THE FEEL HAPPY EATING FIX

YOUNG PEOPLE 'FIXING' EATING DISORDERS: A CULTURAL SHIFT IS REQUIRED
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Young people ‘fixing’ eating disorders:
a cultural shift is required

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The Feel Happy [Eating] Fix was an opportunity for young people with experience of eating disorders to tell their stories, explain their viewpoints and share the issues they are facing or have faced, including the barriers to treatment and support, with each other and with an audience of policy makers and practitioners. What was refreshing, unlike any other event, was that none of the professors or doctors, the adults one would usually regard as the experts, were influencing the voices of the young people, the true experts based on their own experience.

It was, quite simply, a chance for the professionals to listen and learn from young people talking about their experiences of eating disorders outside of a clinical setting.

All these young people are Fixers; they have signed up to use their past to fix the future and get their voice heard on any issue that is important to them. I became a Fixer in 2008 when I was in recovery from bulimia and it set me on course to establish my own charity and become recognised as the voice of male eating disorders in the UK. I coined the term ‘Veteran Fixer’ because that is how I see myself now - somewhat older than the 16 to 25 year age range but still fixing!

Where we can, Fixers and myself still work together specifically to raise awareness and understanding around eating disorders, to improve services and support for everyone.

At the Feel Happy [Eating] Fix, I heard a great deal about the services available still being a postcode lottery and about the ongoing need for early intervention, in particular community-based services. There is too much ‘wait and see’ in terms of getting the treatment young people need, when they need it most. Ultimately, I believe not enough is happening on a Government, policy and commissioning level to ensure that eating disorders are on the agenda.

I’d particularly like to see media professionals, and especially journalists, working with us to reach a better understanding of the real issues around eating disorders. I call upon the media to help expand the reach and impact of the Feel Happy [Eating] Fix and help achieve the cultural shift Fixers are asking for.

“Real understanding of what it means to be a young person living with an eating disorder can only come through genuine engagement and in depth exploration of their experiences. We are delighted to be supporting this project, which does exactly that, and wholeheartedly commend the people involved, especially those Fixers who will be sharing their own stories in their own words.”

Farrah Nazir, National Programmes Adviser at the Wellcome Trust.
Throughout 2015 Fixers undertook a programme of work to bring together new, much needed evidence of young people’s mental health experiences. Young people feature at the forefront of this body of work, which aims to be a truly co-productive approach to informing evidenced based practical and policy solutions in the area of young people’s mental health.

In March (2015) Fixers held the successful Feel Happy Fix Live, supported by Simplyhealth, at the British Film Institute (BFI) and ITV London Studios, which enabled young people to get their voices heard on all mental health issues. This national conference was the culmination of Fixers work with over 265 Fixers (young people) who took part in 16 regional workshops and a survey, across the UK to share their experiences of mental ill-health and how to make positive changes for others in the future. The findings of this research will be available in autumn 2015.

Following on from this broader investigation Fixers held an issue specific event, the Feel Happy [Eating] Fix, supported by the Wellcome Trust, to further highlight young people’s experiences around eating disorders. The following report outlines the findings and recommendations of six focus groups investigating the impacts of eating disorders on the settings young people live their lives (media, home, school, work, health, and play (socialising)).

The initial findings of the Feel Happy Fix Live and the Feel Happy [Eating] Fix can be located on dedicated sub-domains of the Fixers Website, which is home to a number of thought provoking and impactful films and resources made by Fixers (young people) who have experience of mental ill-health and eating disorders more specifically.

You can find the initial findings of the Feel Happy Fix Live here: www.feelhappy.fixers.org.uk and the Feel Happy [Eating] Fix report here: www.feelhappyeatingfix.fixers.org.uk

The following offers an overview of the main findings and recommendations of the Feel Happy [Eating] Fix.

MEDIA FINDINGS

Young people feel that the media does not show enough balance in story formats, with many news and magazine articles focusing on anorexia and statistical representations, such as lowest weight and calorie consumption, while using lowest weight figures. Triggering content is readily available and eating disorders are ignored in the media as a mental health condition.

MEDIA RECOMMENDATIONS

1. Better regulation by a governing body, which involves service users and NGOs (non-governmental organisations) that truly understand the conditions and related issues;

2. Better access to good quality support on social media sites;

3. More robust awareness campaigns supported by the media. For example, using online petitions, calling on the media for new ways of thinking around low weight images. The media to work with young people with lived experience of eating disorders to show the realities of the conditions and not just the sensationalised stories;

4. Images that have been edited should be marked as photo-shopped;

5. Internet providers and social media companies to identify and remove triggering images.
HOME FINDINGS
Young people believe that parents, carers and siblings, struggle to understand what an eating disorder is and how to help them. They also highlighted how eating disorders can have a negative effect on the whole household and that communication broke down at the most difficult times, especially around meal times.

