



# Early Intervention for Eating Disorders

**Youth engagement in  
Buckinghamshire  
January 2023**



## What we did

Healthwatch Bucks is committed to listening to the voices of local people to shape health and social care services. We wanted to get feedback from diverse groups of young people on an early intervention service for eating disorders. The service is called FREED – *First Episode Rapid Early Intervention for Eating Disorders*. It is a service for 16 to 25-year-olds who have had an eating disorder for three years or less. Young people getting help for their eating disorder through FREED are given rapid access to professional support. FREED is currently being rolled out in Buckinghamshire for 18 to 25-year-olds.

We ran a series of five focus groups during December 2022 and January 2023. Thirty-three young people in total took part in these sessions. We contacted youth and community groups as well as schools, further and higher education providers in Buckinghamshire. Reaching out to diverse youth groups, we gathered some valuable information on the issues and challenges facing local young people.

## Strengths of our Qualitative Study

Our study had several strengths. We reached an adequate sample size to look at evidence. We listened to feedback from five different groups with 33 participants in total. We kept recruiting participants until we were not getting any new insights from focus groups (saturation of answers).

We aimed to reach diverse and sometimes lesser heard young people by working in partnership with youth organisations. We worked with:

- St Vincent's Second Generation (SV2G), an African and Caribbean Arts and Heritage organisation based in High Wycombe. SV2G offers a range of creative arts and heritage programmes that empower and develop young people of various diverse backgrounds.

- Khepera CIC – a health and wellbeing organisation supporting young people and their families. Running and working on various projects for the community, with a team of volunteers, Khepera has been helping young people and vulnerable single adults.

We connected with young people within the FREED age range, 16 –25 years old. The median age was 20 years old. They were:

- Mostly from Black/Black British backgrounds (30%)
- Ten had a neurodevelopmental condition (ADHD, ASD, learning disability or difficulties).
- Five (15%) said they had a mental health condition.

## Limitations of our Qualitative study

We aimed to conduct focus groups with young people in Higher Education settings. This was not possible at the time of data collection due to student availability. Other research limitations included:

- Last minute cancellation of 2 focus groups
- Slightly higher turnout of male (17/33) than female (14/33) participants
- Greater representation from Black Asian and Minority Ethnic groups. However, it must be noted that 11 people across all focus groups **did not** describe their ethnic group.

## Key findings

- + Overall young people would recommend the FREED service to others
- + There was an overwhelming concern that FREED service delivery times were too long and that a triage approach could work better i.e., call within 48 hours and simultaneous assessment
- + Young people were more likely to speak to a friend rather than go to a doctor if they thought that they had an eating disorder
- + A fear of being labelled would stop people from seeking professional help
- + There was stigma around prescribed medication
- + Gender-neutral communication for promoting the FREED service was preferred.

## Our recommendations

The young people that engaged in our focus group sessions had never heard about the FREED service. We recommend that Oxford Health NHS Foundation Trust, Community Mental Health Teams, enhance awareness by:

- Developing referral partnerships with youth organisations in Buckinghamshire
- Linking with local educational and training providers
- Distributing FREED leaflets in General Practices across Buckinghamshire. First point of contact in the health care system is likely to be in General Practices
- Targeting FREED promotion in community settings such as youth clubs, leisure centres, further education colleges
- Using digital platforms to inform young people, educators and local organisations about the service
- The FREED service should use:
  - **Gender-neutral** images and language. The younger generation is more open and accepting of gender fluidity. This also breaks down stereotypes that only females experience issues with eating
  - **Positive words** to inform young people about the FREED service with choices and alternative paths to seek help
  - Increased emphasis on **talking treatments**. There are no specific drugs to treat eating disorders. However, focus groups highlighted a fear of being put on medication as part of the treatment process
  - Clear messaging about **confidentiality** and handling of personal information

## What was the project about?

FREED – an evidence based early intervention programme which is being implemented in Buckinghamshire.

