



**A review of users' experiences of
services for people with Eating Disorders
in the East Riding of Yorkshire**
March 2015

A review of users' experiences of services for people with Eating Disorders in the East Riding of Yorkshire

“WE WANTED TO CREATE A REPORT TO HIGHLIGHT THE EXPERIENCES AND OPINIONS OF PEOPLE USING LOCAL EATING DISORDER SERVICES”

Healthwatch East Riding of Yorkshire

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Executive Summary

The views, opinions and statements made in this report are those of the public who have had first-hand experience with an Eating Disorder, specifically young people who have gone through the adolescent service. This report is about putting forward the public perception of local Eating Disorder services. This perception may not fully or accurately reflect all the work being carried out in the local area. Nevertheless, it is the perception from the information we have collected.

Brief background to report

This report provides public opinion, analysis and recommendations of Eating Disorder (ED) services that function in the East Riding, specifically services for those people under the age of 18.

Methodology

Methods of collecting data included a public survey available for anybody to complete and a listening event, which was also open to the public. The majority of engagement in both was from people who had used Eating Disorder services and their families. Information was recorded by the HWERY team. Testimonials submitted by service users and family members also contributed to the collection of relevant information. HWERY then evaluated the information we had collected to create a series of recommendations.

Participants

Those who attended the listening event were a mixture of service users, family members and professionals who work with young people who are service users.

Highlights of findings

The information we collected from public consultation pointed to the following:

- Inconsistent services
- Lack of beds
- Poor handovers in hospitals
- GPs struggling to diagnose early
- Public sector need more information to help support those with an Eating Disorder

Recommendations

1. East Riding of Yorkshire Clinical Commissioning Group (ERYCCG) and Humber NHS Foundation Trust to promote the services available for people with Eating Disorders and improve public awareness.
2. East Riding of Yorkshire Council (ERYC) to commission specific and tailored information for organisations and educational institutions who have first-hand contact with young people to raise awareness of the signs and symptoms of Eating Disorders. This could be training aimed at teachers, parents and anybody else who works with young people.
3. East Riding of Yorkshire Clinical Commissioning Group (ERYCCG) to increase GPs' awareness of eating disorder pathways and support services available locally.
4. ERYC to increase public awareness of support that is available for individuals with an Eating Disorder.
5. ERYC to improve public awareness that an eating disorder is a mental illness not a nutritional one.
6. ERYC Services to ensure Tier 1 and 2 (ERYC) and Tier 3 (ERYCCG) services are commissioned and delivered within the East Riding of Yorkshire to ensure services are available locally for the people who need them.

7. ERYCCG, Humber NHS Foundation Trust and ERYC to work together to provide a seamless and smooth transition from services for children and young people to those provided for adults.

Background

In January 2014 Healthwatch was approached by members of the general public, raising issues and concerns about services in the East Riding for people with eating disorders. Having heard of their concerns the HWERY Board agreed we would collect relevant and accurate information from the community and identify any current issues in eating disorder services for the East Riding.

A listening event was held in July 2014. The event was open to the general public however we expected people who have been affected by eating disorders to be in the majority of those attending.

What is an eating disorder?

Definition

Eating disorders are characterised by an abnormal attitude towards food that causes someone to change their eating habits and behaviour.

A person with an eating disorder may focus excessively on their weight and shape, leading them to make unhealthy choices about food with damaging results to their health.

Types of eating disorders

Eating disorders include a range of conditions that can affect someone physically, psychologically and socially. The most common eating disorders are:

- **anorexia nervosa** - when someone tries to keep their weight as low as possible, for example by starving themselves or exercising excessively
- **bulimia** - when someone tries to control their weight by binge eating and then deliberately being sick or using laxatives (medication to help empty their bowels)
- **binge eating** - when someone feels compelled to overeat

Some people, particularly young people, may be diagnosed with an eating disorder not otherwise specified (EDNOS). This means a person may have some, but not all, of the typical signs of eating disorders such as anorexia or bulimia.

Causes of eating disorders

Eating disorders are often blamed on the social pressure to be thin, as young people in particular feel they should look a certain way. However, the causes are usually more complex.

There may be some biological or influencing factors, combined with an experience that may provoke the disorder, plus other factors that encourage the condition to continue.

Risk factors that can make someone more likely to have an eating disorder include:

- having a family history of eating disorders, depression or substance misuse
- being criticised for their eating habits, body shape or weight

- being overly concerned with being slim, particularly if combined with pressure to be slim from society or for a job (for example ballet dancers, models or athletes)
- certain characteristics, for example, having an obsessive personality, an anxiety disorder, low self-esteem or being a perfectionist
- particular experiences, such as sexual or emotional abuse or the death of someone special
- difficult relationships with family members or friends
- stressful situations, for example problems at work, school or university

Warning signs to look out for include

- missing meals
- complaining of being fat, even though they have a normal weight or are underweight
- repeatedly weighing themselves and looking at themselves in the mirror
- making repeated claims that they have already eaten, or they will shortly be going out to eat somewhere else
- cooking big or complicated meals for other people, but eating little or none of the food themselves
- only eating certain low-calorie foods in your presence, such as lettuce or celery
- feeling uncomfortable or refusing to eat in public places, such as a restaurant
- the use of "pro-anorexia" websites (1)

Treating eating disorders

If not treated, an eating disorder can have a negative impact on someone's job or schoolwork, and can disrupt relationships with family members and friends. The physical effects of an eating disorder can sometimes be fatal.

