healthwatch Derbyshire

Eating Disorder Report

Experiences of health and social care services for people with eating disorders

Collected February 2017

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1. Thank you

This report is based on the experiences of members of the First Steps All Ages Recovery and Self Help Group. This meets twice monthly in Derby, but is open to all people in Derbyshire. The group is for people with eating disorders and their friends and family. It is a positive and inclusive group that covers topics that may be helpful for recovery and is also an opportunity to socialise and talk to First Steps staff and volunteers. The experiences were collected at an engagement session in February 2017.

Healthwatch Derbyshire would like to thank First Steps who supported and cooperated with this engagement activity. We would also like to thank the participants who gave up their time to talk to us about their experiences.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, families, friends and carers who have an eating disorder, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that patients, families, friends and carers have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to complement, other sources of data that are available.

3. About us

Healthwatch Derbyshire is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

Healthwatch Derbyshire was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of local Healthwatch organisations covering every local authority across England. The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

4. What are eating disorders? (*Source NHS Choices*)

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.

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

- anorexia nervosa – when a person tries to keep their weight as low as possible; for example, by starving themselves or exercising excessively
- bulimia – when a person goes through periods of binge eating and is then deliberately sick or uses laxatives (medication to help empty the bowels) to try to control their weight
- binge eating disorder (BED) – when a person feels compelled to overeat large amounts of food in a short space of time.

Some people, particularly those who are young, may be diagnosed with an eating disorder not otherwise specified (EDNOS). This means you have some, but not all, of the typical signs of eating disorders like anorexia or bulimia.

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. An eating disorder may be associated with biological, genetic or environmental factors combined with a particular event that triggers the disorder. There may also be other factors that maintain the illness.

A 2015 report commissioned by Beat estimates more than 725,000 people in the UK are affected by an eating disorder. Eating disorders tend to be more common in certain age groups, but they can affect people of any age.

Treatment for eating disorders is available, although recovery can take a long time. Treatment usually involves monitoring a person's physical health while helping them deal with the underlying psychological causes.

5. Why we produced this report

Following the engagement session at the First Steps All Ages Recovery and Self Help Group, it was agreed that the experiences maybe more powerful if presented together rather than using the usual information sharing protocols used by Healthwatch Derbyshire. Also, many areas mentioned by the participants did not relate to specific services and were of a more general nature. It was felt that it would be useful to share the information with all health and care commissioners and relevant service providers.

Participants at the engagement sessions were not asked specific questions, but instead were invited to talk more generally about their experiences of getting a diagnosis of their condition, support from health professionals, accessing treatment and accessing other forms of support, including support groups.

The engagement session consisted of a group discussion. There were 11 people present; 10 female and one male.

The purpose of this report is to highlight the themes and trends that emerged during the engagement activity and present individuals comments.

6. Key findings

There are several themes that emerged from the engagement, which are as follows:

- Lack of awareness of eating disorders and support available among some health professionals
- Dignity and respect is not always shown to patients
- Eating disorder diagnosis
    - No clear diagnosis pathway
    - Lack of consistency and choice across Derbyshire.
- Eating disorder treatment
    - Gap in provision for people to carry out assessments in order to be able to access help and support
    - Shortage and lack of continuity in community psychiatric nurse (CPN) service
    - Incorrect incentives to access treatment
    - Poor quality psychiatric support
    - Long term health and wellbeing needs are not appropriately addressed
    - People are often referred inappropriately to IAPT service.
- There is insufficient support at a time of mental health crisis
- Lack of services for people over 25 years
- Lack of support for carers.

7. What people told us

There is a lack of understanding of eating disorders among health professionals.

Many participants spoke about lack of understanding of eating disorders. This caused distress among some participants and felt this exacerbated their condition. Some felt awareness and understanding had improved in recent years but there was room for further improvement.

For example:

"While in the appointment the doctor was not interested in what I was saying. There were some Jaffa Cakes on his desk and he offered me one. It was so inappropriate and I was really shocked."

People in the group felt that there was usually one doctor in their GP surgery who had some understanding and empathy of eating disorders. However, people are not always able to access these GPs or there are long waiting times.

"You can wait for three weeks sometimes to see who you want to. It is waste of time seeing someone else as it makes you worse if they are not helpful."

People spoke of a lack of understanding among doctors, nurses and other primary care professionals of eating disorders where people did not lose weight, including bulimia.

"My doctor just told me to lose weight. He had no understanding of my condition and would not do me a referral to a specialist."

"I found it hard to get someone to understand me as I am not anorexic but I still have an eating disorder. Coming to First Steps has been the best thing."

