

Eating disorders and stigma

Research paper

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Executive summary

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.

There is considerable variability in the type of self, public and structural stigma experienced depending on eating disorder diagnosis. Studies have also shown that eating disorders commonly induce less empathy in comparison to other physical and mental health disorders.

Structural forms of eating disorder stigma – laws, policies, and practices which result in the unfair treatment – have been reported in multiple studies. In one study, health care workers said that they viewed patients with Anorexia Nervosa to be manipulative, disrespectful and non-compliant with treatment. This affected their ability to treat eating disorders as they related to patients with discomfort, anger and fear. 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. People with Binge Eating Disorder are likely to experience weight discrimination when seeking treatment.

Butterfly surveyed 25 people with lived experience of eating disorders to explore the impact of self-stigma, public stigma and structural stigma. 92 per cent of survey respondents had experienced self-stigma, with 80 per cent of saying that self-stigma affected their ability to seek help and access treatment.

76 per cent of survey respondents said that they had experienced public stigma in relation to their eating disorder diagnosis and/or body image concerns. Examples which were cited included unsupportive comments about their disorders being about vanity or a choice to simply not eat.

68 per cent of survey respondents said that they had experienced structural stigma in relation to an eating disorder. Experiences of stigma in health care settings from GPs and hospital staff were the most frequently shared examples of structural stigma. One respondent shared how they were denied care and another respondent experienced job loss due to employer concern about them being an 'insurance liability'.

Survey respondents were given an opportunity to provide their ideas on ways to reduce different types of stigma. Several suggestions were shared which largely aligned with the classification used in the research literature to describe anti-stigma strategies, with protest, education and contact approaches suggested as the best ways to tackle eating disorder stigma.

People with lived experience were knowledgeable about stigma and shared many examples of the ways that they manage their experiences of self-stigma, including mindfulness, reframing of self-stigmatising thoughts, increasing self-compassion, sharing their story with others and participating in support groups.

Understanding the different types of stigma experienced by people with eating disorders is central to the development of effective communication campaigns, service responses and public policy. Butterfly will draw on the existing evidence base and lived experience voices to advocate for greater investment in eating disorder stigma reduction.

Background

A goal of Butterfly Foundation's Strategic Plan 2021-2024 is to reduce stigma and increase help-seeking.

Stigma can significantly negatively affect a person's ability to access support and treatment, which can in turn further exacerbate eating disorder symptoms. Understanding the different types of stigma experienced by people with eating disorders is central to the development of effective stigma reduction campaigns, service responses and public policy.

To inform Butterfly's future anti-stigma work and the work of the broader mental health sector, this research paper provides a short summary of the literature on eating disorder stigma and a thematic grouping of responses to a survey distributed to Butterfly's online lived experience reference group, the Butterfly Collective, in May 2022.

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 research paper.

What is stigma?

Defining stigma in the field of mental health is a challenging task as it can involve the intersection of various belief structures, attitudes and behaviours. Stigma can be defined broadly as an experience of discrimination, exclusion, and social isolation of a person due to a particular characteristic or attribute (Crisp, 2005). Stigma can also be defined in the context of systemic mechanisms of discrimination. There is variability in the type, prevalence, and intensity of stigma experienced depending on a person's diagnosis (Griffiths et al., 2018).

Sheehan, Nieweglowski, and Corrigan (2016) defined three main forms of stigma including self-stigma, public stigma, and structural stigma. **Self-stigma** refers to the negative attitudes and beliefs, including internalised shame, that people with mental health conditions have about themselves. **Public stigma** (sometimes called societal stigma) involves stereotyping, discrimination, and negative attitudes toward those who are experiencing a mental ill-health diagnosis. **Structural stigma** (sometimes called systemic stigma) refers to stigma that is entrenched in government policies, institutions and practices that discriminate against people who are experiencing mental ill-health (Sheehan et al., 2016).

As an experience, stigma comprises of three components including cognitive, emotional, and behavioural aspects (Griffiths et al., 2015). Cognitive aspects include stereotypes which can lead to emotive feelings of prejudice towards a certain group of individuals, leading to discriminating behaviours.

Defining the problem

Despite increasing education and awareness, public stigma and misconceptions around eating disorders still prevail. Butterfly's Community Insights Research (2021a) found that a quarter of Australians believe that eating disorders are a choice and that one in four Australians believe that if people diagnosed with eating disorders were stronger, they would not be ill. In addition, 57 per cent of people in Australia incorrectly believe that it is young women who are predominately affected by eating disorders (Butterfly Foundation, 2021a).

Increased exposure to stigmatising attitudes predicts negative psychological, social, and physical outcomes for people with eating disorders as it increases social isolation, reduces help-seeking behaviours, and further exacerbates symptoms of eating disorders (Brelet et al., 2021). Due to negative stereotypes of eating

disorders, 75 per cent of Australians living with an eating disorder do not seek professional help (Butterfly Foundation, 2021a).

Experiences with public stigma are strongly tied to experiences with self-stigma and shame, which create barriers to accessing treatment. Furthermore, there is variability in the type and intensity of self, public and structural stigma experienced depending on the eating disorder diagnosis (McLean et al., 2014). Eating disorder diagnoses can be associated with weight stigma (Hunger et al., 2020), a form of stigma which is defined by negative attitudes and stereotypes surrounding and attached to larger bodies. In addition, as explored in Section 1 below, eating disorders commonly induce less empathy in comparison to other physical and mental health disorders. While stigmatising attitudes toward mental illnesses such as anxiety and depression have lessened as they have become better understood by the community, the variability and incidence of stigma attached to eating disorder diagnoses remains much less understood.

The following section draws on the research literature to explore the impact that self-stigma, public stigma and structural stigma have on individuals experiencing eating disorder diagnoses.

Section 1: Research literature on eating disorder stigma

Self-stigma

Self-stigma refers to the negative attitudes and beliefs, including internalised shame, that people with mental health conditions have about themselves. Self-stigma can also be defined as the process by which an external experience of stigmatisation becomes part of a person's internal representation.

Self-stigma is a predictor of having an undiagnosed eating disorder and delayed treatment (Maier et al., 2014).

In a self-reported questionnaire, Griffiths et al (2015) found that stigma internalisation was associated with social withdrawal and feelings of social exclusion. The social withdrawal of an individual experiencing an eating disorder was associated with a reduction in social capital and an increase in using maladaptive coping techniques, therefore, intensifying eating disorder symptoms (Griffiths et al., 2015). Self-stigma and social exclusion were related but directionality could not be predicted.

Certain individuals and groups are more at risk of experiencing self-stigma. Being male and reporting greater self-stigma in relation to seeking psychological help is associated with an increased likelihood of being undiagnosed (Griffiths et al., 2015). 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 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).

Public stigma

Public stigma refers to negative attitudes and beliefs that motivate people (or are perceived to motivate people) to fear, reject, avoid, or discriminate against people with mental health conditions. Public eating disorder stigma stems from stereotyping and misconceptions about the nature of eating disorders.