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FREED attends to the specific needs of young people in the early stages of an eating disorder. It emphasises early, pro-active engagement; early symptom change; family involvement; attention to the effects of eating disorders on the brain; attention to social media use; and attention to transitions (out of school, to university, into work) and ‘emerging adulthood’.

Source: <https://freedfromed.co.uk/what-is-freed-for-professionals>

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Oxford Health NHS Foundation Trust and Healthwatch Bucks wanted to ensure that the views of young people were considered in shaping the provision of this service. To do this social and community groups who have a lot of people in the FREED age range of 16 – 25 years-old were consulted on the FREED model.

The workshops focussed on:

- accessibility of the FREED service
- age-appropriate promotion to service
- communication channels for youth engagement
- referral times for service delivery
- additional thoughts on the emerging service model

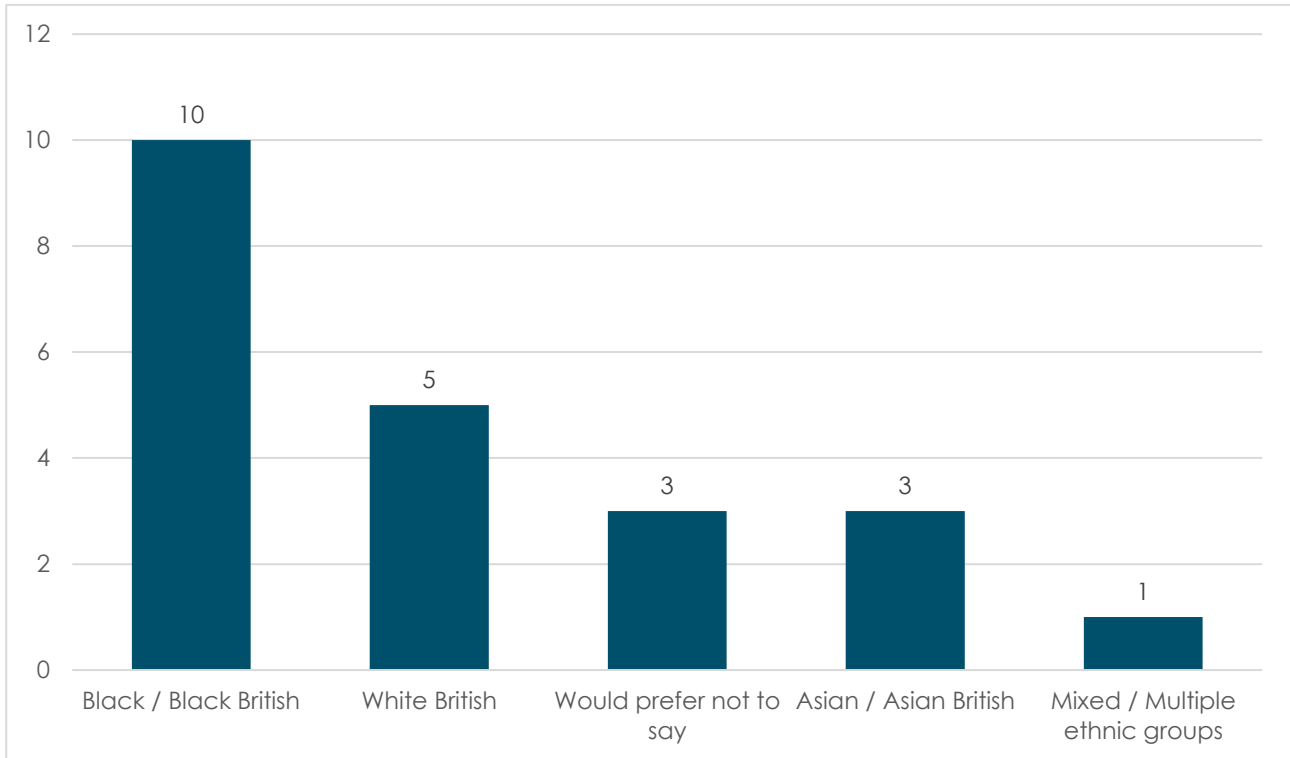
## Who we heard from

We listened to youth voices across Buckinghamshire-based learning programmes, children and young people charities and community heritage projects. We wanted our focus groups to represent the views of young people from diverse backgrounds. In so doing, we engaged with youth training programmes and youth charities that specifically focus on empowering young people by listening to their views.