People would like to see improved knowledge of eating disorders among health professionals so people do not have to repeatedly explain their condition. People accept that not everyone can be experts but knowledge can help to reduce stigma and they will be able to signpost to other services.

"We know they can't know everything as they are general practitioners but they need to be caring and be able to know who to refer to for specific help that can help us if they can't."

There is inconsistency in knowledge about support services available for people with eating disorders.

"I found out about First Steps through friends, my GP did not know about it."

"My doctor told me about First Steps, I am so glad they did."

All people in the group felt there was a need for all GPs to receive training on eating disorders as part of their training. They would also like to know where GPs have specialisms and interests.

"They should advertise better on their websites or in the surgery that they know about eating disorders. We would then go to see them and hopefully get help a lot sooner, rather than talking to lots of different people and getting nowhere."

Dignity and respect is not always given to patients

Some participants commented that they were not always treated with dignity and respect by health professionals when talking to them about their eating disorder.

For example:

"I just was told to lose weight by my GP. I was not treated with any dignity or respect."

"They think you can get better just by telling you to eat. It is not as simple as that."

Several people in the group said they had had a poor experience at St James House from the staff. This is a base where Derbyshire Healthcare NHS Foundation Trust provides mental health services. Receptionists were specifically mentioned showing a lack of dignity and respect. This had happened either face to face or in telephone conversations. A psychiatrist's secretary had ignored someone who felt they were in a mental health crisis. They did not call the person back and ignored their concerns.

The group would like to experience more understanding and compassion from all health staff, not just clinicians and training should be provided by the Trust.

"The staff and Trust need to take ownership of this important issue."

Eating disorder diagnosis

Many participants commented that they had struggled to get a diagnosis. Some people had had issues for many years before they were taken seriously. There is also variation across the county in the quality and speed to access help and support.

For example:

"I have been to see so many people over the years, from doctors to CAMHS. I am never taken seriously. As I am intelligent they cannot understand why I don't just get better and sort myself out. Just because I can talk properly and am eloquent does not mean that I do not need any help. I can't do this on my own."

People at the group felt there is a gap in services to get a diagnosis for an eating disorder. Several people at the group said getting help for their eating disorder took about two years and the pathway for support is not clear or consistent across Derbyshire.

"There needs to be earlier recognition of the disorder. This would speed up diagnosis and treatment and would mean people would not have to suffer for many years without support."

"There should be a diagnosis pathway with different types of support and treatment depending on the eating disorder."

"There is a lack of consistency in treatment across the county amongst the GP surgeries. This is linked to GP knowledge and how things work in different parts of the county. It is not right that there are different services for people living in different parts of the county. Some people have to wait a long time to get help or an assessment and others not so long. There needs to be a fairer system so we will get the same level of help and support across the county. I think it depends on the GP surgeries funding which is not right."

Eating disorder – treatment

Participants gave mixed reports about the quality of treatment received for their eating disorder. A major issue was the lack of community psychiatric nurses (CPNs) to carry out assessments to enable people to access help and to provide on-going support. Some people accessed the eating disorder service, others to mental health services or IAPT services. None were referred to other wellbeing options, yoga, gentle exercise, meditation, mindfulness etc.

People at the group agreed there is a long waiting time to have an assessment of your needs for an eating disorder and that this led to people being ill for longer and potentially the eating disorder getting worse.

People felt their experience would improve if an assessment of their needs could be carried out within a reason able timescale. This would mean they can then concentrate on getting the help that is needed.

"Rather than waiting many months just to get an assessment. You are just waiting and nothing happens."

Specific comments about CPNS included:

"There is a massive shortage of CPNs. I should have been allocated one months ago and I still do not have one."

"There is a lack of 'named' CPNs."

"I have my CPN changed without my knowledge."

"It is hard to build up a relationship with someone as when you have they leave and you have to start all over again."

"Because there are so many changes in the CPNs they are not really bothered about looking at your long term help and recovery, everything is on a short term to get you out of the service. We need time; we cannot all work to the clock. We are all different and need different help and support to get us into recovery."

People at the group felt that it may not always be relevant to have a CPN to help them. Especially as there is a shortage of them, "… and this is not is not going to be improved in the short term as there is not enough money." There were discussions and suggestions that other health workers or the voluntary sector could carry out the assessments, as long as they have had training.

People at the group felt that the arbitrary use of BMI to access the specialist eating disorder service provided by Derbyshire Healthcare NHS Foundation Trust is wrong. This is especially an issue for people with other eating disorders where BMI may not fall to this level at any point.

"It sends out the wrong message so you have to start losing weight and get down your BMI to under 16."