HOME RECOMMENDATIONS
6. Clear guidelines for all carers on spotting the signs of eating disorders and mental illness in general and advice on where to go for support. Parent-to-parent support can be really valuable;
7. Provide support for all household members, recognising that different families need different kinds of support. Carers should be linked into treatment options so that young people get better support at home to recover;
8. All generations need to talk to each other about difficult subjects and to understand that eating disorders are not just about the physical act of eating to get better but also about the underlying mental health issue.

SCHOOL FINDINGS
Young people said that staff in educational settings did not understand eating disorders and general pastoral care was poor. They felt overwhelmed by pressure to achieve high academic standards, which exacerbated their eating disorder. This was further impacted by lack of support, such as counselling services.

SCHOOL RECOMMENDATIONS
9. Mandatory mental health training for all education professionals. In the same way as First Aid is delivered and awarded with a simple badge system. Training should cover;
10. Better teaching around eating disorders and nutrition for children from primary school age. This could be taught creatively through all subjects, such as English and Science;
11. More and better qualified counsellors and stronger support for young people coming out of treatment and transitioning back into mainstream education. There needs to be greater access to counselling in schools, and further and higher education institutions, which is tailored to individual needs.

WORK FINDINGS
Young people said that they had been discriminated against in the workplace, including being sacked for needing time off for treatment. They also said that employers did not offer them support to implement flexible recovery plans in the workplace and managers and colleagues lack understanding about eating disorders and mental ill-health in general.

WORK RECOMMENDATIONS
12. An accredited ‘Mental Health’ kite mark/logo should be introduced into the workplace to signify and reassure that the employer is a ‘Mental Health’ friendly place to work;
13. Work based training on what an eating disorder is and how to support a colleague to build empathy and understanding;
14. Employers to offer employees more flexibility to implement return to work plans, which may include but not exclusive to: flexible hours; regular breaks; a buddy support system; and a quiet space to eat.
**PLAY FINDINGS**

Young people said they had lost their childhood to the condition and were left isolated and out of touch with their friends and peers who did not understand about eating disorders.

**PLAY RECOMMENDATIONS**

19. Information to be delivered to young people about eating disorders and related mental health conditions and how to offer support. This should take place in school (by teachers and peer to peer) and online so that it can be easily shared. The information should be delivered creatively and designed with those with lived experience;

20. An online campaign focused on what an eating disorder is and how to help;

21. Improve signposting to and the quantity of support groups and one to one support for individuals.

The research has also outlined a number of recommendations where Fixers (young people) have suggested that education and awareness is required throughout the settings to help people understand eating disorders and how to support young people.
Mental ill-health is one of the largest public health concerns facing young people today. Recent reports by the NHS highlight concerning figures that in the last year, the number of children aged 10-14 admitted to hospital in England for self-harm is the highest for five years. Furthermore, for UK teenagers with an eating disorder, admissions have nearly doubled over the last three years (Jones, 2015). The vast majority of patients are female, although men also experience eating disorders, and the common age for admission is 15 (Ward, 2015). While there is no single factor that can trigger an eating disorder (Parliamentary Office of Science and Technology, 2007) the Royal College of Psychiatrists attributes this latest alarming trend to the proliferation of online images of ‘perfect bodies’ placing undue stress on vulnerable young people to conform to certain body types (Woolf, 2015). Experts also warn that specialist NHS services are struggling to cope and waiting times are astronomically high, forcing young people to wait longer while their condition worsens and can become critical (Campbell, 2015).

Regardless of the causes, the seriousness of eating disorders as severe mental health conditions remains unwavering. One in 10 people with anorexia will die prematurely either through suicide or organ failure (Campbell, 2015) and while full recovery is possible, 20 per cent of people with anorexia nervosa and 23 per cent with bulimia nervosa will remain chronically ill (BEAT, 2015:19).
To contribute to knowledge in this area, the national social action charity Fixers, has undertaken an initial, exploratory *Feel Happy [Eating] Fix*, with young people who have personal experience of an eating disorder.

Fixers is not a single issue based charity, therefore we do not claim to be experts in any given area of policy. Our unique offer, however, is to provide a platform for young people to get their voices heard on any issue that is important to them.

The aim of this initial research, therefore, is to assimilate young people’s (Fixers) knowledge and wisdom about their eating disorder experiences in the settings they lead their lives (in the media, at home, at school, in the workplace, health service and at play with friends and peers) and what has impacted their condition. Key recommendations, directly from the Fixers (young people), are also documented to inform policy and practice to help support young people with an eating disorder across the UK in the future.

