

Working with children and young people to improve support for those with eating difficulties



What needed improving?

Since the start of the pandemic, the number of young people in England with eating difficulties doubled for both urgent and routine referrals. Worryingly, East Sussex witnessed similar statistics, with the volume of referrals to services for eating difficulties increasing markedly.

To address the issue and spearhead improvements to services, **Sussex Health & Care Partnership (SHCP)** worked in partnership with Children and Young People (CYP) with the aim to:

- assess the existing resources available to children and young people with eating difficulties.
- inform changes to the provision of services to children and young people with eating difficulties.

To support co-production of the project, SHCP commissioned **Priority 1-54**, a community interest company with expertise in engaging children and young people through creative evidence-based practice. Seven young people, aged between 11 to 18, were recruited to form a steering group to oversee the work. The **Family Eating Disorder Service** advised the project team against involving children and young people who were in crisis, so they chose participants who were in recovery to ensure they could safely contribute to challenging conversations within a group setting.

Co-producing workshops

So far, nine workshops with over 65 participants have been conducted by Priority 1-54 within schools and colleges. The principle of 'nothing about us, without us', underpinned the project, ensuring a commitment to engaging young people and their families as 'experts by experience' from the outset.

Valuable insights were gathered from the workshops, such as the need to soften the clinical language around eating difficulties.

"I think 'disorder' is a horrible term and pushes the idea that what is going on for you is wrong and can't be fixed whereas difficulty, restrictions, controls, issues, and concerns feel so much better" (Young person)

Insights from young people

- A significant number of boys and young men struggle to eat in front of people following COVID-19 restrictions.
- Personal, Social, Health and Religious Education (PSHRE) and pastoral care are key to equipping young people to discuss challenging emotions.
- Resources for young people are not user-friendly, insufficiently communicated on social media, and excessively use clinical language.
- 'Eating disorder' can feel like a label – 'eating difficulties' is preferred, especially at early stages of issues.
- Schools need greater support to discuss and understand disordered eating to prevent escalation.
- GPs need better signposting knowledge to support children and young people at early stages, rather than referring to mental health services.

'The first place I go when I need support is online, like TikTok and eating videos like 'Eat with Me' where people eat together for moral support and encourage positive eating' (Young person)



What value has the project created?

In addition to the important insights gained from the workshops, other benefits were:

- **Cohesion.** Increased collaboration across the services that support children and young people, with less 'silo working'.
- **Practice.** The project has benchmarked the standard structure for how the team and associated services could work in cohesion to create a culture of collaboration.

Further value from the project and its outcomes is anticipated.

What helped with co-production?

- **Training.** A third-sector organisation delivered training sessions to SHCP staff to foster an understanding of the key principles around children and young people participation.
- **Partnering with a specialist youth voice organisation.** Working with an organisation that had prior experience of engaging with young people was valuable and streamlined the recruitment process.
- **Project organisation and planning.** Crucial to the success of the project was early development of processes, such as:
 - Scheduling meetings outside of school or college time.
 - Establishing a code of conduct for those involved in the steering group.
 - Ensuring staff understood the process of co-production.
 - Identifying how to measure change by creating logic models, understanding theory of change, and developing a children and young people charter.
- **Ongoing evaluation.** After each session, the team allocated time to discuss what worked well and the areas of improvement. Due to the power imbalance, staff checked with young people that co-production was working to meet their needs, ensuring maintained quality and efficacy.
- **Emotional understanding.** Young people who had experience with pastoral support and/or who have been exposed to PSHRE were better equipped to communicate around mental health and emotional well-being.
- **Using alternative approaches to engagement.** Enabling young people to be creative in the workshops was beneficial to exploring complex issues around eating difficulties, particularly for young people with special educational needs and disability.



"Having something creative helps those conversations happen."

Key learnings



A more blended approach. Wider co-production between young people and adult professionals in the early stages was identified as important for future work.



Involving young people in crisis, safely. Professionals that support children and young people in crisis must be engaged in the project to ensure representation.



Ensuring diversity. A workshop was arranged with a college 'diversity group' but this only included young people from one protected characteristic where it was assumed that there would be more.



Need for a mix of approaches. The project highlighted the importance of using both print and digital media in recruitment of young people, in co-produced resources, and in accessing eating difficulty information and support. Social media needs to be responsive and current.



Next steps

- To complete the workshops and use the findings to develop a resource to support children and young people with eating difficulties.
- A parent and carers workshop will be conducted to understand their experiences supporting children and young people with eating difficulties and inform the development of the resource.
- Two films will be produced with children and young people, focusing on:
 - the process of co-production work with young people.
 - their views on how services should support those with eating difficulties.

These films will be promoted in workstreams within the SHCP, comprising of Sussex local authorities, NHS, schools and further education, and community and voluntary sector organisations. This work will also be presented at an NHS England Exemplar Session.

“Having commissioners in a room together to understand the experience from a young person’s perspective has just been brilliant” (Participation Lead)

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