Treatment for eating disorders is available, although recovering from an eating disorder can take a long time. It is important for the person affected to want to get better, and the support of family and friends is invaluable.

Treatment usually involves monitoring a person's physical health while helping them to deal with the underlying psychological causes. This may involve:

- using self-help manuals and books, possibly under guidance from a therapist or other healthcare professional
- cognitive behavioural therapy (CBT) - therapy that focuses on changing how someone thinks about a situation, which in turn will affect how they act
- interpersonal psychotherapy - a talking therapy that focuses on relationship-based issues
- dietary counselling - a talking therapy to help people maintain a healthy diet

- psychodynamic therapy - counselling that focuses on how a person's personality and life experiences influence their current thoughts, feelings, relationships and behaviour
- family therapy - therapy involving the family discussing how the eating disorder has affected them and their relationships

Medication - for example, a type of antidepressant called selective serotonin reuptake inhibitors (SSRIs) may be used to treat bulimia nervosa or binge eating. (2)

Implications of an Eating Disorder

Health Consequences of Eating Disorders

Eating disorders are serious, potentially life-threatening conditions that affect a person's emotional and physical health. They are not just a "phase." People do not "catch" an eating disorder for a period of time. They are real, complex, and devastating conditions that can have serious consequences for health, productivity, and relationships.

People struggling with an eating disorder need to seek professional help. The earlier a person with an eating disorder seeks treatment, the greater the likelihood of physical and emotional recovery.

Health Consequences of Anorexia Nervosa

In anorexia nervosa's cycle of self-starvation, the body is denied the essential nutrients it needs to function normally. Thus, the body is forced to slow down all of its processes to conserve energy, resulting in serious medical consequences:

- Abnormally slow heart rate and low blood pressure, which mean that the heart muscle is changing. The risk for heart failure rises as the heart rate and blood pressure levels sink lower and lower.
- Reduction of bone density (osteoporosis), which results in dry, brittle bones.
- Muscle loss and weakness.
- Severe dehydration, which can result in kidney failure.
- Fainting, fatigue, and overall weakness.
- Dry hair and skin; hair loss is common.
- Growth of a downy layer of hair called lanugo all over the body, including the face, in an effort to keep the body warm.

Health Consequences of Bulimia Nervosa

The recurrent binge-and-purge cycles of bulimia can affect the entire digestive system and can lead to electrolyte and chemical imbalances in the body that affect the heart and other major organ functions. Some of the health consequences of bulimia nervosa include:

- Electrolyte imbalances that can lead to irregular heartbeats and possibly heart failure and death. Electrolyte imbalance is caused by dehydration and loss of potassium, sodium and chloride from the body as a result of purging behaviours.
- Potential for gastric rupture during periods of bingeing.
- Inflammation and possible rupture of the oesophagus from frequent vomiting.
- Tooth decay and staining from stomach acids released during frequent vomiting.
- Chronic irregular bowel movements and constipation as a result of laxative abuse.
- Peptic ulcers and pancreatitis.

Health Consequences of Binge Eating Disorder

Binge eating disorder often results in many of the same health risks associated with clinical obesity. Some of the potential health consequences of binge eating disorder include:

- High blood pressure.
- High cholesterol levels.
- Heart disease as a result of elevated triglyceride levels.
- Type II diabetes
- Gallbladder disease (3)

Existing Eating Disorder services in the East Riding of Yorkshire

CAMHS

Community Child and Adolescent Mental Health (CAMH) Services in Hull and the East Riding of Yorkshire have recently undergone a service wide redesign. These developments reflect recent CAMHS reviews, consultations with the young people who use CAMH services and their families and the way child and adolescent mental health services are changing across the country.

CAMHS provided by Humber NHS Foundation Trust is made up of **three** key elements

- Contact Point
- Core CAMHS
- Intensive Intervention Team

Contact Point

Contact Point provides a single point of access, staffed by clinicians, that has been designed to improve the ease of access and availability of CAMHS for children, young people and their families. This is new to Hull and the East Riding of Yorkshire.

Referrals will come from professionals working in health, social care, voluntary agencies or education as well as self-referrals direct from families and carers. Young people aged 16 and over will also be able to refer themselves.

There will be a campaign to raise awareness of Contact Point so local families know they can contact the service directly for advice and support without the need for a GP referral. Contact Point will be the Single Point of Access to all CAMHS services.

The primary role of the Contact Point is to review and respond to all referrals and contacts by undertaking a robust telephone triage. They will then determine the most appropriate response to meet the needs outlined and if necessary signpost to other relevant services. Referrals accepted to a CAMHS clinical pathway are then passed to core CAMHS for assessment and treatment.

Core CAMHS

Core CAMHS provides a specialist assessment and treatment service to children and young people up to 18 years of age who are experiencing significant emotional or mental health difficulties. In practice, CAMHS involvement does not usually begin before the start of attendance at primary school but advice can be given to the parents of younger children if needed.