Analysis of eating disorder stereotyping has determined five main themes including the notion of responsibility, character traits, gender attribution, and disease control (Baffsky, 2020). Public perceptions that eating disorder diagnoses stem from sociocultural factors can create beliefs that those with eating disorder have greater responsibility and control over their condition. Public attitudes are often more stigmatising toward some eating disorder diagnoses such as Anorexia Nervosa (AN), over other eating disorder diagnoses due to assumptions made about the character traits of people diagnosed with the condition. Factors such as gender and socioeconomic status can also determine how stigma is experienced, and who is likely to hold stigmatising attitudes.

Public stigma of eating disorders relative to other health conditions

Societal attitudes toward people with eating disorders are significantly more stigmatising than attitudes toward people with depression. People with eating disorders are considered more fragile, more responsible for their disorder, and more likely to use their disorder to gain attention than people with depression (Roehrig & McLean, 2009). A study comparing perceptions of people with AN with perceptions about three other individuals – a healthy person, a person with asthma, a person with schizophrenia – found that evaluations of personal characteristics were most negative for people with AN (Stewart, Keel, & Schiavo, 2006). However, stigmatising beliefs surrounding eating disorders are less prevalent than other mental health conditions such as schizophrenia, alcoholism, and drug addiction (Brelet et al., 2021).

Public stigma based on eating disorder diagnosis

A systemic review of 570 articles found that stigmatising attitudes can vary based on a person's eating disorder diagnosis and the perception of that diagnosis (Brelet et al., 2021). The review found that individuals with Bulimia Nervosa (BN), Binge Eating Disorder (BED), and AN were perceived to lack self-discipline. Participants in one study blamed people experiencing AN for their condition, believing that it was attention-seeking, and superficial and that greater resilience was needed to overcome the condition (Stewart, Keel, & Schiavo, 2006). Participants felt irritated and socially distanced themselves from people experiencing AN however they also praised people with AN, finding it to be admirable and aspirational (Brelet et al., 2021).

Male and female undergraduate students ($n = 361$) read one of four vignettes describing a fictional male or female character with AN or muscle dysmorphia, after which they responded to a series of questions addressing potentially stigmatising attitudes and beliefs toward each character. Characters with AN were more stigmatised than characters with muscle dysmorphia, and female characters were more stigmatised than male characters (Griffiths, Mond, Murray, & Touyz, 2013).

In another study, people with BED experienced greater prejudice and weight discrimination than individuals with AN or BN, and were characterised as weak, lazy, and lacking social support. People experiencing BN were viewed as engaging in destructive behaviours and their diagnosis was frequently attributed to external social determinants including sexual abuse, lack of parental support, and the influence of media (McLean et al., 2014). When exposed to fictional scenarios, a group of 235 undergraduates viewed characters with BN more responsible for their eating disorder and more self-destructive than those with AN, who were viewed as more self-controlled (Wingfield, Kelly, Serdar, Shivy, & Mazzeo, 2011).

Who is most likely to perpetuate eating disorder stigma?

Certain groups in society are more likely to have stigmatising attitudes in relation to eating disorders than others. Some studies have found that men exhibit greater prejudice toward people experiencing an eating disorder as they hold beliefs that eating disorders are attention-seeking and show a lack of willpower (Baffsky, 2020). Austen and Griffiths (2018) argue that this may be due to men's conformity to masculine norms, specifically the norms of self-reliance and heterosexual self-presentation.

Other groups identified as more likely to stigmatise people with eating disorders are people of lower socioeconomic status, young people, people with a low level of education, and people with low literacy in relation to eating disorders (Brelet et al., 2021).

Another study using vignettes found that certain participants had greater understanding, sympathy and less stigmatising attitudes towards people with eating disorders if they had a lived experience, knew a loved one with the condition, were from a higher socioeconomic background, were a psychology student, were Caucasian or were underweight (Brelet et al., 2021).

The relationship between casual factors and blame-based eating disorder stigma

Perry, Weiner, and Magnusson's attribution theory contends that people are more likely to hold blame-based mental health stigma if a condition is believed to stem from sociocultural factors rather than biological factors (Angermeyer et al., 2011). When viewed through the lens of a lifestyle choice, study participants perceived those experiencing an eating disorder as less competent (Baffsky, 2020). By contrast, there is a decrease in stigmatising attitudes when individuals attribute the cause of the disorder to medical, biological, and genetic factors (as opposed to sociocultural factors). In a scenario study, university students believed that characters with a sociocultural etiology as most likely to recover. Characters with a biological etiology were viewed as more likeable than characters with an ambiguous etiology (Wingfield, Kelly, Serdar, Shivy, & Mazzeo, 2011).

Structural stigma

Structural stigma refers to laws, policies, and practices which result in the unfair treatment of people with mental health conditions. This form of eating disorder stigma can occur in a range of areas of public life, including workplaces and health care settings. For example, in a study using scenarios, people experiencing AN were less likely to receive an offer of employment (Stewart et al., 2006).

Eating disorders within health care institutions

Prejudice and discrimination by health professionals and medical communities toward people with eating disorders have been reported in multiple studies. In one study, clinicians were found to be more likely to express negative ideology toward a patient with an eating disorder when they were male and when they lacked professional expertise in treating eating disorders (Anderson, Accursi, Kinasz, & Le Grange, 2016). Health care workers and nurses expressed that they viewed patients with AN 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 BED are likely to experience weight discrimination when seeking treatment (Brelet et al, 2021).

Media stereotyping of eating disorders

Stigmatising attitudes can be reinforced by stereotypes within the media which portray eating disorders through images of young, slender, white women. Individuals outside of this norm, including men, people from multicultural communities, people in larger bodies, and older people may have their experiences devalued and could face greater discrimination when seeking help as a result (Baffsky, 2020).

Eating disorders are under-recognised in African American and Hispanic women. In one study using character scenarios, while participants' responses indicated that they saw eating disorder symptoms regardless of ethnicity, they were most likely to identify the symptoms as eating disorders when the character was white (Gordon, Perez, & Joiner, 2002).

The impact of stigma on seeking and receiving support for an eating disorder

A systematic review on the perceived barriers towards help-seeking for people with eating disorders found that stigma and shame were most frequently identified as a barrier for accessing treatment (Ali, Farrer, Fassnacht, Gulliver, Bauer, & Griffiths, 2017).

In addition to stigma and shame, the most prominent perceived barriers to help-seeking are denial of and failure to perceive the severity of the illness, practical barriers (e.g., 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. Facilitators of help-seeking were reported in six studies, with the most prominent themes identified as the presence of other mental health problems or emotional distress, and concerns about health (Ali, Farrer, Fassnacht, Gulliver, Bauer, & Griffiths, 2017).

Baffsky (2020) identified that the stereotypes portrayed in media may be an indirect barrier to help-seeking for eating disorders.

Limitations of the research

When reviewing psychological databases, heterogeneity in methodological approaches make it hard to compare the available data. Furthermore, qualitative data including case studies are more common than quantitative research, limiting statistical comparisons.

Eating disorder diagnoses and experiences of stigma were frequently self-reported by participants through questionnaires and surveys. Research findings were often associated rather than directional creating challenges in understanding the direct causal factors of eating disorder stigma. A lack of diversity in samples

may bias the results and confounding variables were often not accounted for. Existing research is largely confined to explorations of stigma in relation to AN, BN, and BED. Further research is needed to understand the stigma experienced by individuals diagnosed with Other Specified Feeding and Eating Disorders (OSFED), Avoidant Restrictive Food Intake Disorder (ARFID) and dual diagnoses.