To ensure anonymity we have reported all the demographics together. We did not collect any information except gender from one of the groups.

We heard from 33 young people.

- There was a very even gender split with 17 males, 14 females and 1 non-binary person.
- The highest reported ethnicity was Black / Black British (30% 10/33)



- The median age was 20 years old.
- All participants were single or cohabiting.

- Ten (30%) told us they had a neurodevelopmental condition (ADHD, ASD, learning disability or difficulties) but only three identified this as a disability.

Neurodevelopmental disorders	Count
Autism (ASD)	3
Dyspraxia	1
Dyscalculia	1
Dyslexia	5
Dysgraphia	0
ADHD/ADD (attention deficit hyperactivity disorder, attention deficit disorder)	4
Tourette's	0
Prefer not to say	0

- Five said they had a mental health condition (15%)

The participants were not specifically asked if they had an eating disorder and none disclosed that they had.

## What we heard

Recognising that videos are a useful tool for engaging with young people, focus groups were shown a short (1m 26s) animated FREED promotional video which features on YouTube [Do I have an eating disorder? Help & support for young people | FREED \(freedfrommed.co.uk\)](https://www.youtube.com/watch?v=...)

They were then guided through a set of eight questions by group facilitators. Topic Guide questions are outlined in Appendix 2.

## Eating disorders

### What did young people say about eating disorders?

We asked young people what they knew about eating disorders. Answers varied from mental health issues to engagement with sporting activities.

"I had a friend with an eating disorder, and I think that their mental health issues brought on the eating disorder."

“Majority are caused by mental health issues.”

“It happens when you’re stressed.”

“When people need to feel in control.”

“It happens a lot with people doing sports and dance.”

## Getting help for eating disorders

Young people were asked where they would go to get help for eating disorders. They were given a range of options (Appendix 2: Question 1). They could choose more than one option. They would:

- + Most likely to tell a friend (61%)
- + Just under half would go to their doctor (45%)
- + Speak to a family member (39%)
- + Look for information on the internet (30%)
- + None would talk to a teacher/student advisor (0%)
- + Others would engage in self-referral (3%)

## Barriers to getting help

We wanted to understand more about the barriers to seeking help. So, we asked young people what would stop them from seeking professional help for eating disorders.

Perceived barriers included:

- Embarrassment
- Insecurities
- Concerns about trust

- Fear of being judged
- Fear of needing help
- Fear of being labelled
- Issues with masculinity
- Fear of being given medication
- Being 'called-out' on social media
- Pride
- Not knowing you have an eating disorder

There was particular focus and discussion around social media in two of the groups. Some participants felt that social media could have a negative effect on young people with unrealistic body images. Another group said that digital platforms could corrupt and label young people.

On the flipside, it was pointed out that social media is good for communicating messages.

"Everyone feels peer pressure or pressure / insecurities from social media. Also, social media has heightened awareness, which one good thing".

## FREED Service Model – Referral times

Focus groups were asked if they thought the following response times were adequate after referrals had been made to FREED:

- a call within 48 hrs
- assessment within 2 weeks
- treatment within 4 weeks

Overall, it was thought that assessment and treatment times should be shorter with many groups agreeing that treatment should commence within 1 week after assessment:

- + 79% (26/33) of young people thought that a referral call within **48 hours** was too long
- + 3% (1/33) thought that an assessment **within 2 weeks** was adequate
- + 42% (14/33) believed treatment **within 4 weeks** was too long



- + One group suggested a triage approach to referrals where an assessment would be done within the 'referral call'.