**YOUNG PEOPLE TELL THEIR STORY: FINDINGS AND RECOMMENDATIONS**

The following accounts have been taken from 12 young people, aged between 16-25, all with experience of an eating disorder and a treatment programme. The Fixers were divided into two groups and took part in six focus group sessions with each centring on a different area of their lives. **All participants were asked the same general question, namely what issues came to mind when they thought about their eating disorder and the setting under discussion (i.e. at work).**

They also took part in a wider participation event with policy makers and practitioners to discuss the findings and make their case for positive change. They shared their experiences of eating disorders with world-renowned experts including Professor Janet Treasure OBE, the world’s foremost expert on eating disorders, and Dr Dasha Nicholls of Great Ormond Street Hospital, who chaired the debate. Other attendees included Beat, the highly regarded eating disorders charity, representatives from the policy department of the Department of Health, Child and Adolescent Mental Health Services (CAMHS), the Royal Society for Public Health and NHS England.
The media plays a significant role in young people’s lives. From the moment they wake up they are exposed to mass media (television, films, billboards, magazines, music, newspapers, fashion designers, the Internet, and social media) for social, educational and work purposes. There has been a long running public and academic debate about the influence of the media on young minds. Increasingly this debate has focused on a new paradigm of food and eating and whether the media promotes a low weight ideal body (Jade, 2012; The Royal College of Psychiatrists, 2010; Morris & Katzman, 2003; The British Medical Association, 2000).

Contributing to this debate young people from across the Feel Happy [Eating] Fix were asked a broad question about what issues came to mind when they thought about their eating disorder and the media. The Fixers did not attribute the cause of their eating disorder to media influence. However, the majority of young people involved in the focus groups felt strongly that the media had exacerbated their eating disorder.

The Fixers outlined a number of problems related to the media and the reporting of eating disorders. They felt that there was 

There’s a lot of focus on anorexia. Most people who struggle with bulimia can appear normal. That can make you feel like you’re not ill enough and kick starts a cycle of shame.

not enough balance in story formats, with many news and magazine articles focusing on anorexia and statistical representations, such as lowest weight and calorie consumption, while using lowest weight images to depict someone experiencing an eating disorder.
“All the media does is promote the perfect body image when there is no perfect body. The people (you see in the media) are far too skinny.” (Michael)

“There’s a lot of focus on anorexia. Most people who struggle with bulimia can appear normal. That can make you feel like you’re not ill enough and kick starts a cycle of shame.” (Claire)

“They always want to know your lowest weight and always ask if you have pictures of yourself at that weight. I want them to appreciate you don’t have to be a low weight to be anorexic.” (Kate)

On social media the Fixers said that there was an abundance of ‘triggering content’, easily accessible on Tumblr, Instagram, and pro-anorexia and bulimia sites. The pictures and advice promoting weight loss were considered to be the most triggering factors. Young people said that the posting of images was to ‘get likes’ from followers (peers) possibly to gain recognition and validation for posting the extreme images. The Fixers said it made them want to go to ‘extremes with their eating disorder’.

“We all seem to want to put ourselves on a platform on social media. If you get more likes on your ill photo than that must be good. We need to educate children about this at an early age.” (Tabitha)

“The trouble is you might be struggling but you might look fine. Maybe you’ve got to a healthy weight and people think you’re better and the help stops. I was in hospital for six years from 11 to 17. As soon as my BMI was high enough, I was discharged and relapsed every time until I finally got better. But now I want people to know, I’m better but it hasn’t gone.” (Kate)

The Fixers also reflected on what they would like to change in the media to help themselves and others experiencing an eating disorder engage more positively with media platforms. They decided on several solutions:

1. Better regulation by a governing body, which involves service users and NGOs (non-governmental organisations) that truly understand the conditions and related issues;
2. Better access to good quality support on social media sites;
3. More robust awareness campaigns supported by the media. For example, using a change.org petition, calling on the media for new ways of thinking around low weight images. The media to work with young people with lived experience of eating disorders to show the realities of the conditions and not just the sensationalised stories;
4. Images that have been edited should be marked as photo-shopped;
5. Internet providers and social media companies to identify and remove triggering images.

With the heavy focus by the media on the physical representations of what an eating disorder looks like the young people felt that eating disorders are ignored in the media as a mental health issue. They felt that the psychological aspects of living with an eating disorder as a mental health condition needed to be portrayed more readily across media platforms.
For many young people home is a safe and secure place, however, for those with an eating disorder home life can become a source of anxiety and friction. The illness can also have an extreme consequential effect on families and carers trying to support young people with the condition. Families can become overwhelmed and desperate to seek out ways to help those in their care to recover (BEAT, 2015). In a recent survey by BEAT, 90 per cent of those involved in the survey (sufferers, carers, and families) reported a very significant or significant impact on their well-being and quality of life due to the condition (BEAT, 2015:43).

Adding further to this body of knowledge, the young people engaged in the Feel Happy [Eating] Fix were asked to consider what the most significant issues were for them in the home environment when they thought about their eating disorder experiences.

All of the young people involved in the study reported that their home life had been adversely affected by the eating disorder. They highlighted that parents, carers, and siblings struggled to understand what was happening to them. They also identified that there was a generational gap in thinking that needed to be overcome and also disparity in understanding eating disorders between male and female members of the family. Many also reported that there was a significant amount of lying and secrecy around the eating disorder. Young people would hide their behaviours (for example throwing away food, over
exercising, purging) and family members would keep things from them, such as family deaths and relationship breakdowns, in order to protect the young person from further trauma. Both the former and the latter scenarios created environments of distrust.