People were generally negative in their comments of help received from psychiatrists. People felt there is lack of support for complex cases with little help or support from psychiatrists.

"I feel rushed when I am there." Other people agreed with this statement. Other comments included, "They are not interested"; "One of them is so rude."; "They think there is nothing wrong with you and you should sort this out for yourself if you are clever."

Other comments for psychiatrists included:

"When you see the psychiatrists you may be seen when you are having a good day and so they make judgements on this. Also, when you go to the appointments you do try to have a good day. However, when this happens they say you no longer need any help which is not the case. You are punished for getting better. We don't want to be pushed out."

One specific psychiatrist, who was named by several group members, is perceived as giving very poor treatment which is of little use to people who need help.

People attending the group said there is an emphasis in getting people out of services as quick as possible. They said this is not positive for long term recovery. People would

rather have knowledge that that there is support there if needed. When taken out of services this can be a challenge and not be a positive part of recovery.

"It would be nice to know there is someone you can go to if you need a bit of help rather than having to waiting many months and get really ill before you get it."

Some people felt they were given or offered anti-depressants because of limited access to the CPN service or to get to see a psychiatrist to address long term and deep seated issues that will take time to resolve.

People would like to see more talking based therapies, not tablets, and for them not to be time or session restricted. Would like the service to be locally based if possible and not travel too far.

"I think there is a gap in knowledge as there is help out there. I have used the counselling services and the voluntary sector has activities and courses that can help. The doctors should know about them and tell people."

Many people reported that they had been advised to access the IAPT service. People felt these were often not appropriate as they we classed as 'too complex'.

"How can an eating disorder be sorted out in six weeks?"

"A few sessions of CBT are often not enough to make a difference in the long term."

Insufficient support at a time of mental health crisis

Many participants spoke about their mental health needs relating to their eating disorder. People had had experience of trying to access support at a time of mental health crisis and felt that the service did not meet their needs or expectations.

For example:

"I tried to access the crisis team three times but they were not interested and said I was not serious enough."

"There is a gap in service for people with eating disorders who need help at specific times to prevent people going into crisis or accessing accident and emergency centres."

"At a time of crisis you are not in the right frame of mind to take on information."

Support for people over 25 years

Participants at the group felt there was a gap in specific services for people over 25.

"There are lots of things there for you now if you are younger but there is nothing for us. We are meant to have sorted ourselves out by now. We have been left out and we need on-going support."

Support for carers

Participants mentioned the help they received from loved ones. Their carers did not receive support. Some participants said their partners were their full time carers.

"I do not know how I would manage without the support I get from my parents."

One parent carer at the group felt that insufficient support was provided and with few people to know who to refer.

"It was a struggle and it is a constant struggle; you do not know who to turn to get help for your child and there are not enough people who know enough about eating disorders."

8. What should happen now?

Services and commissioners should consider:

- Improving awareness among health professional of eating disorders
- Education and training among health professionals and support staff of eating disorders to improve dignity and respect for service receivers
- Providing and promoting a clear diagnosis and treatment pathway for eating disorders and follow NICE NG69 Guidelines (published May 2017)
- Equal access to treatment for eating orders across the county, including on-going access to CPNs if required
- Health and voluntary sector professionals to work with patients to find correct treatment, including medication (if appropriate) and support to long term recovery
- Removal of incentive to lose weight to be able to access eating disorder service
- Improved access to mental health support for people with eating disorders – including psychiatrists, CPNs or other talking therapies which are not restricted to six sessions
- Ensuring their service addresses the needs of people over 25
- Support offered for carers of people with eating disorders
- Improved access to and signposting to other wellbeing services that could be of benefit to people with eating disorders.

9. Service Provider/Commissioner responses

Derbyshire Healthcare NHS Foundation Trust

Thank you on behalf of the Trust for your report on the experiences of Health and Social Care services for people with Eating disorders.

Service context

The Trust has a clinical risk register and the Eating Disorders is a named service on the risk register. This service is restricted and the service model and staffing is substantially below the national recommended service size for the population. Our commissioners are fully aware of this. Eating Disorders is a significant area of risks for our community and this condition has one of the highest mortality rates in mental health. This is a known risk in clear view.

To give you a sense of scale:-
1. We have no service for bulimia
2. We have no service for binge eating disorder
3. We have a restricted service for anorexia nervosa, restricted to a body mass index of 16.9.

Eating Disorders Service

Our Eating Disorder Service cares for adults living in Derby City and Derbyshire County with severe eating disorders. The service offers treatment to individuals with anorexia nervosa with a body mass index (BMI) of 16.9 and under. In some circumstances we also see people who present with physical health issues for example diabetes or Crohn's disease at higher BMI's and severe bulimia with physical health risks or those who are rapidly losing weight.