"Everything takes time."

"People could have cured themselves by then or got help somewhere else and taken up space."

"Stress can cause it and waiting causing more stress."

## FREED Target audience

### Age range

Young people agreed that the target age group for FREED (16–25 years) was appropriate for the early intervention. But there was some debate over expanding the age range.

Some participants argued that eating disorders can occur at primary school age:

"Treatment should start at 10 – I know 9-year-olds with issues. Even 10-year-old should be able to self-refer or at least get help if they are with a parent or an adult they trust. School nurses are not good as they can't be trusted. By the time they're 16 they could have had an issue for longer and by then it's a long time and will need even more treatment."

"The age limit should start at 10, they get stressed because of exams and school, social media and peer pressure. They should also be able to self-refer because they might not have anyone they trust."

Others suggested that services should go beyond the 'youth' age group. However, they concluded that different services exist for older cohorts:

"Upper limit should stay at 25 as there are other services for older people."

Self-referral and professional referral is a good idea.”

## Gender stereotypes

We heard from two all-male focus groups, one all-female focus group and one mixed male/female focus group. Group facilitators observed slight differences between the same gender groups. It was noted that participants in the female group were hesitant to engage in general discussion about eating disorders. They needed more probing than the participants in the male group to answer topic guide questions.

We found that all focus groups were keen to dismiss gender stereotypes that eating disorders only affect girls.

“It’s not a boy or girl thing, both can have eating disorders.”

One group felt that treatment should be different for both.

“Treatment for boys should be different than girls.”

## FREED Promotion

Focus groups were presented with a list of options about where they would expect to see information about the FREED service (Appendix 2). These options included a mixture of health care and community settings as well as online platforms. We found that:

- + Most young people, 72%, said that they would expect to find out about the FREED service from a doctor or health professional
- + Over 60% would expect to hear about the service through various sports and dance clubs
- + Youth organisations were also considered as places where 57% of young people would expect to hear about FREED
- + Over one third of young people said that they would expect to hear about the service from a friend but only if the friend knew about the service
- + 64% would expect to find information about FREED on the internet; and 24% via social media
- + Other sources where young people would expect to hear about FREED included school nurses and colleges/universities.

## Conclusion

Overall, it appears that young people would benefit from learning more about eating disorders and their causes. The stigma surrounding eating disorders might deter young people from seeking support.

There was a great emphasis on peer support with most focus group participants claiming that they would speak to friend if they had an issue with eating.

Social media was seen as a double-edged sword for accessing information about treatments. Some young people said that digital media can be a trigger for eating disorders.

None of the young people in our focus group sessions had ever heard about FREED. They liked the emphasis on rapid early intervention for eating disorders but thought that FREED referral times were still too long.

## What are we doing to ensure these recommendations are achieved?

We have sent our findings to Oxford Health NHS Foundation Trust and Healthwatch England as the independent national champion for people who use health and social care services.

We will pass our findings to the Buckinghamshire Oxfordshire and Berkshire West Integrated Partnership Board (BOB ICB).

## Acknowledgements

We would like to thank all the young people who talked to us. We would also like to thank our local focus group facilitators: St Vincent and the 2<sup>nd</sup> Generation (SV2G) and Khepera CIC.

## Disclaimer

Please note this report summarises what we heard and what was observed in focus group settings. It does not necessarily reflect the experiences of young people with eating disorders.

# Appendix 1

## More about our approach

We took a qualitative approach to collecting data using focus groups to gather feedback from young people.

Focus group facilitators with experience of working with young people managed group discussions. Group sizes varied from 11 to 4 people. Healthwatch Bucks provided focus group facilitators with a detailed script to guide questions.