Section 2: The lived experience of stigma

Butterfly sought the views of people with lived experience on the issue of stigma through a questionnaire which was distributed to the Butterfly Collective – an online community reference group hosted on the Butterfly website. Collective members were asked to complete a short survey which aimed to uncover how the various forms of stigma are experienced in relation to eating disorders and body image concerns (see survey questions at Appendix 1). Participation in the survey was voluntary, members did not have to answer all questions and had the option of answering the survey anonymously. 25 members completed the survey. The majority of participants, 60 per cent, were aged between 16 to 34 years, and were predominately living in New South Wales (48 per cent) and Victoria (20 per cent). 22 respondents used the pronouns she/her, 1 used he/him, and 2 members identified themselves using they/them pronouns.

Lived experiences of eating disorder self-stigma

92 per cent of survey respondents had experienced self-stigma in relation to their eating disorder and/or body image concerns. 80 per cent of members expressed that self-stigma affected their ability to seek help and receive treatment for an eating disorder and/or body image concerns while 16 per cent felt that self-stigma did not affect their ability to seek help, as they had found strategies to combat self-stigma.

Lived experiences of eating disorder public stigma

76 per cent of survey respondents said that they had experienced public stigma in relation to their eating disorder diagnosis and body image concerns while 16 per cent said they were not sure if they had experienced this form of stigma. This result may be because public stigma is an unfamiliar concept to some people and/or the ways in which public stigma (sometimes known as societal stigma) and structural stigma can be confused. Some examples of public stigma that were shared also overlapped with experiences of structural stigma.

Survey participants shared experiences of public stigma in a range of contexts, with some members highlighting stigma experienced from those closest to them.

“When my eating disorder first developed, my parents were unsure of how to approach helping me. They treated me as if my eating disorder was a choice, unaware of how harmful this was to my mental health. This attitude prevented me from being able to validate my own experience, as it was new for me as well . . .” (June, NSW)

“My friends’ reactions were of concern but also came from a place that believed that I ultimately had control over the situation. I think anyone who has had an eating disorder knows that you don’t feel control of it and that it’s not a simple recovery process.” (Elizabeth, NSW)

Other respondents discussed their experiences being invalidated by colleagues when trying to access support or embed their lived experience in their professional lives.

“I disclosed to my Team Leader at work that I am recovering from an eating disorder and the response was not supportive and just focussed on my ability to continue to work.” (Elise, NSW)

“In my job I work as a Health and Physical Education Teacher, but also take pride in participating in staff and student wellbeing activities, programs and support. General lack of understanding has resulted in my struggles being silenced and told to not be shared as it could impact my role and how I am seen as a teacher. I also was told that we shouldn’t discuss or look at body positive programs because it would risk triggering and causing students to engage in disordered behaviour. As a result of this I have been left feeling ashamed, unseen and like my illness makes me a bad person or unable to participate or be seen without it reflecting poorly on me or other people.” (Emily, Qld)

Survey respondents also described stigma generated by harmful stereotypes.

“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.” (Amanda, SA)

Lived experiences of eating disorders structural stigma

68 per cent of survey respondents said that they had experienced structural stigma in relation to an eating disorder, while 20 per cent were not sure, and 12 per cent selected that they had not experienced any structural stigma. Examples shared were stigmatising views expressed by GPs and other health care professionals when seeking urgent support and treatment. Experiences of public stigma and structural stigma overlapped as participants mentioned stigma in relation to health institutions, use of diagnostic metrics, and the views of medical staff working within these contexts. Several of the experiences of eating disorder stigma that were shared also point to low levels of mental health literacy among health care providers and others; there is some slippage between discussion of low eating disorder literacy and stigma, which is not surprising given the relationship between these two concepts. Weight-based discrimination, including ineffective assessment processes, in health care, emergency departments and inpatient care in hospitals negatively impacted many survey respondents' ability to access effective treatment, and in some cases exacerbated eating disorder symptoms.

“I have been excluded from treatment for anorexia in the past because, in the doctor's words, I was 'not skinny enough'.” (Annie, NSW)

“At a GP when I went to get a MHCP for the first time in order to access treatment for my eating disorder . . . I felt invalidated by the GP who did not take my concerns seriously.” (Sophie, WA)

“. . . doctors did not believe that I had suffered previously and would still comment on my weight and BMI, as a larger person with an eating disorder it was and still is hard.” (Elise, NSW).

“The societal stigma that someone must be underweight to be suffering from an eating disorder meant that once I was discharged from hospital at a healthy weight people assumed I was 'cured' when really, I was still just as unwell in my mind. This meant that I never received/accepted the psychological help I needed and instead continued the cycle of relapse-readmission for years.” (Jemma, Qld)

“In the emergency department my electrolytes were low and was told I would need to stay in. Less than 5 minutes later I am cleared by mental health and sent home. My physical body did not matter anymore.” (Alice, NSW)

“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 the requirements]. This caused me to increase my ED behaviours to try and change my EDE-Q score. It's frustrating that my hard work was getting penalised by the health care system.” (Jeanette, Vic)

“When I was hospitalised for the first time, they based my admission on physical symptoms. I was discharged shortly after being admitted, even though my presenting at the emergency department was advised by medical professionals. This led to a rapid decline in my mental and physical health. Subsequently, I was hospitalised for much longer than was initially necessary, and recovery is taking longer.” (June, NSW)

"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." (Rosie, SA)

"I've received the message from a number of ED specialising mental health providers and programs/organisations that even [when] hospitalised I could be given a meal plan that promotes 'weight loss in a healthy way'." (Louise, Vic)

". . . the punitive and disempowering treatment of eating disorders in public hospitals feels highly stigmatised." (Jemma, Qld)

"A new doctor asked what my relationship with food was like, and when I replied that I was in ED recovery she asked me if I had BED based on my appearance (I'm in the 'healthy' weight range according to the BMI) though I had been suffering from AN." (Eve, NSW)

"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 with that health care professional as I thought they may have been ill-equipped to help me considering they didn't know anything about my ED. This only reinforced my eating disorder by reinforcing his belief that I wasn't 'sick enough' to get help." (Matilda, NSW)

"Health professionals assuming I wasn't getting better because I wasn't trying hard enough and telling me I was making excuses or not being honest. They seemed to have believed my difficulties in recovery were a motivation issue. I felt very misunderstood by the people that were supposed to be helping me . . ." (Amelia, NSW)

"I was the target of derogatory and discriminatory attitudes and discourses while [an] inpatient. However, this was not exclusively related to the eating disorder diagnosis alone . . . I was denied proper care based on being autistic . . . while inpatient at specialised eating disorder unit . . . neuroaffirming and friendly care is urgently needed." (Laurence, NSW)

"Hospital treatment programs focusing on food and weight rather than underlying issues. Assuming eating disorders are all about food and weight and or one's vanity." (Samantha, NSW)

"The doctor . . . didn't assess or test for the Anorexia, and only wrote on his discharge summary 'background of Anorexia'. I was discharged with no treatment. I deteriorated further and was back about two weeks later when they did assess me properly and admit me, but only because that time I advocated for myself and made sure they knew the NSW Health admission criteria for eating disorders. I've been turned away too many times from hospitals that won't admit me, despite meeting criteria for admission, and psych wards that simply say that don't treat eating disorders, again, despite the state's admission criteria." (Sharon, NSW)

Survey respondents also shared experiences of workplace discrimination from inflexible policies.