CAMHS has clinical care pathways in place to help with problems including depression and mood, eating difficulties, self-harming, ADHD, severe behaviour problems and psychosis.

A comprehensive range of services and interventions are available in a variety of community settings across Hull and the East Riding. A Key worker is allocated to remain with each family throughout their time with CAMHS.

CAMHS Intensive Intervention Service

The team offers a specialist Children and Adolescent Mental Health Service provision to children and young people whose needs (usually due to risk and/or severity of presenting problems) cannot be met by core CAMHS. Intensive Intervention should be considered as an extension of the integrated Pathway Model, ensuring continuity of care for the child, young person and family and enabling an effective step-up, step-down service delivery model.

The team offers high intensity; time limited interventions, into existing care plans without duplicating services. The service aims to support the principles of a Care Programme Approach (where relevant) and reduce the gap between community CAMHS and inpatient care. It also aims to address the needs of young people and families who have worked with CAMHS for some time but change has been difficult to achieve. (4)

Public Health

East Riding of Yorkshire Council Public Health team are taking steps to increase the awareness of Eating Disorders and are involving local organisations in the planning and delivery.

Public and Professional Awareness:

Article to be sent to the press, targeting parents

Article to be included in the Head teacher's bulletin directing people to resources which can be used in PSHE

BEAT (National Charity) posters and leaflets ordered and disseminated to GPs by the CCG

BEAT posters and leaflets ordered and to be disseminated to schools and colleges

Building Capacity within the Public Sector workforce:

This will include BEAT (National Charity) delivering two one-day training '*Understanding Eating Disorders*' events for frontline staff. These will be delivered in February 2015, to 60 people. CAMHS and the Eating Disorder Support Service (SEED) will be attending the above sessions to signpost people to local services

The course content includes:

- Signs and Symptoms
- Causes and risks
- Sources of help
- Diagnosis, treatment and recovery
- Key facts and figures
- Eating Disorders and the law
- The impact of peer pressure and the media
- Increasing self esteem

Resource Development- Guidance for Schools for Supporting Children and Young People within an Eating Disorder

A working group will be looking at guidance for schools on supporting pupils with an eating disorder and facilitating the delivery of two self-help awareness sessions in the East Riding (these currently only occur in Hull)

Service Development and Joint Working

Public Health in partnership with Library Services delivers the Reading Well - Books on Prescription scheme which contains a resource for people with Bulimia
Public Health also commission the Youth Mental Health First Aid training which includes information about Eating Disorders

National Support Services and Resources

Within the UK there are numerous organisations and resources that are available to those affected by ED. These organisations include:

- BEAT (Beating Eating Disorders) - Beat is the UK's leading charity supporting anyone affected by eating disorders or difficulties with food, weight and shape.
- National Centre for Eating Disorders - We believe that you have the right to have good help from someone who cares and understands.
- ABC (Anorexia & Bulimia Care) - For over 25 years, ABC has provided personal care and support for anybody affected by anorexia, bulimia, binge eating & all types of eating distress.

Humber Foundation Trust

Humber Foundation Trust are one of the main providers of Eating Disorder services and mental health services in the East Riding.

Humber NHS Foundation Trust provides a comprehensive range of mental health, learning disability, community and addictions services to people from Hull and the East Riding, a population of almost 600,000. The Trust also provide forensic services to patients from the wider Yorkshire and Humber area and employs approximately 3000 staff in locations across 70 sites.

As a Teaching Trust, we work closely with our major academic partners, Hull York Medical School and Hull University, nurturing a workforce of tomorrow's doctors, nurses and other health professionals. (5)

Eating Disorder Support Service (SEED)

Seed is a charity whose volunteers have first-hand experience of supporting individuals with eating disorders, making a difference to those people whose lives are blighted by this devastating illness.

SEED help with:

- Drop in sessions
- Young people
- Nutritional Information
- Buddy Systems
- Keeping Safe
- Workshops
- Online Resources

Research Methodology

Important reminder

The views, opinions and statements made in this report are those of the public who have had first-hand experience with an Eating Disorder, specifically young people who have gone through the adolescent service. This report is about putting forward the public perception of local Eating Disorder services. This perception may not fully or accurately reflect all the work being carried out in the local area. Nevertheless, it is the perception from the information we have collected.

Objective

To gain insight into the service-user perspective of ED services in order to make recommendations to local health and social care service commissioners and providers to inform and improve future planning and delivery.

Timescale

The timescale of all the research that HWERY conducted was from June through till September 2014. This gave us enough time to record results from numerous formats.

Recruitment & Publicity

HWERY wanted to ensure that the research we gathered for the report was first-hand. Using numerous tools we publicised an upcoming public listening event (Focus Group) in which HWERY would record information from those currently going through treatment, those with experience of the services or anybody who has any other connection to Eating Disorders locally.

The following methods were used to help recruit people to attend the event:

- Social Media - Using HWERY's social media pages we advertised the event
- ERED - East Riding Eating Disorders group sent out the information to anybody affiliated with their group via their mailing list.
- SEED - The Hull-based Eating Disorder support group also promoted the event to their members

Criteria

There was no set criteria in place for the type of attendee that we wanted at the event. Obviously those who have experience of the services are useful but we also received interest from teachers and public sector workers who encounter people with Eating Disorders and wanted to share their opinions. We did not specify that the event was for a certain age, race or gender. It was an open event.