Consent handouts were given to young people to inform them that:

- Participation in the study was voluntary
- Personal information collected would be stored in accordance with the Data Protection Act 2018
- Transcripts would be anonymised
- Participants could withdraw from the study within 7 days and request that their information be removed and destroyed, where possible

## Appendix 2

### Topic Guide for Focus Groups

#### Sheet 1 - Getting support for eating disorders

[Do I have an eating disorder? Help & support for young people | FREED \(freedfromed.co.uk\)](http://freedfromed.co.uk)

**Play video 1.27 minutes at beginning of focus group session**

#### Q.1 Having watched the video, what would you do if you thought you had an eating disorder?

Options to write out:

- Speak to a family member
- Tell a friend
- Look for information on the internet
- Talk to a teacher/student advisor
- Go the doctor
- Other

[Note taker: please try to capture numbers and other options]

#### Q.2 What would stop you from getting help?

#### Q.3 What do you know about eating disorders? [Probe: different types, characteristics]

#### Q.4 Do you have any comments about the video?

#### Sheet 2 – FREED Service

Facilitator to read out:

**Young people referred to FREED will receive:**

- **a call within 48 hours of referral** – The goal of this call is to find out a bit more about the person's eating difficulties and when they started.
- **assessment within 2 weeks of referral** – Eating difficulties are discussed in more detail during the assessment to find the right support and person-focussed treatment
- **treatment/support within 4 weeks of referral**

#### Q.5 Where would you expect to hear about the FREED service?

Options to write out:

- Doctor or health professional
- Clubs – Sports/Fitness/Dance

- Youth organisation
- Friends
- Internet
- Social media
- Other

[Note taker: please try to capture numbers and other options]

**Q.6 What do you think about the delivery times after referral?**

- a call within 48 hrs? *Adequate time?*
- assessment within 2 weeks? *Adequate time?*
- treatment within 4 weeks? *Adequate time?*

### Sheet 3 – Closing feedback

**Q.7 Would you recommend FREED to somebody if you thought that they had an issue with eating?**

**Q.8 Do you have any other thoughts about FREED that you would like to share with us?**

## Appendix 3

### Who did we hear from?

These questions are optional so the number of responses doesn't reflect the number of people we heard from. To ensure anonymity we have reported all the demographics together. We didn't collect any information except gender from one of the groups.

#### What age group are you in?

<b>16 to 17 years</b>	7
<b>18 to 25 years</b>	15
<b>Prefer not to say</b>	3
<b>(blank)</b>	7
<b>Grand Total</b>	<b>33</b>

#### Are you a:

<b>A man</b>	17
<b>A woman</b>	14
<b>Non-binary</b>	1
<b>(blank)</b>	1
<b>Grand Total</b>	<b>33</b>

#### Is your gender identity the same as your sex recorded at birth?

<b>No</b>	2
<b>Yes</b>	21
<b>Prefer not to say</b>	1
<b>(blank)</b>	9
<b>Grand Total</b>	<b>33</b>

### What is your sexual orientation?

<b>Asexual</b>	1
<b>Heterosexual / Straight</b>	15
<b>Prefer not to say</b>	1
<b>(blank)</b>	16
<b>Grand Total</b>	<b>33</b>

### How would you describe your marital or partnership status?

<b>Cohabiting</b>	4
<b>Single</b>	13
<b>Prefer not to say</b>	6
<b>(blank)</b>	10
<b>Grand Total</b>	<b>33</b>

### How would you describe your pregnancy or maternity status? (tick all that apply)

<b>Currently pregnant</b>	0
<b>Currently breastfeeding</b>	0
<b>Given birth in the last 26 weeks</b>	0
<b>Prefer not to say</b>	3
<b>Not applicable</b>	20