“There’s a lack of understanding at home. My parents didn’t want to come to my therapy because they thought it was my issue. My parents’ generation shrug off eating disorders.” (Tabitha)

“Mum was more understanding than Dad. He just thought I should eat. He understood more once he got some support.” (Michael)

“Dad used to shove a Gregg’s mince pie in front of me.” (Toni)

“Whenever there was a family death they would hide it from me. They didn’t tell me.” (Michael)

All of the young people consulted said that eating disorders can have a negative effect on the whole household. Some of the Fixers talked about how their parents felt responsible for their eating disorder and guilty for the disproportionate amount of time they spent focused on them compared to their siblings. Relationships with siblings also suffered as the eating disorder would cause them to get angry and act out their frustrations on their siblings and other family members, causing them emotional distress. The Fixers said they felt guilty and ashamed for the impact their condition had on the family.

“My sister was very sad. She worried about everything, about me not being able to get better and not being the way we used to be as brother and sister. She was also scared of the psychiatric hospital, so she couldn’t always visit me.” (Michael)

“My parents felt guilty and thought it was their fault. They didn’t understand my mental illness because they didn’t have one. I’d love to make them understand.” (Tabitha)

“My eating was part of something else. Even now I’m still not better but I’m scared my younger sister will look up to me and follow in my footsteps.” (Toni)

All of those consulted agreed that communication between family members broke down at the most difficult times, particularly around mealtimes where there was pressure to eat. They felt that lack of understanding from family members was largely the cause. Young people described feeling significant pressure to get better.

“Foster families don’t have the skills to deal with it. I assaulted a foster parent because they locked me in a room to force me to eat.” (Florence)

“The dietician told my mum, in front of me, to add cream to food. This increased my anxiety and made me not trust my mum and her cooking.” (Michael)

“My sister had to live with my Grandma and I didn’t see her for almost a year because she couldn’t be around me and she was only in primary school.” (Michael)

The young people talked about a number of positive and practical solutions to support those experiencing eating disorders and their families to improve the home environment:

6. Clear guidelines for all carers on spotting the signs of eating disorders and mental illness in general and advice on where to go for support. Parent-to-parent support can be really valuable;

7. Provide support for all household members, recognising that different families need different kinds of support. Carers should be linked into treatment options so that young people get better support at home to recover;

8. All generations need to talk to each other about difficult subjects and to understand that eating disorders are not just about the physical act of eating to get better but also about the underlying mental health issue.
Experiencing an eating disorder and attending school, college or university, can be incredibly traumatic for young people. More than ever before young people are under increasing societal pressure to achieve academically and be popular amongst their peers. There are many complex reasons eating disorders develop and school pressure, such as bullying and exams, can be a precursor and contributing factor (The Independent, 2014). For many young people symptoms of eating disorders are initially recognised under the age of 16 in 62 per cent of cases. This is at a critical time in their compulsory learning period and has severe implications for educational attainment and longer-term impacts on their employment and earning potential (BEAT, 2015:7).

Offering further insight into eating disorders and the learning environment young people told the Feel Happy [Eating] Fix that their eating disorder was difficult to manage while in education. They highlighted several issues, of which, the following were deemed to be most pertinent.

All of the young people involved in the focus groups agreed that the greatest problem was that staff in educational settings lack understanding around eating disorders and mental health issues in general, and there was generally poor pastoral care. The Fixers said that education professionals simply did not know how to help because they did not have any suitable training. They were unaware of the signs and symptoms of eating disorders. As a result communication between students and professionals was poor and the subject of eating disorders avoided. Instead the focus was largely on obesity and the importance of eating five fruit and vegetables a day. They also said that their peers lacked understanding and

I’d sit in class and openly be taking diet pills and using hunger strips but the teachers turned a blind eye. Only one asked me if I was ok.
would avoid them. Moreover, due to long periods out of school for treatment they were left feeling ‘out of synch’ with their peers.

“I’d sit in class and openly be taking diet pills and using hunger strips but the teachers turned a blind eye. Only one asked me if I was ok.” (Toni)

“Once you came out of treatment, and returned to school you were the focus of attention which lead to problems [bullying].” (Michael)

“My friend said I made her feel negative about her body. I was bullied and called names before the diagnosis. I spent all my time in extra support even though I was already in a specialised school environment.” (Toni)

“Education should also focus on puberty, the calories needed for a body going through change and the physical changes that happen [in relation to the ‘5 a day message’].” (Claire)

All of the young people agreed that there was too much pressure on young people in school to achieve high academic standards. They also acknowledged that there was significant pressure on teachers too to ensure pupils met target grades (5 A*-C at GCSE for example). Many of the Fixers felt that the pressure of exams had been a contributing factor in their eating disorder and/or exacerbated the condition.