"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." (Samantha, WA)

"Due to the nature of eating disorders, my ability to work, my performance and participation in work, and what I can or cannot teach has been impacted. 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 impacts me in my role as a HPE teacher as the many stereotypes of the illness are put on me . . . I am constantly set up to fail because of this as

these policies prevent me from engaging in meaningful work and instead leaves me working and teaching in areas that result in high stress and often exacerbation of illness.” (Emily, Qld)

Limitations of the survey

The survey of people with lived experience had a small sample size and mostly consisted of responses from young women. Survey participants were not asked about what type of eating disorder they have/have had, or how having a particular diagnosis determined what type of stigma they experienced, so any differences were not able to be explored. While definitions of self-stigma, public stigma and structural stigma were provided to survey participants, a variance in knowledge of these concepts may have influenced the way responses were framed.

Section 3: Strategies to reduce eating disorder stigma

While research has been conducted on the determinants and types of stigmas experienced by people living with eating disorders, further research is needed to identify effective, evidence-based interventions (Ali et al., 2017). Existing research is summarised below, along with the suggestions shared by people with lived experience.

Interventions to reduce eating disorder self-stigma

The existing research literature has identified several interventions to effectively address self-stigma, including cognitive behavioural therapies, acceptance and commitment therapies, psychoeducation, peer support, and mindfulness. Interventions for parents and carers are needed to approach self-blame (Brelet et al., 2021). Building 'stigma resistance' – the ability to reframe the stigma experienced into the pursuit of justice – has also been identified as an effective intervention to prevent social withdrawal and treatment delays (Griffiths et al., 2015). Interventions are also needed to address the internalisation of weight discrimination and the cognitive processes associated with anticipated weight stigma (Hunger et al., 2020).

Interventions to reduce eating disorder public stigma

Corrigan and Watson (2002) identified three main strategies for addressing public stigma surrounding mental ill-health. These include **protest strategies**, such as intervening within the media to address negative perceptions of people with mental illness. **Educational strategies** seek to inform the public about an illness and reduce discrimination, while **contact strategies** involve the public meeting and sympathising with people experiencing mental health conditions.

Improving public awareness and understanding of misconceptions surrounding eating disorders may help to reduce social stigma. While literature broadly presents the determining factors toward public stigma, greater research is needed to define and reinforce causal explanations of eating disorder stigma to create effective interventions.

Interventions that seek to increase the mental health literacy of the public have been effective in reducing stigmatising attitudes and behaviours (Doley et al., 2017). In a review and meta-analysis of stigma interventions, educating the public about the biological etiology of eating disorders significantly improved attitudes and decreased stigma surrounding eating disorders in comparison to a control group. Combining education and contact-based interventions, where participants have direct contact with an individual experiencing an eating disorder, helped to reduce stigmatising behaviours post-program (Doley et al., 2017). This review also found that knowledge and stigma are independent components and that higher levels of knowledge do not necessarily translate to lower stigma levels, creating implications for the design of stigma-reduction programs.

In public stigma interventions, weight discrimination at all levels should be addressed (Hunger et al., 2020). Stigma interventions need to be tailored toward the specific eating disorder diagnoses and content should be designed to educate target groups who are statistically more likely to stigmatise eating disorders, such as men (Brelet et al., 2021). For example, contact-based strategies can be adopted to prevent young people from stigmatising eating disorders including virtual reality technologies and hearing from people with lived experience.

Interventions to reduce the structural stigma of eating disorders

Greater research is needed to uncover stigmatising attitudes and behaviours of health care workers and the medical community toward people with eating disorders.

In the Australian context Baffsky (2020) argues that media regulation could be a powerful way of reducing blame-based stigma surrounding eating disorders. Organisations such as Butterfly have advocated for the

Commonwealth Government to hold a national inquiry body image, and to pursue an updated code of conduct to help challenge how people with eating disorders are represented within the media (Butterfly Foundation, 2021b). A regulatory code could improve the diversity of representations of people with eating disorders, including people in larger bodies, address the etiology of eating disorders, prohibit the use of derogatory or discriminatory language around eating disorders, and realistically represent the recovery process.

Ideas for reducing stigma from lived experience

Survey participants were asked to provide their ideas, strategies and actions that could be used to develop effective approaches to stigma reduction.

Ideas for reducing eating disorder self-stigma

When asked about strategies that participants used to help reduce self-stigma, survey respondents cited personal coping mechanisms focused on self-care techniques or the seeking of formal and informal external supports. Internal coping mechanisms included daily mindfulness, reframing self-stigmatising attitudes to change the narrative around their diagnosis, distancing their sense of identity from their illness, reducing self-judgement, increasing self-compassion and acceptance, and sharing their story with others.

“Adopting a daily mindful approach to the way I see myself via a combination of kindness and mindfulness . . .” (Matt, SA)

“Tried not to compare myself to others. Focussed on myself and not other people and how they look.” (Rosie, SA)

“Using some of the fire against social injustice and compassion for others, to talk to myself about the situation.” (Louise, Vic)

“I find it helpful to try and remind myself of the facts; that eating disorders are a mental not physical illness, that I do not need to be underweight to deserve help, etc.” (Jemma, Qld)

“Reminding myself that my habits and thoughts are disordered, and that I deserve treatment for them, regardless of the way that I look.” (Eve, NSW)

“To remember that eating disorders have stemmed out of modern-day capitalistic beauty standards and that I am smarter than to fall into this trope. To remember how common eating disorders are and that [they] can affect anyone.” (Elizabeth, NSW)

“I have articulated to various individuals in the health profession that my ED does not define me . . . I am an individual, a daughter, sister, aunt, carer, advocate, animal lover and basically have my own lived experience.” (Samantha, WA)

“Reframing and self-talk: Knowing that getting through an eating disorder is making me a strong and empathetic person, and that I can use my lived experience to make a difference to peoples’ lives one day”. (Emma, Vic)

“Sharing my experience publicly as a speaker for Butterfly Foundation, doing podcasts, media and recovery talks.” (Sophie, WA)

Some survey respondents mentioned that they sought external support, including speaking with a health professional, or participating in a support group to share and understand their experiences in a non-judgemental environment.

“Participating in eating disorder support groups to validate my own experiences.” (Jeanette, Vic)

"Staying in contact with my supports." (Alice, NSW)

"Sought advice from professionals that has provided relief from self-judgement." (Amanda, SA)

"Being open and honest with trusted non- judgemental people." (Ally, Tas)

Other survey respondents discussed the importance of information, reading stories of others with similar experiences, and viewing media that positively portrays people recovering from eating disorders.