Questionnaire

Prior to and for some time after the event we had a questionnaire available to anybody from the public. Those results are published in this report.

Data Protection & Anonymity

Throughout the time that HWERY was conducting research we knew that the subject was very personal and to some it would be difficult to put their name to anything publicly. Our survey/questionnaire was anonymous, also those who attended our focus groups did not have to contribute their name to anything that was to go public. HWERY ensured that privacy was maintained throughout.

Consent

All individuals who contributed gave their consent prior to information being added to the report. We also ensured anonymity by not providing names of those who provided testimonials.

Listening Event

The event took place at a primary school in Beverley on the 9th July 2014. The event was advertised as a listening event and HWERY facilitated the opportunity for those who have first-hand experience to tell us what is good or bad about local services.

To provide some structure and to stimulate conversation, we had two questions-

- a) What are your experiences of Eating Disorder services in the East Riding?
- b) What would you like to see changed with local services?

In total we had 17 participants who attended the listening event and these participants were split into two groups. Both groups had roughly 40 minutes to discuss the chosen topics and map out any and all answers. HWERY staff observed the conversations and made notes when appropriate. The attendees also made notes and mapped out their own ideas that were then shared with the other group taking part in the event. When ideas were shared this opened up a full conversation about the subject because the other group often had further observations and experiences to contribute.

The following themes emerged:

- Some GPs struggle to diagnose quickly
- Services are inconsistent
- There is a gap between services being provided to young service users and those provided to adults.
- Treatment tends to be shaped around nutritional information and does not address the fact that this is a mental illness.
- When using hospital services there is a lack of communication between staff especially when switching shifts which impacts on service users.
- Lack of provision within the East Riding for children who require 24 hour care and treatment.
- Some schools struggle to cope with students with an eating disorder.

The following comments expand on these six themes:

Healthwatch would again like to state that the views and opinions being put forward throughout this report are the opinions of those who have experience using the Eating Disorder services.

Some GPs struggle to diagnose early

This was a major issue raised by attendees. The concern being that Eating Disorders can rapidly deteriorate and lead to other health concerns as well as the individual developing other mental health conditions. Participants felt that if signs of eating disorder were caught early then this would help alleviate a lot of the long term conditions that occur as a result of a late or misdiagnosis.

It was highlighted that not all GPs are in this position and on some occasions GPs have diagnosed and followed through with the individual to ensure that they are receiving the correct and appropriate treatment for their diagnosis.

Inconsistent Services

One area identified was a lack of consistent services. This was a theme specifically with parents of the service users. The transition of the service from seeing a GP for an initial

consultation to leaving the service was described by one individual as being “...lacklustre and disappointing.”

Service users and family want a service that is “clear and transparent with an identified pathway to highlight how far they have come and the options and opportunities ahead.” Healthwatch does recognise that each service user has different needs however they all require treatment.

Transition to adult services

Users highlighted concerns about the transition between services for young service users and those for adults. Participants in our research felt that at age 17 you are too old for the youth service, however you are not old enough for the adult service. 17 is a vulnerable age for young people suffering with an eating disorder and any gap in service could lead to a relapse and other mental and emotional symptoms.

Nutritional or Mental

Users and carers said they felt that the general public and in some instances professional opinion regard Eating Disorders as a nutritional problem. They felt that to understand the complexities of an eating disorder it needs to be seen as a mental health issue. This was a stigma that a lot of the delegates who attended our listening event shared with us. A major issue highlighted was that the first information that they would receive when starting treatment would be a nutritional program. Service users described feeling deflated and in a difficult position as they did not feel they lacked an understanding of nutrition and the benefits of eating certain things, they felt that their main issue was an uphill mental battle.

Poor handover in hospital

Service users highlighted lack of communication between ward staff at shift handover.

Lack of beds

Another concern raised by participants was that families and service users were not getting access to adolescent beds locally. Some families had experienced their children being sent out of area to receive inpatient treatment. Concern was raised that families may not be able to afford to travel to visit, leaving the individual isolated and alone. The group also felt that young people need to be in a familiar setting.

Schools struggling with how to support students

Schools are tasked with supporting children and certainly this can be challenging with regard to mental health. Participants felt that some school staff tasked to work with the students may not have the required skills to work with those who experience mental ill health. Schools are seeking information, advice and training according to a teacher who attended the event.

Testimonials

As part of this report we invited testimonials from individuals within the community that have either had first-hand experience or are a family member of a service user. The testimonials are from the perspective of those people that have been through the service.

Service User

“My experiences with the East Riding Eating Disorder Service have been quite haphazard. This is not ideal for someone with an eating disorder as we need structure and to be able to engage with the services on a regular basis to keep us on track.”

“After waiting a long time for an initial assessment when my condition became critical about 18 months ago, I was assigned a key worker who I saw roughly every 3 - 4 weeks, although at times the gap between appointments was much longer because of holidays,

sickness etc. Unfortunately my key worker left to take up another appointment in the summer and I was without a replacement for quite a few weeks.”