“There is too much pressure. There is too much stress on young people and teachers. This can be because of exams and can lead to mental health issues.” (Claire)

The Fixers all agreed that there was a lack of support for young people at risk and those struggling with an eating disorder in the education environment. Where there was support, such as a counselling service, it was felt to be inconsistent across educational settings, with universities offering more support than schools and further education institutions. Some young people said that transitioning back into the school environment after a period of treatment was a very difficult time because the support and attention they received in hospital or as an out-patient was no longer available. Without support in schools (not excluding other environments) they were concerned about relapsing, and indeed some did.

“It’s important to have someone to support you when you return to school and to have a say in who is giving you that support. I didn’t trust the person who was assigned to me.” (Toni)

“It was all about obesity and getting your 5 a day. There was no support or focus on nutrition and wellness education.” (Tabitha)

“Help transitioning [back into school] is needed most people have more than one condition at a time.” (Michael)

Throughout the focus group discussions the young people agreed on a number of solutions to support young people with eating disorders throughout their engagement with the education system.

9. Mandatory mental health training for all education professionals. In the same way as First Aid is delivered and awarded with a simple badge system;

10. Better teaching around eating disorders and nutrition for children from primary school age. This could be taught creatively through all subjects, such as English and Science;

11. More and better qualified counsellors and stronger support for young people coming out of treatment and transitioning back into mainstream education. There needs to be greater access to counselling in schools, and further and higher education institutions, which is tailored to individual needs.
Gaining and maintaining employment while living with an eating disorder can have significant impacts on young people, in relation to both the personal and economic effects time off work for treatment can have on their future earnings and professional development. Indeed, it is estimated to cost a young person, under the age of 20, approximately £650 per annum to be unwell with an eating disorder (BEAT, 2015:9). Managing an eating disorder in the workplace can be incredibly difficult for young employees. While anyone at any age can develop an eating disorder, young people may be particularly vulnerable in the workplace. With little experience and understanding of the workplace it can be difficult to know how best to seek the support they need to manage their condition at work. Add to the equation workplace stress and demanding situations, the workplace can be a challenging environment for those experiencing an eating disorder (BEAT, 2015).

The majority of the young people engaged in the *Feel Happy [Eating]* Fix shared a negative experience of having an eating disorder whilst in employment.

All of the young Fixers said that their main concern in the workplace was the discrimination that they had experienced. Some had been sacked due to the need to seek urgent in-patient treatment. Some were also told they were a health and safety risk and a danger to themselves and others. They also found the physical environment discriminatory, for example, where there was no working lift and they had to take the stairs. The Fixers also said it was difficult to gain employment in the first instance.
because they needed time off for numerous and ongoing appointments to support their recovery.

“I got told I wasn’t allowed to return to work when I was put in hospital. My parents told them that I couldn’t go into work and my manager said I was a disgrace and that I’d left them understaffed. That’s all they cared about.” (Tabitha)

“I was physically unable to work because there were stairs and they told me I was a health and safety danger in case I collapsed or something. The employers were more interested in covering themselves than making sure I was okay.” (Sophie)

“There is a problem even trying to get work. I have to tell them that I need so much time off and then I don’t hear back. You interview and you never hear anything back and then you start thinking ‘oh it’s because of my mental health’.” (Natalie)

A continuing theme throughout the Feel Happy [Eating] Fix is the lack of understanding people have about eating disorders and mental health conditions in general. This was also prevalent in the workplace and the Fixers all felt that employers and colleagues had limited or no knowledge at all of eating disorders and that in particular they lacked compassion.

“It’s a lack of understanding. Whenever I’m working I get told that I should be better now. There is a shock about me still going to appointments. They think that because I’m eating now I should be better.” (Michael)

“I’ll only work in the voluntary sector as long as it’s mental health related because there is a such a lack of understanding in other sectors.” (Natalie)

“There isn’t a compassionate nature in work, it’s all about getting stuff done. If someone is in a wheelchair they would do stuff so why not for mental health.” (Andrew)

“General education is needed on what is okay to say to people and what isn’t. That would help. People commenting on my weight don’t know that what they say is hurtful, they just don’t know.” (Louise)

A further area of consensus from the Fixers was the lack of flexibility to implement recovery plans in the workplace. This ranged from lack of understanding and support to implement flexible working hours to attend treatment appointments, to not being able to take regular breaks to follow recovery meal plans.

“They said they wouldn’t give me work credit or even a reference. I was told that I shouldn’t be in an academic faculty and that I should be committed. I felt so let down because all I’d asked was to go part-time because I needed time off for hospital appointments.” (Florence)

“Workplaces being weird with lunchbreaks is bad because it can affect an important routine. There is a lack of understanding about why you actually need that break. If you had diabetes they’d let you go for a break!” (Kate)

“Having a quiet place to eat is important because some people don’t like eating in front of others.” (Natalie)

The young people discussed a number of practical recommendations for employers and industry regulators to support young people and others in the workplace who have an eating disorder:

12. An accredited ‘Eating Disorder’ kite mark/logo should be introduced into the workplace to signify and reassure that the employer is a ‘Eating Disorder’ friendly place to work;