### What is your religion or belief?

<b>Christian</b>	8
<b>Muslim</b>	5
<b>Sikh</b>	2
<b>No religion</b>	6
<b>Prefer not to say</b>	1
<b>(blank)</b>	11
<b>Grand Total</b>	<b>33</b>



## How would you describe your ethnic group?

<b>Asian / Asian British: Chinese</b>	1
<b>Asian / Asian British: Indian</b>	2
<b>Asian / Asian British: Pakistani</b>	3
<b>Black / Black British: African</b>	2
<b>Black / Black British: Caribbean</b>	5
<b>Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic groups background (please tell us below)</b>	1
<b>White: British / English / Northern Irish / Scottish / Welsh</b>	5
<b>Prefer not to say</b>	3
<b>(blank)</b>	11
<b>Grand Total</b>	<b>33</b>

## Deprivation (IMD2019 based on postcode sector)

Scale	Category	Explainer	Count
<b>Least deprived</b>	A	95% or more of the postcodes in this sector are in IMD2019 Quintile 1	0
	B	95% or more of the postcodes in this sector are in IMD2019 Quintile 1 and 2	1
	C	Other	14
	D	95% or more of the postcodes in this sector are in IMD2019 Quintile 4 and 5	2
<b>Most deprived</b>	E	95% or more of the postcodes in this sector are in IMD2019 Quintile 5	0

This is our own measure of levels of deprivation, based on postcode **sector**.

For example, if a postcode is in category E, there is a 95% chance that postcode is in the lowest quintile, i.e. the most deprived 20% of households in the UK.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/853811/loD2019\\_FAQ\\_v4.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/853811/loD2019_FAQ_v4.pdf)

### Do you consider yourself to be a carer?

Prefer not to say	5
Yes	5
(blank)	23
<b>Grand Total</b>	<b>33</b>

### Do you have a disability?

Prefer not to say	4
Yes	4
(blank)	25
<b>Grand Total</b>	<b>33</b>

### Which of the following disabilities apply to you? (tick all that apply)

Physical or mobility impairment	1
Sensory impairment	0
Neurodevelopmental condition (ADHD, ASD, learning disability or difficulties)	2
Mental health condition	2
Long term condition	1
Prefer not to say	0
Other	1

### Do you have a long-term health condition?

Prefer not to say	3
Yes	6
(blank)	24
<b>Grand Total</b>	<b>33</b>

### Which of the following long-term conditions? (tick all that apply)

Asthma, COPD or respiratory condition	2
Blindness or severe visual impairment	0

<b>Cancer</b>	0
<b>Cardiovascular condition (including stroke)</b>	0
<b>Chronic kidney disease</b>	1
<b>Deafness or severe hearing impairment</b>	1
<b>Dementia</b>	1
<b>Diabetes</b>	2
<b>Epilepsy</b>	0
<b>Hypertension</b>	1
<b>Learning disability</b>	1
<b>Mental health condition</b>	1
<b>Musculoskeletal condition</b>	1
<b>Prefer not to say</b>	0
<b>Other</b>	2

**Neurodevelopmental conditions - Have you been diagnosed with any of the following? (tick all that apply)**

<b>Autism (ASD)</b>	3
<b>Dyspraxia</b>	1
<b>Dyscalculia</b>	1
<b>Dyslexia</b>	5
<b>Dysgraphia</b>	0
<b>ADHD/ADD (attention deficit hyperactivity disorder, attention deficit disorder)</b>	4
<b>Tourette's</b>	0
<b>Prefer not to say</b>	0
<b>Other</b>	0

If you require this report in an alternative format, please contact us.

Address:

Healthwatch Bucks  
PO Box 958  
OX1 9ZP

Phone number: 01494 32 48 32

Email: [info@healthwatchbucks.co.uk](mailto:info@healthwatchbucks.co.uk)

Website URL: [www.healthwatchbucks.co.uk](http://www.healthwatchbucks.co.uk)

Twitter: @HW\_Bucks

Facebook: HealthWatchBucks

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