"To reduce stigma surrounding my eating disorder diagnosis I did research into the experiences of others with the same diagnosis. This helped me to feel less alone in my experiences, and to navigate my recovery more easily." (June, NSW)

"I was in denial for so long but seeing a therapist break down the symptoms of self-stigma and understand how I was understanding myself and what was happening to me really helped." (Audrey, Vic)

"Following healthy recovery Instagram accounts has been helpful to reduce self-stigma." (Elise, NSW)

"Education on what actually is an eating disorder and what is best practice to support." (Emily, Qld)

"Representation; by being aware that people in bigger bodies can suffer from eating disorders it allowed me to understand that it was possible I was sick with an eating disorder, despite my weight and how I looked." (Matilda, NSW)

"Understanding the history of weight bias and diet culture has helped me to understand where these attitudes of mine around weight and eating disorders came from and why I and so many others have internalised them. This has then helped me to take the blame off myself." (Amelia, NSW)

Ideas for reducing eating disorder public stigma

Survey participants said that education and awareness campaigns would help to reduce public stigma surrounding eating disorders. Education should centre on informing the general public that eating disorders are not based on appearance but are a mental health condition.

"By making the public aware that eating disorders shouldn't be feared. That an eating disorder can happen to anyone. That ongoing, public awareness on eating disorders are a great step to ending stigma." (Matt, SA)

"Help people understand that having an ED is not a choice. It's also not necessarily because of having body image concerns either." (Jeanette, Vic)

"Continue to represent a diverse community of people with different eating disorders in various body sizes/types." (Reggie, NSW)

"Advocate for accurate portrayal of eating disorders in all forms of media . . ." (Emma, Vic)

"Continue projects similar to 'it looks like me' to educate that eating disorders don't have a particular 'look'." (Elise, NSW)

"Continued education campaigns around not being able to tell if someone has an eating disorder by their appearance, how eating disorders are a mental illness, a longer-term illness, etc" (Jemma, Qld)

“Widespread education and understanding of what actually an eating disorder is and reducing shame by educating people on diet culture and how it [is] reflected in the behaviours of many across Australia, just some people it impacts more.” (Emily, Qld)

“EDUCATION! More information on what eating disorders are, information about how they are a serious mental illness and [don’t] happen because the individual is self-absorbed with their looks, and how eating disorders can affect ANYONE!” (Matilda, NSW)

“Help educate other about where messages about weight and body come from. If people understood the racist and sexist history maybe they would be more likely to reconsider the blame they place on people who struggle with these issues.” (Amelia, NSW)

Participants responses reflect the strategies that Corrigan and Watson (2002) outline for addressing public stigma including educational strategies informing the public about eating disorders to reduce discrimination and contact-based interventions where the public hear from people with a living experience of an eating disorder. Participants responses also indicated a need to educate the public on the biological etiology of eating disorders.

Ideas for reducing eating disorder structural stigma

A large majority of survey respondents said that education for health care workers (including those working in hospitals) and the provision of peer workers in emergency departments, would help to reduce structural stigma. Ideas included revising diagnostic criteria focusing on BMI and weight-based measurements that perpetuate stigma and cause harm to people when they access treatment and support.

“Education. Peer workers in emergency departments.” (Alice, NSW)

“Ongoing awareness and training for clinicians, educators, staff and management that encourages support and focuses on ending stigma.” (Matt, SA)

“Educate GPs and health care professionals about EDs and their many representations.” (Reggie, NSW)

“Education about other implications of eating disorders aside from weight loss.” (Rosie, SA)

“Education to health care providers, and in schools, on HAES, Intuitive Eating, set point theory etc.” (Louise, Vic)

“Educating health care professionals that a sufferer doesn't chose to be unwell, they are not being 'difficult' on purpose, they are a real person with hopes and dreams not just a diagnosis, etc.” (Jemma, Qld)

“Educate health providers . . . to look at thoughts, behaviours, and health rather than weight.” (Eve, NSW)

“I believe there also needs to be more advocacy among health and the medical field for ‘Health at Every Size’ as without it and what it stands for I'm unsure I would have found my incredible dietitian and be on my road to recovery.” (Matilda, NSW)

“Continue awareness especially in schools, and amongst GPs of various EDs, prevalence rates amongst certain populations etc and non-stereotypical physical presentations” (Louise, Vic)

“People of all weights and sizes can have eating disorders, even restrictive eating disorders. And this needs to be made clear to medical professionals.” (Elise, NSW)

"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. We should not be turned away from any mental health service or psychiatric facility." (Sharon, NSW)

"Educating services by encouraging individuals with lived experience and peer workers to share their story and reality living with an eating disorder defining their experience and ensuring that people know that a diagnosis does not define a person's individuality." (Samantha, NSW)

"Advocate for changing requirements for eating disorder plan. [Otherwise] it may result in people believing that you only have an ED if you fit the criteria for treatment under the plan." (Jeanette, Vic)

"I feel that people who live outside of metropolitan areas are discriminated against because there is little or no specialised treatment available out of the capital cities. Until you get sick enough to be hospitalised treatment appears to be non-existent." (Annie, NSW)

Some respondents highlighted the importance of educating health care professionals on the intersection of autism and eating disorders, noting limited understanding despite high comorbidity rates.

"Lobby for all clinicians working with eating disorders to have training in autism. The rates of autistic people with eating disorders are too high to continue with the current lack of awareness. It is very damaging to be misunderstood by health professionals when you are trying your best to help yourself." (Amelia, NSW)

"Raise awareness about neurodivergence and eating disorders; advocate for the implementation of neurodiversity-friendly and neuroaffirming care pathways; [and] advocate for better training about neurodivergence and eating disorders for clinicians." (Laurence, NSW)

Conclusion

This paper has reviewed literature on eating disorder stigma and shared the responses of people with lived experience in relation to various forms of eating disorder stigma. It is clear that stigmatising attitudes and behaviours can have detrimental effects on the ability of people with eating disorders to receive support from people around them and to access to effective early intervention, treatment services and recovery support.

Weight-based and blame-based stigma and discrimination within the general community, media, workplaces and health services has many negative effects for people with an eating disorder. For some survey respondents, this has both generated and perpetuated self-stigma. Despite these experiences, survey respondents display a high level of awareness of stigma and its effects, as well as the capacity to implement self-care strategies and seek appropriate support when needed. People with lived experience want to see better education for health care workers in particular, and ongoing advocacy to create systemic change.

Further exploration of experiences of stigma is required, including developing the evidence base for stigma prevention strategies targeting settings such as health care and workplaces, universal stigma reduction strategies to change community attitudes, and promotion of individual strategies to develop stigma resistance as part of recovery support. Research on the factors leading to public and structural stigma related to various types of eating disorders and comorbidities is also needed to underscore these efforts.

In response to the findings documented in this paper, Butterfly will continue to engage with the community in order to develop recommendations to share with policy makers, practitioners, professional bodies, other mental health organisations and media professionals to prevent and reduce eating disorder stigma.

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Appendix 1: Lived experience survey questionnaire

Demographic questions (opportunity to be anonymous)

Self-stigma:

Self-stigma can be defined as internal shame and negative attitudes toward one's own diagnosis stemming from societal stigma

Have you ever experienced self-stigma from your eating disorder diagnosis and/or body image concerns?