13. Work based training on what an eating disorder is and how to support a colleague to build empathy and understanding;

14. Employers to offer employees more flexibility to implement return to work plans, which may include but not exclusive to: flexible hours; regular breaks; a buddy support system; and a quiet space to eat.
For young people experiencing an eating disorder early intervention and access to good quality and timely healthcare are significant factors in the successful treatment of eating disorders and prevention of relapse. It is important that treatment is secured early as research suggests that “over time, untreated, eating disorders may become entrenched with more profound physical and psychiatric co-morbidity” factors (BEAT, 2015:6). Moreover, neuroprogressive (brain structure) changes occur as the body adapts to prolonged periods of starvation and/or abnormal eating behaviours and this can make the illness even more difficult to treat. Furthermore, it severely impacts physical and emotional health, and overall quality of life. This can render young people dependent on their families or the state for longer periods of time (BEAT, 2015).

All of the young people involved in the Feel Happy [Eating] Fix had experience of ongoing in-patient and/or out-patient hospital and wider clinical care. They had all experienced various parts of the NHS, including primary care through first presenting to their General Practitioners with symptoms and then via referral to secondary care involving specialised child and adolescent mental health services (CAMHS). The following accounts and recommendations for action aim to enhance understanding of the often difficult

“I think mental health staff need training from people who have had an eating disorder - because nurses just read from a textbook. I can’t just put food in my body like I’m putting petrol in a car. There are no feelings in a car.”
NHS journey young people experience while in treatment for an eating disorder.

There was broad agreement across the focus groups that the Fixers all experienced some negative elements to their care.

A key finding from the *Feel Happy [Eating] Fix* is that the majority of young people were told they were not considered ill enough to receive treatment. The young people felt the focus by clinicians was on the physical aspects of the eating disorder, for example whether their Body Mass Index (BMI) was in a ‘healthy’ range. If it was, they would not receive treatment. There is a strong trend for this practice. The Fixers said that the attention paid to the physical aspects of the illness caused them further harm and in some instances made them more critically ill as they tried to ‘prove’ they were ill enough to receive treatment by losing more weight.

“I could be waiting months for a letter telling me that I’m not bad enough for services.” (Natalie)

“There are no precautionary measures, it’s like they just wait until you’re at your worst.” (Sophie)

“What they don’t realise is that in itself [being told you are not ill enough for treatment] is a trigger because you think ‘oh god I’m still not skinny enough’.” (Tabitha)

“I was given BMI tests but because I was working out so much and had muscle mass, my BMI would always say I was at a healthy weight.” (Michael)

The Fixers also told the *Feel Happy [Eating] Fix* that they often felt ignored and not listened to by healthcare professionals and that clinicians focused on the physical aspects of the condition and not the mental health issues. This approach was considered to be detrimental to their treatment and limited their recovery. Many young people talked about physically gaining weight but psychologically feeling exactly the same. Therefore, when they were given complete autonomy over their lives again they would relapse.

“You get put on anti-depressants because they just want to palm you off and they don’t want to listen.” (Tabitha)

“I was just given a book for professionals and was told to read that. But I’m not a professional. You go to the experts because they’re supposed to be!” (Matilda)

“They don’t treat me as a person they just treat me as an illness.” (Natalie)

“With my GP I feel compared to when I’ve been more unwell. They say ‘well you’re not as bad as you were before.” (Florence)

“Whenever I was given complete freedom again I would just relapse.” (Louise)

“With my GP I feel compared to when I’ve been more unwell. They say ‘well you’re not as bad as you were before.” (Florence)

“I think mental health staff need training from people who have had an eating disorder - because nurses just read from a textbook. I can’t just put food in my body like I’m putting petrol in a car. There are no feelings in a car.” (Kate)

Young people also told the *Feel Happy [Eating] Fix* that there was a lack of treatment options available close to home. The majority of the Fixers talked about how they had to travel long distances, in some cases up to 200 miles for treatment. The physical distance between the young person and their family and friends enhanced feelings of isolation and in some cases hindered recovery. Once in treatment many of the Fixers felt that the range of therapies available to them was limited and not always suitable to their needs.

“I had to travel over 200 miles to visit a team that could actually cope with my eating disorder” (Florence)
“I’ve been in seven different psychiatric units and only one of them offered me a talking therapy. I had to wait three and half years for 6 months of that talking therapy” (Natalie)

“There needs to be better options for care and what treatment you can get. There needs to be more diversity in care” (Andrew)

“I was waiting for letters of referral and when I chased up it turned out I wasn’t even on the list” (Toni)

“Eating disorder NHS services they think that their way of treating you is going to work the same way for everybody. They don’t cater for different eating disorders or things like that. I had nutritional supplement drinks called Fortisip. I got dependent on them. I only got used to drinking and not eating so how was I supposed to learn how to eat solid food again. They would also put on Fortisip the calorie intake on the front of the bottle. So obviously you know you’re only having 300 calories 3 times a day, you’re only having 900 calories a day. I can go and burn that off”. (Tabitha)

