value of Peer Workers and lived experience workers

In response to action points 1g, 1h, and 1i, Butterfly would like to see increasing consensus on the value of peer workers within mental health and eating disorder organisations and services.

Developing guidelines for lived experience workforce roles and scaling up the lived experience workforce through the national capacity building will be incredibly important in reducing stigma and discrimination. Due to the unique nature and manifestations of eating disorder stigma, the lived experience workforce must include the voices of people with a lived experience of eating disorders. Clear structure, expectations, support, training, and sustainable funding must be applied to lived experience roles. Negative attitudes or biases towards lived experience workers in organisations must be reduced through education to leverage higher level positions and governance roles for people with lived experience. People with lived experience and lived experience organisations should also work in partnership with health care commissioners, medical associations and accreditors, and public health organisations, such as the Public Health Association of Australia, to reduce stigma and discrimination of mental ill-health in systems of care and health promotion.

Peer workers not only can support people with eating disorders in treatment and supporting their long-term recovery, but can advocate on behalf of people with lived experience to ensure that they receive a high quality of care and do not face stigma or discrimination while going through treatment. Peer workers are people who draw on their lived experience and knowledge of recovery from an eating disorder to help others achieve improved recovery outcomes. Peer work provides a non-clinical collaborative approach as an adjunct to treatment. Connecting with others who have had similar life experiences can improve understanding and increase hope (Basset et al., 2010) with a consequent improvement in engagement in treatment and a reduction in the severity of relapse (Lawn, Smith & Hunter, 2008; Sledge et al., 2011).

Furthermore, development, implementation and evaluation of a training program to professionalize the eating disorder peer workforce, ensuring safe and effective non-clinical support for people affected by eating disorders, disordered eating, and body image issues, is needed. For this to be feasible strategies to address self, public, and structural stigma of lived experience and peer workers in the eating disorder workforce and mental health workforce need to be addressed to ensure that peer workers can be supported and protected in their roles.

Harmful and stigmatising representations of eating disorders, body image and physical appearance within the media, including social media, need to be addressed in the Strategy

Butterfly would like to see more strategies under priority 3.2 that address stigma and discrimination of eating disorders, including weight stigma and appearance-based bullying, on social media platforms. The portrayal of eating disorders within mainstream media and particularly through social media channels such as Facebook, Instagram and TikTok can exacerbate misconceptions and stigmatising attitudes towards people with eating disorders and body image concerns.

In the absence of interventions that support the development of positive body image, many children and young people access social media for information and guidance. However online environments are filled with diet culture messaging, weight stigmatising views, and associated discrimination, including weight stigma. In recent years social media influencers and celebrities have become an omnipresent force on social media and therefore in the lives of children and young people. There is evidence that there is a stronger association between social media usage and eating disorder risk for social media and internet exposure when compared to traditional media exposure (e.g., magazines and television) (Tiggemann & Miller, 2010).

Social media use is a risk factor for body dissatisfaction, disordered eating and eating disorders in children and young people.

> "In early adulthood I am a lot more influenced by those I follow on social media. Seeing the perspective of achievement and happiness through largely thin privileged individuals that the algorithm favours lead me to belief that thinness was the reason [for developing poor body image]. Viewing that lifestyle compounds the narrative given by family and friends around body image being the catalyst" (Rachel, WA).

To address this, we are developing an innovative multi-lesson, e-learning body image program called 'Body Kind Online Education'. With funding from the e-Safety Commissioner, this project aims to strengthen social media literacy in relation to body image, support body image resilience online, and promote help-seeking behaviours among children aged 12-16. We are also developing evidence-based universal resources for parents and educators, in support of a whole of school community prevention approach to body image safety in online environments. Subject to the program's evaluation results, this program could be funded in an ongoing capacity. There may also be scope to strengthen regulation of social media platforms through e-Safety legislation, for example, through defining and proscribing body image harm.

Social media advocacy-based campaigns created by Butterfly such as "An ED Looks like me" have helped to raise awareness of common misconceptions regarding what an eating disorder looks like. Further campaigns need to be developed to educate the public on eating disorders and reduce stigmatising attitudes. Research also suggests that media regulation could be a powerful way of reducing blame-based stigma surrounding eating disorders and educating the public on the aetiology of eating disorders (Baffsky, 2020). Butterfly has also advocated for the investigation into weight and eating disorder stigma in the media through a national body inquiry into body image (Butterfly Foundation, 2021b).

> "Comments that have been made to me have included that anorexia is about wanting to look like someone in a magazine. [That] it's about vanity [or that] I'm choosing not to eat on purpose [or that] I would be fine if only I would just eat". (Butterfly Foundation, 2022a).

5. Anything missing: Are there any critical issues or actions to address stigma and discrimination that are not referenced or sufficiently prioritised in the Draft Strategy?

As noted in section 1 above, we recommend the addition of appearance-based discrimination to the areas for scoping and review as part of the human rights and anti-discrimination foundation for the Strategy. This is because of the physical elements of eating disorders and body image concerns and the interaction between weight stigma and other forms of eating disorder stigma.

We also suggest the following additions for consideration to ensure that eating disorder stigma is adequately addressed by the Strategy.

Generic campaigns and strategies that address the stigma of mental ill-health cannot sufficiently address eating disorder stigma and weight discrimination

If the priority actions are to be feasible, then eating disorder stigma and weight stigma (and discrimination) must be addressed alongside stigma of mental ill-health. While stigmatising attitudes toward eating disorders are sprinkled throughout the draft Strategy, the priority actions are more targeted toward addressing stigma and discrimination of mental ill-health more generally and may not sufficiently address eating disorder stigma in the given timeframes.