“I was eventually assigned a new key worker with whom I have had a couple of meetings. I feel that I am starting from scratch again as I need to get to know and trust her before I can open up. The service has been trying to set up a meeting with the mental health team and my GP and hopefully a dietitian, but to date that has not happened as it is difficult to get everyone together. Hopefully this will be sorted out in the next few weeks. I am currently on the waiting list to see an NHS psychologist, but as the waiting list is quite long I may end up seeing a student.”

“I feel that when a sufferer finally admits they have an eating disorder, they are usually at a very low ebb both mentally and physically. They need prompt intervention on a regular basis from a team they know and trust to give them the best chance of recovery. Unfortunately this is not happening at the moment in the East Riding.”

“Fortunately, throughout my illness I have had the support of my GP. If it were not for her early intervention and continued support in looking after my **medical wellbeing** through regular appointments, blood tests, weigh ins and medication, I would I am sure, have ended up being hospitalised.”

“I was also fortunate that I was pointed in the direction of SEED.... (They) have been with me every step of the way.”

“I was also fortunate that I was pointed in the direction of SEED, a voluntary organisation based in Hull that supports people with various eating disorders. SEED have been with me every step of the way and have been the one constant source of regular help with my psychological wellbeing. They were able to arrange for me to have individual counselling sessions on a regular basis. They also offer a monthly Self Help Group Meeting that keeps me on track and I have recently embarked on a 12 week recovery programme offered by the group.”

Parent of service user

“Our daughter’s struggle with the mental health illness Anorexia started when she was 11. There followed emergency admission and re-admission to Hull Royal children’s ward, two admissions to Eating Disorder Units both of which were in London, many meetings with local CAMHS team members (none of whom our daughter engaged with) and we parents attending courses for carers and some family therapy as well as trying to get whatever help we could for our daughter.”

“The following year there was another admission to Hull Royal for re-feeding.... her mental state continued to deteriorate and it was a while before any weight gain was achieved. Eventually she came home for a while but it was soon apparent that she was deteriorating despite the best efforts of the Intensive Intervention Team. Due toher refusal to accept any help my daughter was sectioned under the Mental Health Act so that she could be treated. After a few weeks on the ward she was transferred to an Eating Disorder Unit in Maidenhead. Here she remained for six monthsand her progress at this unit was the best to date and for the first time she engaged with and actively partook in individual therapy. While she was there we requested transferral to a new CAMHS team as our daughter still hadn’t engaged with the team we had, we knew that for her progress to continue when she came home we needed a therapist she could engage with. To this end we fought for a transferral to York CAMHS. This has been going well thus far. Our daughter is back in school trying to achieve the 5 GCSE needed to go to college.”

“This story has been summarised.... What it cannot convey is the mental torture of the child and what is imposed on them. Or the effect that living in this can have on the sufferer’s family too, struggling with lack of understanding, fighting for help, (in our case) masses of travelling, endless worry.....”

Parent of service user

“Our story... is more like a living nightmare as we have been terribly let down by all the systems that you hoped would help and support you in such a situation.”

“.. My daughter had been troubled with her eating/ purging/ self-harm/ low self-esteem. We took her to the doctor (who has been extremely supportive) on several occasions who advised us to take her out of school ... home tuition helped her through exams.”

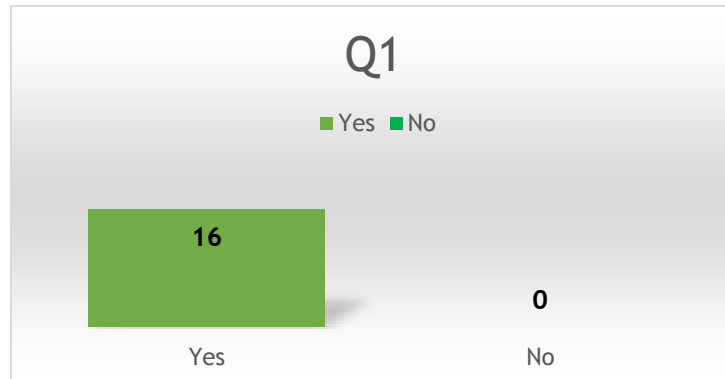
“16-18 year olds are in a terrible loop hole. People want to wash their hands of this age group. I feel like our hands are tied and there is not a thing we can do about it because every part of the system has let us down!! It is now 10 weeks on and it is a living nightmare!”

Survey results /Findings

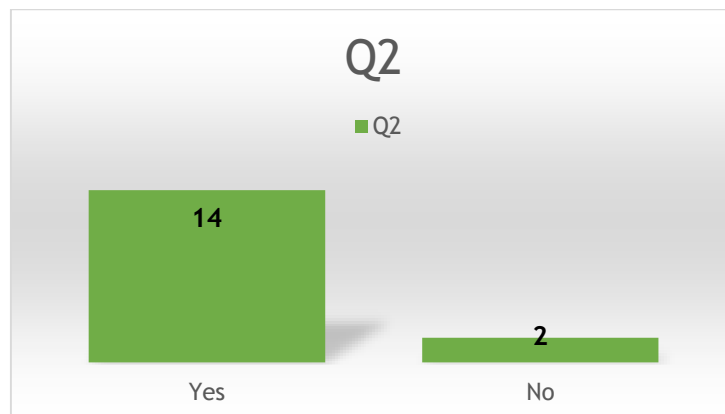
Prior to the listening event we ran a survey and invited the public to complete. The survey included 10 questions and we received 16 returns.