The team is based at Unity Mill in Belper, but in order to make the service as accessible as possible to the communities we serve, the team travel to healthcare settings across the city and county.

We are the gateway for admissions to specialist inpatient units and regularly liaise with commissioners to ensure admissions are timely and appropriate. We have close working relationships with the local regional inpatient unit at Leicester. We also have a good working relationship with the Gastroenterology team at the Royal Derby Hospital and arrange brief re-feeding admissions as an option if deemed appropriate.

If this had been a commissioned review, we would have provided Healthwatch with the service specification, to understand the realities of the restricted service which is commissioned by our clinical commissioning group. Although we do not operate a waiting list, we are in a position where our teams can only provide a restricted service which goes against our clinical advice. Our staff would very much like to provide a comprehensive service to the population. However, this is not a commissioned service.

I would like to bring your attention to the Futures In Mind project and the investment in Derby City and in a Child and Adolescent and Young Person's service which commenced in 2016 to undertake the majority of the issues you have highlighted below. The number of staff in the service model is to support up to fifty referrals and treatment in Derby City and in the Chesterfield Royal CAMHS services. Although this progressive development is in place, the reality of the number of individuals this service will be able to support, I am afraid will continue to be restricted. Please see detail of the restricted service.

http://www.northderbyshireccg.nhs.uk/assets/Future_in_Mind/2016_10_31_Derbyshire_and_Derby_FIM_refresh_submitted_to_NHSE_Final.pdf

Services and commissioners should consider:

1. Improving awareness among health professional of eating disorders

We agree that all staff in all settings should be Eating Disorder aware. We offer to primary care and secondary care settings, awareness training. Our own Trust psychiatrists had a 'Continuing Professional Development' event including eating disorders this year. Our team offer training and our staff have undertaken training for GPs trainees, gastroenterologists and liaison teams. If any of the participants would like to share

specific areas that lack knowledge so that specific practices or service can be targeted, we can do this with pleasure.

In addition in 2017 / 2018, the Trust will be holding an eating disorders specialist event on changes in the evidence based practice, and revised protocols in working with people effectively should they require admissions to an acute hospital.

In addition, our team are very willing to offer bespoke events to the GP practice education groups. This offer is open to clinical commissioning colleagues as and when our team is required.

In addition a specific example was raised regarding reception staff and a medical secretary at St James House. This feedback has been raised with the Trust-wide administration lead to feedback to all Trust administrates on eating disorders and the feedback on this service. This will include a bespoke training session on what eating disorders are and the impact upon the person.

2. Education and training among health professionals and support staff of eating disorders to improve dignity and respect for service receivers

Dignity and respect for service receivers and their families should be core to any experience in our care and we will address and feedback to our Trust services a copy of this report and the details of the eating disorder service to liaise with. It is not acceptable to state that anyone's condition is unknown in a modern healthcare service. Our expectation of care is for staff to empower individuals to discuss what their condition is and how it impacts upon them. At the Trust, we believe that people are very often an expert in their own condition and how it applies and impacts upon them is the most important aspect. We do expect clinicians to seek advice and support on effective treatment and care planning for all.

3. Providing and promoting a clear diagnosis and treatment pathway for eating disorders and follow NICE NG69 Guidelines (published May 2017)

Our Trust is aware of the NICE NG69 Guidelines. The Trust is not able to fully comply with this guideline, due to the service size restrictions, therefore we are unable to commit to this. Please formally write to our commissioners to address these issues.

4. Equal access to treatment for eating disorders across the county, including on-going access to CPNs if required

Our Trust is not able to agree to equal access and on-going access to CPNs. As an organisation we would very much like to provide this level of service.

There is a shortage of over 60 community practitioners in Derbyshire and each practitioner would hold a caseload of 35 people who they support. This gap is very real and our commissioners fully accept this deficit is very real to our community.

In addition, the full report also raises access to the Trust crisis team. This again is a known risk and some external work form a national body to support our commissioners and the Trust to address the risks is in development in 2017. We do hope that this results in a more accessible service. Nationally, the five year forward view for mental health does highlight the needs of individuals with any psychological crisis and the gap in providing full 24-

hour, self-referred seven day a week accessible crisis support and we hope and will endeavour to gain investment for our community.

The Trust is not able to fully comply with this request, due to the service size restrictions and severed pressure on our community mental health services. Therefore, we are unable to commit to this. Please formally write to our commissioners to address these issues.