Butterfly recommends the inclusion of priority actions (or sub-sets of priority actions) that specifically address the factors of eating disorder stigma, weight stigma, and appearance based discrimination, which intersect with mental ill-health stigma for the communities we serve.

Generic mental health campaigns do not sufficiently address eating disorders, which are a set of complex mental health conditions with physiological features and distinct manifestations of stigma (Stewart, Keel, & Schiavo, 2006; Roehrig & McLean, 2010). As shown in the National Survey of Mental Health-Related Stigma and Discrimination (2022), eating disorder myths, misconceptions and stigma manifest in ways which differ from other types of views about mental health.

In the recent National Survey of Mental Health-Related Stigma and Discrimination (BETA, 2022) 16 per cent of survey respondents believed that people with an eating disorder could snap out of it if they wanted, and 12 per cent of respondents believe that the problem is a sign of personal weakness. Survey participants were more likely to agree with the statement 'It is their own fault that people with this problem are in this condition' in relation to eating disorders than any other mental health condition. Another study found that attitudes toward people with eating disorders are significantly more stigmatising than attitudes toward people with depression (Roehrig & McLean, 2010). Recently published research conducted by Butterfly with a large, representative community sample (n = 3,030 people) shows that one in four people in Australia believe that if people with eating disorders 'were stronger people, they wouldn't be doing this to themselves', while three in five people believe that 'most people think that bingeing/purging is disgusting' (Butterfly Foundation, 2021b).

Existing research on eating disorder stigma in community samples – largely from the USA – shows that eating disorder stigma differs from other types of mental health stigma. Studies have also shown that eating disorders commonly induce less empathy in comparison to other physical and mental health disorders. This may be due to the fact that certain eating disorders, such as Anorexia Nervosa, are viewed as a lifestyle choice (Baffsky, 2020). Attribution theory contends that people are more likely to hold blame-based stigma if a condition is believed to stem from sociocultural factors rather than biological factors (Angermyer et al., 2011). For example, in one study people with anorexia nervosa were viewed as 'most to blame for his/her condition', were best able to 'pull him/herself together if he/she wanted to', and were 'acting this way for attention' compared to people with other conditions (Stewart, Keel, & Schiavo, 2006). People in larger bodies can experience greater discrimination and assumptions regarding their eating disorder diagnosis.

> "Not believing my diagnosis due to my body size. Making assumptions I have Binge Eating disorder rather that Anorexia" (Butterfly Foundation, 2022).

A lack of public education and understanding of eating disorders, beliefs regarding the appearance of eating disorders, and negative judgment all make a person with a lived experience of an eating disorder susceptible to greater stigma and discrimination.

As noted earlier, there has been limited investment in stigma reduction initiatives that focus on eating disorder stigma. While stigmatising attitudes toward mental illnesses such as anxiety and depression have lessened as they have become better understood by the community, the variability, intensity, and incidence of stigma surrounding eating disorder diagnoses remains much less understood. Stigma reduction initiatives that are eating disorder specific are needed as not all stigma reduction strategies for mental ill-health will be applicable to eating disorders and weight discrimination.

Furthermore, eating disorder stigma is complex and nuanced stigmatising attitudes can vary based on a person's eating disorder diagnosis and the perception of that diagnosis (Brelet et al., 2021). For example in one research study, people diagnosed with Binge Eating Disorder experienced greater prejudice and weight discrimination and were characterised as weak, lazy, and lacking social support over individuals diagnosed with Anorexia Nervosa (McLean et al., 2014).

With a high comorbidity between eating disorders and other mental ill-health-related diagnoses, eating disorder stigma will need to be sufficiently addressed through tailored interventions in order to reduce stigma more generally of mental ill-health. Butterfly Foundation is in the position to create a public health-style campaign that will be informed by health behaviour theory, drawing on the existing evidence base in consultation with experts and sector collaborators. A co-design approach will be taken inclusive of people with lived experience of various forms of eating disorder misinformation, stigma and discrimination, building on the findings of Butterfly's Eating Disorder Stigma Research Paper (2022a).

Health promotion campaigns and preventative health policy must align with eating disorder prevention policy to prevent weight discrimination and eating disorder stigma

One area that is not addressed in the Strategy is the need to regulate public health promotion activity and health policy, to ensure that concepts and language used, particularly in anti-obesity and physical activity initiatives, are not exacerbating eating disorder stigma.

Butterfly recognises the need for preventative health policy, including investment in promoting good nutrition and physical activity to reduce the incidence of diabetes, heart disease and stroke. However, concepts and language that are frequently employed in anti-obesity initiatives can be detrimental to those experiencing – or at risk of developing – eating and body image concerns. We frequently observe public health promotion activity conceptualised according to the 'weight-centered health paradigm' (O'Hara & Taylor, 2018), 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'; applies dichotomous thinking to food (framing food as 'healthy/unhealthy' or moral terminology such as 'good/bad') and features an over-reliance on population health measures such as Body Mass Index. Nutrition education and messaging in schools is a particular area of concern given an Australian study that 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).

We recommend that resourcing under the Strategy be dedicated to investigation of eating disorder stigma within the public health field, including research and work with public health organisations and professional bodies to support best practice in physical health promotion. Butterfly is well-placed to develop a multi-year behavioural change campaign and targeted education and skills development to support non-stigmatising 'health not weight' approaches to physical health policies, practices and promotion.

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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