Below is an overview of the survey questions and answers.

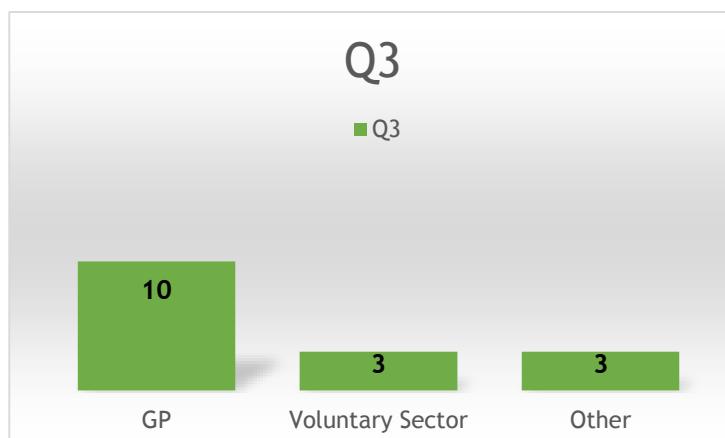
Q1. Do you, a family member or a friend have or think you may have an Eating Disorder?



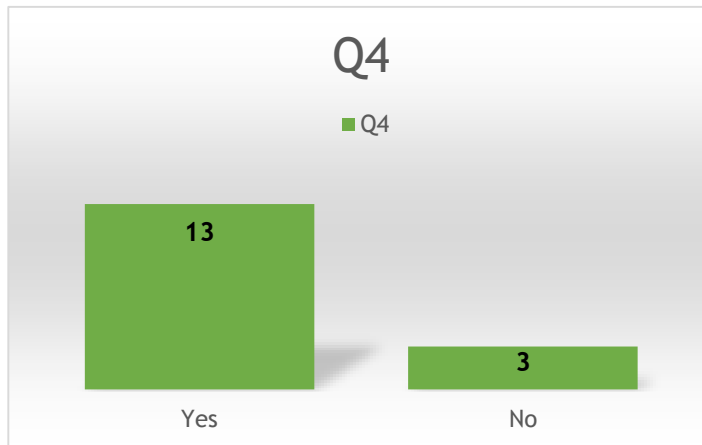
Q2. Have you, a family member or a friend sought help for an Eating Disorder?



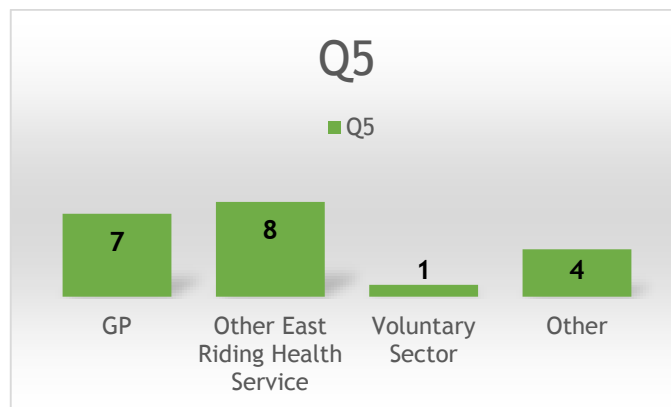
Q3. If yes, where did you try and get support?



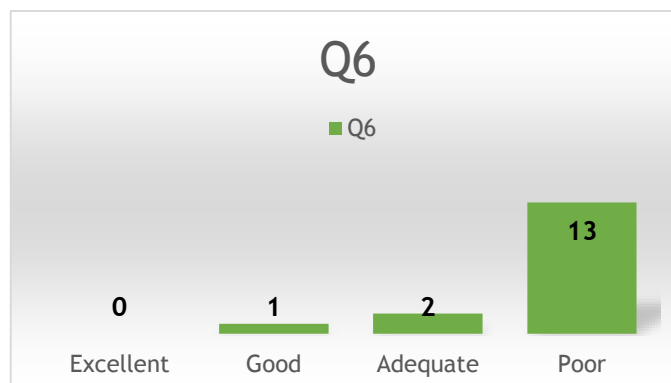
Q4. Have you, a family member or a friend seen an Eating Disorders Health Professional?



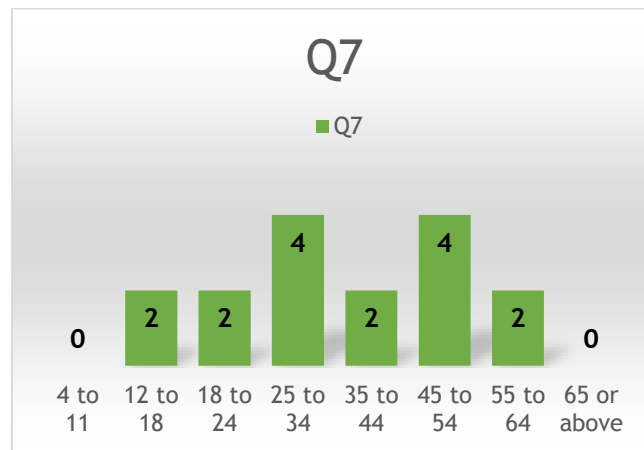
5. If yes, who did you see?