- Yes
- No
- Not sure

If yes to the above, did experiencing self-stigma affect your ability to seek help and receive treatment for an eating disorder and/or body image concern?

- Yes
- No
- Not sure

What is one strategy you have used/have found helpful to reduce self-stigma around your eating disorder diagnosis and/or related experiences?

Public/social stigma:

Public stigma can be defined as stereotyping, discrimination, exclusion, and negative attitudes received from other people in society toward someone with an eating disorder.

Have you ever experienced public stigma toward you in relation to your eating disorder diagnosis and/or body image concern?

- Yes
- No
- Not sure

If yes, please provide one example where you experienced public stigma and any negative implications that came from this experience.

What is one action Butterfly could take to help reduce public stigma surrounding eating disorders and/or body image concerns?

Structural stigma:

Structural stigma can be defined as stigma experienced on a macro level that is embedded in institutions, systems and policies.

Have you ever experienced structural stigma in relation to your eating disorder diagnosis and or body image concerns?

- Yes
- No
- Not sure

If yes, please provide one example where you experienced structural/systemic stigma and any negative implications that came from this experience.

What is one action Butterfly could take to help reduce structural stigma surrounding eating disorders and/or body image concerns?

Appendix 2: Qualitative responses from lived experience survey questionnaire

Question 3: What is one strategy you have used/have found helpful to reduce self-stigma around your eating disorder diagnosis and/or related experiences?

- Staying in contact with my supports (Alice, NSW).
- Adopting a daily mindful approach to the way I see myself via a combination of kindness and mindfulness. Using this way alone helps keep my day in balance. On days, when things aren't going to plan this is even more powerful. (Matt, SA)
- Participating in eating disorder support groups to validate my own experiences (Jeanette, VIC)
- To reduce stigma surrounding my eating disorder diagnosis I did research into the experiences of others with the same diagnosis. This helped me to feel less alone in my experiences, and to more easily navigate my recovery. (June, NSW)
- To remember that eating disorders have stemmed out of modern day capitalistic beauty standards and that I am smarter than to fall into this trope. To remember how common eating disorders are and that it can affect anyone. (Elizabeth, NSW)
- Tried not to compare myself to others. Focussed on myself and not other people and how they look. (Rosie, SA)
- I was in denial for so long but seeing a therapist break down the symptoms of self-stigma and understand how i was understanding myself and what was happening to me really helped. (Audrey, VIC)
- Trying to take a helicopter lens view, and consider what I would say ot other people in this situation. Use some of the fire against social injustice and compassion for others, to talk to myself about the situation. (Louise, VIC)
- Sharing my experience publicly as a speaker for Butterfly Foundation, doing podcasts, media and recovery talks. (Sophie, WA)
- I just tried to accept it as something happening to me, not my whole self (Elise, NSW).
- Following healthy recovery instagram accounts has been helpful to reduce self-stigma - not feeling alone or 'not sick enough' (Elise, NSW)
- I find it helpful to try and remind myself of the facts; that eating disorders are a mental not physical illness, that I do not need to be underweight to deserve help, etc. (Jemma, QLD)
- Reminding myself that my habits and thoughts are disordered, and that I deserve treatment for them, regardless of the way that I look (Eve, NSW).
- Sought advice from professionals that has provided relief from self-judgement (Amanda, SA).
- Being open and honest with trusted non- judgemental people (Ally, TAS).
- Education on what actually is an Eating Disorder and what is best practice to support. (Emily, QLD)
- Representation; by being aware that people in bigger bodies can suffer from eating disorders it allowed me to understand that it was possible I was sick with an eating disorder, despite my weight and how I looked. (Matilda, NSW)
- Actively learning more about weight stigma and other social issues such as feminism and racism. Understanding the history of weight bias and diet culture has helped me to understand where these attitudes of mine around weight and eating disorders came from and why I and so many others have

internalised them. This has then helped me to take the blame off myself. It has also helped me to talk about it with others because I have more language to verbalise my experiences and it helps me to feel less shame and feel less alone (Amelia, NSW)

- It helps me to know the diagnostic criteria so I can remind myself that I do fit the criteria, even if I haven't gotten as underweight as others, or as sick as others. And it helps me to know the signs and symptoms too, so that I can acknowledge that my body is really actually suffering from my restrictive eating behaviours, that what I'm doing isn't really okay or normal (Sharon, NSW).
- I have articulated to various individuals in the health profession that my ED does not define me. A diagnosis stereotypes and I am an individual a daughter sister aunt carer advocate animal lover and basically have my own lived experience. I am Samantha not Anorexia not Bulimia. I face challenges with Eating Disorders but they do not define my existence (Samantha, WA).
- Reframing and self-talk:
 - Thinking about all the other things that make up who I am. Sure I have weaknesses, everyone does, but we don't define people by their weaknesses. There are so much more to people/us than that.
 - Knowing that getting through an eating disorder is making me a strong and empathetic person, and that I can use my lived experience to make a difference to peoples lives one day (Emma, VIC).

Question 5: If yes, please provide one example where you experienced public stigma and any negative implications that came from this experience?

- family making comments which showed that they did not understand (Katrina, VIC)
- When I first sought help, a gp printed out a blank mental health plan, signed it and told me to go home and google someone. This was the first a many stigma experiences. (Alice, NSW).
- Friends had a negative reaction and then completely changed the subject. Negative implication was that I felt it was not okay or normal to experience an eating disorder and to talk about it. (Jeanette, VIC)
- When my eating disorder first developed, my parents were unsure of how to approach helping me. They treated me as if my eating disorder was a choice, unaware of how harmful this was to my mental health. This attitude prevented me from being able to validate my own experience, as it was new for me as well. Seeking professional help was also made more difficult, due to lack of knowledge on how to reach out independently, and being too physically unwell to care for myself. (June, NSW)
- My friends reactions were of concern but also came from a place that believed that I ultimately had control over the situation. I think anyone who has had an eating disorder knows that you don't feel control of it and that its not a simple recovery process. (Elizabeth, NSW)
- I remember i went swimming at a beach and girls whispered 'she has anorexia she is so skinny' (Audrey, VIC)
- On learning I have an ED history and struggle with restriction most, and can't eat in front of others, I've had my psychiatrist tell me I'm too fat, ask why my family were letting me kill myself, and during an inpatient admission were there was only a communal dining room, not make any provisions for me, [whilst the emaciated lady with anorexia got to eat in her room], or even engage in conversation about why I wasn't eating. (Louise, VIC)
- I have been excluded from treatment for anorexia in the past because, in the doctor's words, I was "not skinny enough". (Annie, NSW)
- At a GP when I went to get a MHCP for the first time in order to access treatment for my eating disorder. I felt invalidated by the GP who did not take my concerns seriously. (Sophie, WA)
- Problem is I was an overweight person with a restrictive eating disorder which lead to me losing a lot of weight. And we all know what society does when people lose weight, they congratulate them. So after I had lost weight and re-gained some with recovery, doctors did not believe that I had suffered

previously and would still comment on my weight and BMI, as a larger person with an eating disorder it was and still is hard. (Elise, NSW).