Young people across the Feel Happy [Eating] Fix’s focus groups agreed on several key recommendations to support young people experiencing eating disorders and engaged in health services:

15. Revise the treatment criteria in NICE guidelines and remove the BMI measure;

16. All medical professionals to receive mental health training to be delivered by those with lived experience of an eating disorder. The training should encourage empathy and understanding;

17. Government to prioritise funding for more services and different types of therapy, so that young people can access treatment closer to home and whole person treatment with different therapy options (such as more different types of talking therapy and art therapy);

18. Remove the calorie intake information from Fortisip bottles and ensure ‘meal plans’ include solids as well as fluids.
The ability to form bonds, develop and maintain relationships are a crucial part of the life cycle, particularly in childhood and adolescence. However, for some young people experiencing an eating disorder the effects of the illness can make establishing and upholding relationships with their friends and peers problematic. Due to the often secretive behaviour associated with eating disorders many young people can feel isolated by their illness both physically and psychologically (Healthtalk, 2015) and feel that others their age lack understanding about what is happening to them and how to help.

There was broad agreement among the Fixers to the Feel Happy [Eating] Fix that their relationships with friends and peers had been impacted by their eating disorder in the following notable contexts.

**Isolation was felt to be a significant factor for young people experiencing an eating disorder.** Many of them experienced the co-occurrence of physical and emotional isolation. There was self-imposed isolation due to the modern culture of socialisation around food and alcohol, which they found difficult to be around. Isolation was also unintentionally enforced due to long periods in treatment and being too physically exhausted to communicate with friends. Some Fixers also reported that the effects of the illness caused their personality traits to change and they could be angry towards friends, which made maintaining relationships hard while they were particularly unwell. The male Fixers also noted that there was more compassion and understanding for girls and women with an eating disorder than young men. Thus, creating a gender bias towards girls and unfairly discriminating against males with eating disorders. The young men felt their masculinity was challenged by what is seen as an illness that only affects girls and women.

“It starts with self-isolation then your friends give up. Then you feel worthless and it just snowballs.” (Sophie)
“For me it was the isolation. In our culture a lot of socialisation revolves around food. It’s really hard because you don’t know what to do with your friends and it adds to the isolation. Alcohol as well because people with eating disorders often have alcohol misuse. I turned into not a nice person to be around.” (Toni)

“You can’t put yourself away from food when socialising and therefore you have to keep cancelling and your friends think you’re being rude.” (Claire)

“It was hard being a boy and being diagnosed with an eating disorder. Whenever I went back to school my friend would call me a ‘fruit’ or a ‘pansy’ because they said I had a girl’s illness.” (Michael)

The cohort of young people also told the Feel Happy [Eating] Fix that they felt they had lost their childhood. They did not feel part of the day to day experience of being a young person and had to mature quickly to understand their illness and begin treatment and recovery.

“Having to grow up too quick is really difficult.” (Natalie)

“For a lot of people they talk about their teen years but my teen years were spent in hospital. You feel abnormal because your experiences are so different.” (Florence)

“People my age are out partying but I can’t relate to that. I can’t relate to older people either so I don’t have these close relationships.” (Natalie)

“I didn’t think I’d be in rehab at 18, I thought I’d be in Ayia Napa with my mates.” (Tabitha)

All of the Fixers raised the issue of a lack of understanding among friends and peers about eating disorders. This theme continues throughout the Feel Happy [Eating] Fix. The young people said their friends would often, unintentionally, upset them by commenting on their weight, what they ate, and talking about ‘fad’ diets friends were trying. In the more extreme cases some Fixers said their friends stopped being friends with them because their parents said they were a bad influence.

“It’s a lack of understanding and fear of the unknown. Because mental health is so unknown people feel uncomfortable and they make jokes. My friends actually stopped hanging out with me because their mums said I was a bad influence.” (Natalie)

“My friends accused me of attention seeking but if it was more understood friends would understand why you are like you are more.” (Kate)

“If I am not having a slice of cake it’s just because I don’t fancy it!” (Claire)

“We’ll go out for dinner and they’ll [friends] make comments like ‘aren’t you going to have a salad’ and they’ll start to talk about fad diets and I just want them to be more courteous.” (Tabitha)

The young people also reflected on what they thought would help support young people with eating disorders to forge and maintain relationships with their friends and peers. There was an overwhelming consensus for information and training around what an eating disorder is and how to support someone experiencing the condition:

19. Information to be delivered to young people about eating disorders and related mental health conditions and how to offer support. This should take place in school (by teachers and peer to peer) and online so that it can be easily shared. The training should be delivered creatively and designed with those with lived experience;

20. An online campaign focused on what an eating disorder is and how to help;

21. Improve signposting to and the quantity of support groups and one to one support for individuals.
The research has outlined a number of recommendations where Fixers (young people) have suggested that education and awareness is required throughout the settings to help people understand eating disorders and how to support young people. Young people believe that such programmes should be designed and delivered by young people with lived experience and cover:

- Spotting early signs;
- How to react;
- How to communicate with people who are unwell;
- How to support young people after treatment (to include educational attainment);
- How to support friends of young people with eating disorders;
- The importance of being flexible and empathetic;
- How to support/manage timetable/exams/homework;
- The difficulties people experience eating in front of others. Teachers should sit and chat and monitor;
- Praising the positive;
- Making everyone feel they have their self-worth;
- How to reinforce that health and happiness is as important as exam success;
- How to avoid encouraging perfectionism.
CONCLUSION

This exploratory research sets out to uncover the most significant issues facing young people with an eating disorder in the UK today, paying particular attention to the settings in which they live their lives. The broad question of: What issues come to mind when you think about your eating disorder in X setting? (i.e. at work) was asked throughout the 6 focus group sessions. The answers and corresponding recommendations for change were wide ranging and offer thought provoking and practical measures for policy makers and practitioners alike.

The Feel Happy [Eating] Fix uncovered the relationship between the media and its influential impacts, which often exacerbate eating disorders in young people. Young people cited that the media failed to represent eating disorders as mental health conditions, instead favouring more sensationalised story formats focusing on specific eating disorders, low weight pictures, and how little they ate. Social media was cited as a significant medium perpetuating triggering content with little concern for users’ safety. The key recommendation for policy makers in this context was to introduce regulation by a governing body to oversee balance in the reporting of eating disorders and to stamp out potentially triggering content.

In the home environment there was recognition of the negative effect that eating disorders can have on the whole family. This was keenly felt around meal times. Young people noted a generational divide between older members of the family failing to understand the condition and its relation to a mental health issue. This was even more pronounced for male family members. Young people urge policy makers and practitioners to provide clear guidelines for all carers on spotting the signs of eating disorders and where to go to get help.

Educational settings have been proved to be highly pressured problematic environments for young people experiencing an eating disorder. They feel misunderstood by teaching professionals, peers, and experience poor on-site support. The Fixers call for mandatory mental health training for all teaching professionals and access to counselling services in education institutions.

The Feel Happy [Eating] Fix has also highlighted how difficult young people with an eating disorder find it to gain and maintain employment, with many employers actively discriminating against young people who need to take time off for appointments. Young people want to see employers taking mental health conditions, such as eating disorders, seriously, and offer them flexible working conditions to support them in the workplace.

The evidence presented also outlines the need for major revisions in the health service. There is a worrying trend among clinicians to refuse treatment, in line with strict NICE guidelines, and reserve it for the most severe cases. The Body Mass Index measure (BMI) is described by young people as particularly unhelpful to measure the severity of an eating disorder, particularly for young men, who have a high muscle mass and therefore a higher corresponding BMI. The BMI measure also fails to account for the debilitating psychological impacts of an eating
disorder. A young person may be within the ‘healthy’ weight range but psychologically extremely unwell. Young people do not feel listened to by healthcare professionals and often feel that the physical side of the eating disorder is treated separately to the mental health elements of the eating disorder. The combination of these factors, coupled with long waits for treatment miles from home, creates a toxic environment for young people, who can become critically ill while waiting for treatment. The Fixers are calling on policy makers and practitioners to prioritise funding for more services and revise treatment criteria.

In the Play (socialising) setting, the Feel Happy [Eating] Fix has found that young people experiencing eating disorders feel isolated and alone as they struggle to forge and maintain friendships. The evidence outlines that this is largely due to lack of understanding by friends and peers about eating disorders but also due to popular culture, such as eating out and drinking alcohol, which young people with an eating disorder struggle to engage in and tend to avoid. At a crucial time in young lives when socialising with friends and having fun is the norm, young people with eating disorders are mourning the loss of their childhood. Crucially, the evidence also highlights a distinct gender bias towards girls and women with eating disorders which unfairly discriminates against males with the condition. The Fixers are calling on policy makers to ensure that information about eating disorders, related mental health conditions, and how to offer support is delivered in schools. This should be alongside better signposting to support services and online eating disorders awareness campaigns.

What underpins the Feel Happy [Eating] Fix however, are two key themes that run throughout. Parents, carers, professionals and peers, lack understanding of eating disorders, the symptoms, and how best to support young people with the condition. Furthermore, the heavy focus by society as a whole on the physical manifestations of eating disorders renders the psychological aspects a poor relation. Fixers (young people) outline how education and awareness raising campaigns, designed and delivered by young people with lived experience, are a critical remedy to these problems. The Feel Happy [Eating] Fix outlines that eating disorders are complex mental health issues that require understanding and a significant cultural shift is required, throughout society, to recognise their severity and the need for accessible and timely treatment. Only then might we strive to reverse the worrying trend blighting young lives throughout the UK.

This report is the work of 12 young people with experience of eating disorders who have become Fixers to use their past to fix the future. It has been compiled by Dr Gemma McKenna, Public Affairs, Policy and Research Lead at Fixers.
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