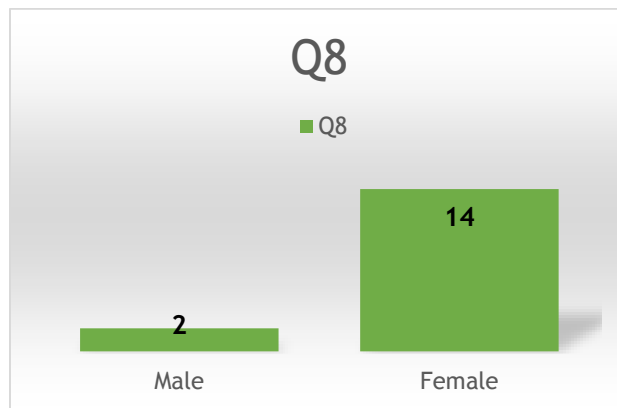
Q6. How would you rate the Eating Disorder services in the East Riding?



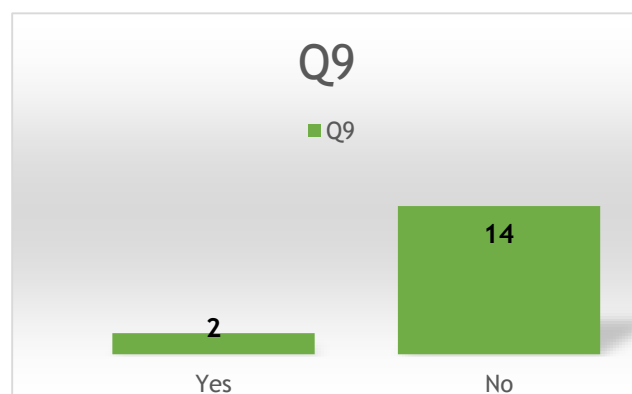
Q7. What is your age?



Q8. What is your gender?



Q9. Do you feel you get enough information about Eating Disorders?



Q10. Do you have any additional comments?

“It would be immensely helpful if a) more information could be made available & b) all this information could be more accessible i.e. outside the urban centres. If there were a central source of a great deal of high quality information, the existence & extent of which could be made known through all possible channels across & throughout all areas of The East Riding, that is the ideal. Also, Family Therapy is extremely effective: please promote its availability & uptake everywhere in the East Riding, town & country. With good wishes & thank you for your good & important work”

“I was referred to single point of access by my GP. I was told at my assessment that there was no provision in East Riding for eating disorder services and there would be an 18 month wait for cognitive behavioural therapy It was suggested that I register with a Hull

**“THE SERVICES LACKED IN SUPPORT
... VERY DISAPPOINTING. LACK OF
KNOWLEDGE FROM GPs AND
HOSPITALS AND HEALTH CARE
SECTORS.”**

GP too so I could be assessed by Evolve but couldn't do that as I live in Beverley. I have since seen a private counsellor who suggested I ask my GP to refer me to the eating disorder unit in Grimsby. I originally saw my GP regarding this in January and 6 months later I have still not been seen by someone who specializes in treating eating disorders. My

eating disorder began when I was 17 and I am now 34. There needs to be an eating disorders service in the East Riding so that young people can be treated early before the behaviour becomes embedded. I also work for the NHS in the East Riding and am aware of a number of cases of people presenting to their GP with eating disorder who would benefit from such a service. I am glad that the gap has been recognised and hope this will be rectified.”

“The services lacked in support and was very disappointing. Also no services in our area for eating disorder. Lack of knowledge from GPs and hospitals and health care sectors.”

“At the start of all this in 2010 when our daughter was 11 little did we realise how much we would have to do to get help and when we did get help how quickly our hopes of it helping were dashed. In the middle of all of this was a child missing out on a lot of life and she still is as we are still struggling. Due to lack of services she is, yet again, over 200 miles away from us to try and get her the help she needs. If it wasn't for a local charity organisation and reading whatever literature that was recommended by other sufferers etc. I don't know how we would have got through this far.”

“I am the mother of a 14 year-old girl with anorexia and I feel that the provision of specialist care whilst she has been in hospital is inadequate. Despite her physical needs being cared for, her mental health has deteriorated. This is no criticism of the hospital staff, nor of CAMHS who are working under enormous pressure, but of a system that does not recognise the need for a specialist mental health unit for young people.”

“There is no support for people with compulsive eating disorder or binge eating. Their idea of treatment is to follow a healthy balanced diet! Surely if someone was suffering with anorexia was given "this" as support or advice it would cause an outrage.”

“I am a parent of an adolescent with Anorexia, she has suffered with this illness for two and a bit years. We as a family have found it hard to get help up until 14 months ago. The only real help is admitting our daughter into an Eating Disorder Unit in Sheffield were she lost even more weight since being in there, more

distressed anxious and depressed as she is home sick. We need a place for eating disorder patients with qualified staff that includes complementary therapists from massage to aromatherapy, meditating, body image, dieticians etc. Where adolescents can go on a day to day basis to get the help that is needed and get back to living a happy healthy normal life. This needs to be in the East Riding.”