- Others disbelief that I have an eating disorder due to being in a normal weight range
I disclosed to my Team Leader at work that I am recovering from an eating disorder and the response was not supportive and just focussed on my ability to continue to work
I was in a private eating disorder inpatient ward for a short time and a GP within the ward told me "If you keep acting like this (distressed) your fiance will think you're crazy and leave you" (Elise, NSW)
- My eating disorder journey involved many lengthy hospital admissions to restore weight. The societal stigma that someone must be underweight to be suffering from an eating disorder meant that once I was discharged from hospital at a healthy weight people assumed I was 'cured' when really I was still just as unwell in my mind. This meant that I never received/accepted the psychological help I needed and instead continued the cycle of relapse-readmission for years. (Jemma, QLD)
- Comments that have been made to me have included - That anorexia is about wanting to look like someone in a magazine. It's about vanity. I'm choosing not to eat on purpose. I would be fine if only I would just eat (Amanda, SA).
- In a workplace having my food labelled 'compost' & saying can't be seen side on
- In my job I work as a Health and Physical Education Teacher, but also take pride in participating in staff and student wellbeing activities, programs and support. General lack of understanding has resulted in my struggles being silenced and told to not be shared as it could impact my role and how I am seen as a teacher. I also was told that we shouldn't discuss or look at body positive programs because it would risk triggering and causing students to engage in disordered behaviour. As a result of this I have been left feeling ashamed, unseen and like my illness makes me a bad person or unable to participate or be seen without it reflecting poorly on me or other people. (Emily, QLD)
- For a little while I had a few support people helping me, making meals, but when I struggled with how they did it and couldn't eat the meals, they said they thought I wasn't really wanting to get better, or not really trying, or not committed to making progress, so they stopped helping me. People often think that it's a matter of wanting to or not (Sharon, NSW).
- My mum used to speak negatively about purging and eating disorders in general. This meant I hid my eating disorder for a long time for fear of my mum being so ashamed and angry at me (Emma, VIC).

Question 6: What is one action Butterfly could take to help reduce public stigma surrounding eating disorders and/or body image concerns?

- increasing open discussion to educate others (Katrina, VIC)
- Education! (Alice, NSW)
- By making the public aware that eating disorders shouldn't be feared. That an eating disorder can happen to anyone. That ongoing, public awareness on eating disorders are a great step to ending stigma. (Matt, SA)
- Help people understand that having an ED is not a choice. It's also not necessarily because of having body image concerns either. (Jeanette, VIC)
- I can share my own experiences with an eating disorder, to help others the way they've helped me. (June, NSW)
- Continue to represent a diverse community of people with different eating disorders in various body sizes/types (Reggie, NSW).
- To communicate to others only to say something about someone's body to them directly and when they're worried. Not to gossip. (Audrey, VIC)
- Continue projects similar to 'it looks like me' to educate that eating disorders don't have a particular 'look'. Somehow assist in improving private eating disorder clinics to people get the help they need (Elise, NSW)

- Continued education campaigns around not being able to tell if someone has an eating disorder by their appearance, how eating disorders are a mental illness, a longer-term illness, etc. (Jemma, QLD)
- Educate people about common drivers of eating disorders - control, managing strong emotions, trauma etc. (Amanda, SA)
- Normalising conversation around ED as is now happening with anxiety and depression (Ally, TAS)
- Wide spread education and understanding of what actually is an eating disorder and reducing shame by educating people on diet culture and how it has reflected in the behaviours of many across Australia, just some people it impacts more. (Emily, QLD)
- EDUCATION! More information on what eating disorders are, information about how they are a serious mental illness and doesn't happen because the individual is self absorbed/focused on their looks, and how eating disorders can affect ANYONE! (Matilda, NSW)
- Help educate other about where messages about weight and body come from. If people understood the racist and sexist history maybe they would be more likely to reconsider the blame they place on people who struggle with these issues (Amelia, NSW).
- Sharing people's stories and photos, perhaps with brief statements like 'if only wanting to eat normally was enough... Eating Disorders are an illness.' You know, something like that, I'm not a marketing expert. Perhaps with data/statistics. eg. 99% of ED sufferers look normal. :-D I just made that statistic up (Sharon ,NSW).
- Advocate for accurate portrayal of eating disorders in all forms of media. I.e. that it's not a choice, that it's literally torture (Emma, VIC).

Question 8: If yes, please provide one example where you experienced structural/systemic stigma and any negative implications that came from this experience

- An assumption that low weight automatically means eating is disordered (Katrina, VIC)
- In the emergency department my electrolytes were low and was told I would need to stay in. Less than 5 minutes later I am cleared by mental health and sent home. My physical body did not matter anymore. (Alice, NSW)
- 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) (Eating Disorder Examination Questionnaire) to meet the requirements. I have complex mental health conditions and was already accessing a mental health care plan. This caused me to increase my ED behaviours to try and change my EDE-Q score. It's frustrating that my hard work was getting penalised by the healthcare system. (Jeanette, VIC)
- When I was hospitalised for the first time they based my admission on physical symptoms. I was discharged shortly after being admitted, even though my presenting at the emergency department was advised by medical professionals. This demonstrates the stereotyping that anorexia patients are always underweight, when only 6% of those struggling are underweight. This led to a rapid decline in my mental and physical health. Subsequently, I was hospitalised for much longer than was initially necessary, and recovery is taking longer. (June, NSW)
- 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. (Rosie, SA)
- I was too sick to be an inpatient at a private psychiatric hospital but felt I wasn't sick enough. (Audrey, VIC)
- As someone with atypical anorexia who has been infatuated down to mid fat, I've butted up against stigma and nonsensical policies in treatment settings. I've had a GP say if your anorexia is just about weight loss we can get you in with a bariatric surgeon. I've received the message from a number of ED specialising mental health providers and programs/organisations that even hospitalised I could be given a meal plan that promotes 'weight loss in a healthy way.' Or that I should stop losing weight,

but absolutely not gain any back. Or that on a maintenance MP weight will fluctuate a little naturally and you shouldn't obsess or try to influence it, but any weight loss will get you kicked out of the program, which I was for a 100g weight loss! (Louise, VIC)