5. Health and voluntary sector professionals to work with patients to find correct treatment, including medication (if appropriate) and support to long-term recovery

This is absolutely our aim with the confines of a restricted service. However, clinical assessment and diagnosis cannot be made by a non-registered clinical professional. We would not enable non-clinically qualified staff to diagnose cancer and the seriousness of eating disorders and the risk to the person are on an equal footing, therefore we are unable to commit to this. Please formally write to our commissioners to address these issues.

6. Removal of incentive to lose weight to be able to access eating disorder service

This is absolutely our aim and we would like to remove these criteria. However, this is in place due to the confines of a restricted service. Therefore, we are unable to commit to this. Please formally write to our commissioners to address these issues.

There are additional comments with regard to psychiatry. It is a generic comment that we really cannot offer a full response without additional information. If you are able to provide more information, our Trust will fully respond and learn from the feedback. We would not expect any member of staff to be rude and all of our psychiatrists do have feedback on the experience of care. We are very willing to open a complaints investigation and/or address the feedback that one of our Derbyshire psychiatrists was rude. One named psychiatrist was named by many group members. We would very much like to receive the feedback on this behaviour so we can assist in feeding back and supporting a change in this experience.

7. Improved access to mental health support for people with eating disorders - including psychiatrists, CPNs or other talking therapies which are not restricted to six sessions

This is absolutely our aim and we would like to remove these restrictions due to the service size restrictions and severe pressure on our community mental health services. Therefore, we are unable to commit to this. Please formally write to our commissioners to address these issues.

8. Ensuring their service addresses the needs of people over 25

We are very willing to explore this further. We are aware that the investment in CAMHS is having a positive outcome, but has not been matched with the adult service component. This again is the reality of a sub optimal service size against the county population.

9. Support offered for carers of people with eating disorders

We do provide carers support. We offer all our carers relatives support from the team. Not all family members accept this, but it is offered routinely at the initial appointments. If the group could share a little more information so we can feedback to our current service and learn about what areas we need to improve. We are very open to ideas about what might help.

10.Improved access To and signposting to other wellbeing services that could be of benefit to people with eating disorders

Improving access to psychological therapy is specifically mentioned. There are many providers of this service in our county and this is a specific target and time limited intervention. This is likely not to be appropriate for a significant number of individuals with eating disorders. However, it may support individuals to begin their journey of understanding of whom they are and some techniques to support guided self-help or consider how they feel. This may support the first steps of getting help.

We agreed we will look into working with the First Steps Trust to open up the wider community health and recover offers to members. One of our staff would happily attend the self-help group from time to time, to hear about feedback and listen to feedback. We would like to offer a long term relationship at a visit three times a year, to give our staff an opportunity to listen and feedback to teams on live experiences.

Can we re-iterate that we fully agree with the underlying theme of your feedback and would welcome your support to reflect on what we can improve internally within existing resources and gain momentum to review the service offer in our county.

Hardwick CCG – on behalf of Derbyshire CCGs

Thank you for undertaking this review and we find the feedback very helpful.

The NHS Service commissioned from DHcFT has been limited largely to people with very severe anorexia. Whilst there is a guideline based on BMI this is not absolute and the specification does not preclude clinicians using their judgement on who should be supported. We have recently reviewed the service specification and aim to make this clearer. There is not an upper age limit for accessing the eating disorder service. We do accept that there is confusion about the BMI and it is concerning to hear the patient feedback about how this is being applied. We will ask our providers and general practice MH leads to consider what they can do to provide more consistent advice on this.

The CCGs recognise that there is a case for a wider eating disorder service but we do not have the funds to invest to expand the teams remit. We have concentrated on providing the support to those in highest clinical need. We have increased funding for children's services as many disorders start in younger people and this has been the national priority. We do see access to community psychiatric nurses as being helpful and recognise that it this is difficult in many areas of the county as the threshold for care coordination is high due to a combination of both increased demand and staff availability.

We recognise the excellent work of First Steps who have recently won a Kings Fund award. They have been running training courses on eating disorders for our practices and are highly rated by primary care teams who have been on this training. We do fund them to

work in partnership with the eating disorder service provided by DHcFT and where the services work together we see good outcomes as your respondents noted. We will encourage higher take up of their offer by our practices. Freed Beaches in Worksop also provide counselling services to patients particularly from North Derbyshire and Hardwick and the type of eating disorder is not such a limiting factor for their service.

We will consider with the services what we can do to increase awareness of the support available in Derbyshire as your feedback suggested.

Your feedback

Eating Disorder Report

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

……

……

……

3) Since reading this report:

a) We have already made the following changes: ……

……

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b) We will be making the following changes: ……

……

……

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Your name: ……

Organisation: ……

Email: ……

Tel No: ……

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire, DE56 0RN