“I was very lucky with my GP, but that's as far as I felt supported. Most of the information I was given was 'if you lived in Hull you'd have access to...' which doesn't really help when you live in ERY. I was also told it would be better if I was an adolescent as I would have easier access to support, which again is not very helpful when you're 28”

“I had seen 2 psychologists who were hopeless and had to fight for further help. No monitoring was done by the GP. The dietician couldn't help until I had further help which I had to fight for. This took 4 months during which time I had severe suicidal thoughts.”

“Just being referred for CBT [cognitive behavioural therapy] doesn't treat the eating disorder. Only works in the short term.”

“My sister has waited over 12 months for a referral to a councillor has had to pay! GP service appalling has had to fight for help her GP dismissed her without any follow up or guidance. We got help and advice from SEED in Hull without them my sister would be in hospital or worse.”

“THIS IS NO CRITICISM OF THE HOSPITAL STAFF, NOR OF CAMHS WHO ARE WORKING UNDER ENORMOUS PRESSURE, BUT OF A SYSTEM THAT DOES NOT RECOGNISE THE NEED FOR A SPECIALIST MENTAL HEALTH

Recommendations

Based on our research and the feedback from service users, HWERY suggest the following recommendations to improve Eating Disorder service statistics in the East Riding. It is also hoped that through these recommendations there becomes a clear pathway for service users to follow through from start to recovery.

1. East Riding of Yorkshire Clinical Commissioning Group (ERYCCG) and Humber NHS Foundation Trust to promote the services available for people with Eating Disorders and improve public awareness.
2. East Riding of Yorkshire Council (ERYC) to commission specific and tailored information for organisations and educational institutions who have first-hand contact with young people to raise awareness of the signs and symptoms of Eating Disorders. This could be training aimed at teachers, parents and anybody else who works with young people.
3. East Riding of Yorkshire Clinical Commissioning Group (ERYCCG) to increase GPs' awareness of eating disorder pathways and support services available locally.
4. ERYC to increase public awareness of support that is available for individuals with an Eating Disorder.
5. ERYC to improve public awareness that an eating disorder is a mental illness not a nutritional one.
6. ERYC Services to ensure Tier 1 and 2 (ERYC) and Tier 3 (ERYCCG) services are commissioned and delivered within the East Riding of Yorkshire to ensure services are available locally for the people who need them.
7. ERYCCG, Humber NHS Foundation Trust and ERYC to work together to provide a seamless and smooth transition from services for children and young people to those provided for adults.

Conclusion

This report was written to help voice the opinions of the general public, some of whom have been service users or family members to service users in the East Riding. Through events, surveys and first hand testimonials we have been able to capture a range of opinions both positive and negative.

It is acknowledged that some of the issues that people have raised throughout this report may now have been addressed. However if this is the case then there appears to be a need to improve the awareness of, and communication with, service users, their families and the wider public.

What will happen next with this report?

The report will be submitted to the East Riding of Yorkshire Council, Humber NHS Foundation Trust and East Riding of Yorkshire CCG under the Healthwatch power to make reports and recommendations. Services have 20 days from receipt to respond. The report will also be presented to the East Riding of Yorkshire Health and Wellbeing Board.

Healthwatch East Riding of Yorkshire will monitor responses to our recommendations and keep members of the public and stakeholders informed of progress and actions to deliver improved services.

Acknowledgements

This report received contributions from the following:

- ERYC Public Health
- ERED (East Riding Eating Disorders)
- Eating Disorder Support Service (SEED)
- Members of the public
- Service users /Carer's

Appendices

Recruitment Literature used

The poster features a yellow house-shaped background. At the top left is the 'healthwatch East Riding of Yorkshire' logo. At the top right is the 'ERED' logo with a green ribbon. The central text reads 'Improving Eating Disorder Services in the East Riding' above silhouettes of five diverse people. Below this, the main title 'Listening to your experiences of eating disorder services' is written in bold. The text continues: 'Join us on Wednesday 9th of July as we aim to gather your views on and experiences of eating disorder services in the East Riding. With your help we can highlight improvements that the services can make.' The event details are: '7pm - 9pm', 'St Mary's Primary School, Key Stage 1 Hall', 'Eden Road, Beverley, HU17 7HD'. At the bottom, it says 'Thank you' and provides the email 'mfawcett@healthwatcheastridingofyorkshire.co.uk'.

References

The following is a list of references used during this report.

1	What is an Eating Disorder?	http://www.nhs.uk/conditions/eating-disorders/Pages/Introduction.aspx
2	Treating Eating Disorders	http://www.nhs.uk/Conditions/Eating-disorders/Pages/Introduction.aspx
3	Implications of an Eating Disorder?	https://www.nationaleatingdisorders.org/health-consequences-eating-disorders
4	CAMHS service information	http://www.humber.nhs.uk/services/camhs
5	Humber Foundation Trust	http://www.humber.nhs.uk/about-our-trust