- I feel that people who live outside of metropolitan areas are discriminated against because there is little or no specialised treatment available out of the capital cities. Until you get sick enough to be hospitalised treatment appears to be non-existent. By then things are firmly established and treatment is less effective. (Annie, NSW)
- I'm not sure if this would be considered structural stigma, but the punitive and disempowering treatment of eating disorders in public hospitals feels highly stigmatised. (Jemma, QLD)
- A new doctor asked what my relationship with food was like, and when I replied that I was in ED recovery she asked me if I had BED based on my appearance (I'm in the 'healthy' weight range according to the BMI) though I had been suffering from AN. (Eve, NSW)
- Not taken seriously in healthcare setting- you're not that thin, how can you have an ED (Ally, TAS).
- Due to the nature of Eating Disorders my ability to work, how my performance and participation in work and what I can or can not teach has been impacted. 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. My performance and participation is based on physical indicators not mental, I am not supported with my mental health and how that is impacted I as a high functioning person work well until I can't due to the lack of policy and procedure. Stigma in particular around the illness particularly impacts me in my role as a HPE teacher as the many stereotypes of the illness are put on me before even asking or considering what I am good at, what I am passionate about and what does or does not trigger my illness. I am constantly set up to fail because of this as these policies prevent me from engaging in meaningful work and instead leaves me working and teaching in areas that result in high stress and often exacerbation of illness (Emily, QLD)
- 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 less than because my eating disorder wasn't one of the main three, and also made me feel uncomfortable proceeding with treatment with that healthcare professional as I thought they may have been ill-equipped to help me considering they didn't know anything about my ED. This only reinforced my eating disorder by reinforcing his belief that I wasn't "sick enough" to get help (Matilda, NSW)
- Health professionals assuming I wasn't getting better because I wasn't trying hard enough and telling me I was making excuses or not being honest. They seemed to have believed my difficulties in recovery were a motivation issue. Turns out I was autistic all along and that is why I was struggling so much with what was being asked of me. For example, when I was saying things like "I couldn't eat it because it was too slimy" it wasn't because I was trying to be difficult, it was because I have difficulties with sensory processing and slimy foods are very overwhelming for me. There were many other examples like this. I felt very misunderstood by the people that were supposed to be helping me and I didn't know how to fix the problem because I always knew I was trying my best to explain my experiences to them and to help myself. (Amelia, NSW)
- Stigma mostly arose from the very people that you expect the least. Indeed, I was the target of derogatory and discriminatory attitudes and discourses while inpatient. However, this was not exclusively related to the eating disorder diagnosis alone. Of course, I did receive unsolicited advice every now and then in relation to my disordered eating. However, the most serious incidents relate to me being autistic with an eating disorder. I was denied proper care based on being autistic. A nurse once said, referring to me, "Why do we even help people like this?". This was in June 2021. More recently (April 2022), while inpatient at specialised eating disorder unit from the Royal Prince Alfred

Hospital in Sydney, 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." This refusal to implement simple accommodation is a clear case of indirect discrimination as per the Disability Discrimination Act 1992. Not to mention how hurtful the following sentence was. Ironically, it is autistic people that are supposedly "lacking empathy". In addition, if that nurse had any knowledge of autism, and neurodiversity, she would have realised how utterly absurd her comment was. This is why neuroaffirming and neurodiversity-friendly care is urgently needed.

Autistic women die by suicide at rates 13 times higher than non-autistic women. Upwards to 70% of autistic women experience sexual violence. Approximately 80% of autistic women are misdiagnosed. It is time for change. (Laurence, NSW)

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- I could share so many similar examples, but for just one I'll share how recently I presented to my local Emergency Department with chest pain, palpitations, dizziness etc. I'd recently contracted Covid, but had been worse with the Anorexia for a while too. I made sure to tell them that I was there also because of the Anorexia, but I didn't look like it. I'd been in treatment - 12 admissions in the past 18 months and had regained weight from 15 BMI up to 20 BMI. The doctor didn't ask me much about it, he didn't assess or test for the Anorexia, and only wrote on his discharge summary "background of Anorexia". I was discharged with no treatment. I deteriorated further and was back about two weeks later when they did assess me properly and admit me, but only because that time I advocated for myself and made sure they did postural obs and knew the NSW Health admission criteria for Eating Disorders. I've been turned away too many times from hospitals that won't admit me, despite meeting criteria for admission, and psych wards that simply say that don't treat eating disorders, again, despite the state's admission criteria (in Qld. and NSW).
- 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 (Samantha, WA)
- Hospital treatment programs focusing on food and weight rather than underlying issues Assuming Eating Disorders are all about food and weight and or ones vanity (Samantha, NSW).

Question 9: What is one action Butterfly could take to help reduce structural stigma surrounding eating disorders and/or body image concerns

- increasing education around how disordered eating and weight can be different for different people (Katrina, VIC)
- Education. Peer workers in emergency departments (Alice, NSW).
- Ongoing awareness and training for clinicians, educators, staff and management that encourages support and focuses on ending stigma. (Matt, SA)
- Advocate for changing requirements for eating disorder plan. It may result in people believing that you only have an ED if you fit the criteria for treatment under the plan. (Jeanette, VIC).
- Advocating towards more preventative mental health care in the public healthcare system. (June, NSW)

- Educate GPs and health care professionals about EDs and their many representations (Reggie, NSW)
- Education about other implications of eating disorders aside from weight loss. (Rosie, SA)
- Education to health care providers, and in schools on HAES, Intuitive Eating, set point. theory etc. (Louise, VIC)
- Training for those working in the healthcare system. (Sophie, WA)
- Educating health care professionals that a sufferer doesn't chose to be unwell, they are not being 'difficult' on purpose, they are a real person with hopes and dreams not just a diagnosis, etc. (Jemma, QLD)
- Educate health providers re EDs with an emphasis on thoughts, behaviours and health rather than weight. (Eve, NSW)
- Raise awareness about neurodivergence and eating disorders; Advocate for the implementation of neurodiversity-friendly and neuroaffirming care pathways; Advocate for better training about neurodivergence and eating disorders for clinicians (Laurence, NSW)
- Public education (Ally, TAS).
- enquiry into policy supporting people with eating disorders and mental illness in work places and how to have effective and supportive policies and procedures (Emily, QLD)
- More information and training for health care professionals on eating disorders, it shocks me how uneducated a lot of them are on the topic. I believe there also needs to be more advocacy among health and the medical field for "Health at Every Size", as without it and what it stands for I'm unsure I would have found my incredible dietitian and be on my road to recovery. (Matilda, NSW)
- Lobby for all clinicians working with eating disorders to have training in autism. The rates of autistic people with eating disorders is too high to continue with the current lack of awareness. It is very damaging to be misunderstood by health professionals when you are trying your best to help yourself (Amelia, NSW).
- Continue awareness esp in schools, and amongst GPs of various EDs, prevalence rates amongst certain populations etc and non stereotypical physical presentations. (Louise, VIC)
- Raise awareness about neurodivergence and eating disorders; Advocate for the implementation of neurodiversity-friendly and neuroaffirming care pathways; Advocate for better training about neurodivergence and eating disorders for clinicians (Laurence, NSW)
- Awareness raising campaigns targeted towards those who would not usually engage with eating disorders e.g. typically 'masculine' spaces (Sophie, WA)
- People of all weights and sizes can have eating disorders, even restrictive eating disorders. And this needs to be made clear to drs and medical professionals. (Elise, NSW)
- Raise awareness about neurodivergence and eating disorders; Advocate for the implementation of neurodiversity-friendly and neuroaffirming care pathways; Advocate for better training about neurodivergence and eating disorders for clinicians (Laurence, NSW)
- Lobby for all clinicians working with eating disorders to have training in autism. The rates of autistic people with eating disorders is too high to continue with the current lack of awareness. It is very damaging to be misunderstood by health professionals when you are trying your best to help yourself (Amelia, NSW).
- 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 most deadly one at that. So I would say, advocate for equality of service, rights of patients. We should not be turned away from any mental health service or psychiatric facility (Sharon, NSW).

Educating services by encouraging individuals with lived experience and peer workers to share their story and reality living with an Eating Disorder defining their experience and ensuring that people know that a diagnosis does not define a person's individuality (Samantha, NSW).