

The experiences of young people and their families living with excess weight

Key messages from engagement and research



About this project

Awareness of the impact of excess weight on an individual's wellbeing is increasing. In order to reduce complications and improve outcomes the NHS is testing new ways of providing services to children and young people.

As set out in the NHS Long Term Plan¹ these services focus on treating the “complications” related to excess weight. Understanding the perspectives of service users and involving them in the design of new services is critical to their success.

To support this process the **Association for Young People's Health (AYPH)** led a scoping review of evidence and a programme of engagement work with young people and parents living with obesity and excess weight, to find out about their perspectives.

The work was linked to a process also being undertaken with clinicians and others to identify the outcomes that the new clinics should focus on. This briefing summarises the themes from the engagement work report and the scoping review. Both of these are available on the **AYPH website**.

How we carried out the work

In order to explore the experiences of young people living with excess weight, and their views of services, we undertook two workstreams:

(1) Engagement workshops with families and young people.

Excess weight is a sensitive and difficult topic for young people to discuss. To ensure young people and families had wrap around support and appropriate safeguarding we worked with SHINE (Self Help Independence Nutrition and Exercise), a community based service in South Yorkshire for young people living with obesity and excess weight. The engagement with six young people and six parents took place over three structured workshops; two online via zoom and one in person.

(2) Scoping review of existing research on young people's perspectives on excess weight and related services.

Relevant papers were identified through a call for evidence, online searches, and consultations with colleagues working in the field. A broadly inclusive approach was taken, but the evidence base proved limited. After a process of screening, a total of 19 studies were included in the review, dating from 2009.

This work was funded by NHS England and NHS Improvement to support patient engagement in the Children and Young People's Transformation Programme to develop Complications from Excess Weight (CEW) clinics.

¹ The NHS Long Term Plan, 2019

Key themes

Similar themes emerged from the engagement work and the scoping review. Children and young people are deeply affected by their experiences of obesity and the complications of excess weight, and these experiences affect how they engage with services.

Improving mental health and wellbeing:

Improving mental health and wellbeing was unanimously held by the young people we spoke to as being the most important focus for new clinics. Mental health was important for motivation, for making positive changes, and for doing sports and other activities. Young people said that getting mental health help quickly and for the long term was really important. Short term treatment was not great and they spoke about challenges when services or interventions ended. Parents also ranked mental health improvements as one of the most important outcomes from clinics. Existing research also emphasised that both parents and young people have suggested that psychological factors have to be a part of all programmes.

“I really don’t know – my mental health is quite bad at the moment – I’ve got a lot of help, but it’s just the help that you need to help with all the stuff you bottle up...”

Young Person

“...he wasn’t very sympathetic in the way that its big news that you’ve got this particular condition.. he didn’t seem to care... it’s like you’ve got to deal with it....spoke to my mum more than me...which was a bit demeaning like I couldn’t handle it on my own”

Young Person

Communication – services that are understanding, non-judgemental and patient centred:

Good communication with healthcare staff was also key. In the engagement sessions young people stressed that they wanted doctors who explained things clearly, “in a way I understand” with an empathic and non-stigmatising approach, in a ‘safe place’, and directed to them, not just to their parents. Parents also highlighted the importance of a good relationship with professionals and said a young person centred approach was particularly helpful in supporting attendance at clinics and adherence to advice. They spoke about feeling judged as parents and feeling that their children were being judged. The scoping review also highlighted the fundamental importance of how doctors talk to young people and parents.

Consistency, continuity and follow up:

The scoping review suggested that how comfortable young people feel once they reach a service is key to the success of the intervention. Parents taking part in the project said that young people and families want to feel individually known by services. Young people involved valued regular checkups between hospital appointments to help motivation and reduce isolation. Parents were wary of the impact of repeated weight measurements and welcomed centralised systems for recording data to reduce the need for multiple stigmatising contacts with different professionals. Young people and parents felt strongly that some of this directly impacts treatment.

“One hospital appointment made my child feel set for self-destruction”

Parent

Peer support:

Young people involved in this work highly valued their experiences of peer support activities in a safe community setting. They talked about the importance of friends in the group and how peer support had increased their motivation to engage. Parents highlighted the significance of peer relationships for good and for bad. They spoke about the trauma of being overweight and the negative peer pressure and online bullying their children had experienced. Peer support for parents is also important and reduced the isolation they often felt.

“I felt that as a person I am rubbish.”

Parent

Recognising and responding to experiences of stigma:

Both young people and their parents reported almost universal experiences of stigma and negative judgement, from both their peers and from health care professionals. This was clearly mirrored in the scoping review. Being seriously overweight results in a particular lack of self-esteem and feelings of trauma. Services should not contribute to feelings of criticism, blame and stigma.

Holistic provision with access to activities and exercise:

Young people talked about having a space to exercise that is safe and fun physical activities in groups. Learning to cook together with peers and socially interact over food was also important. Parents stressed the importance of being able to access all services including exercise facilities in one place as well as the fact that the cost of activities, after school clubs and healthy food is a barrier to access for some families.



Conclusions and recommendations

The engagement work and scoping review illustrated that the things that matter to young people and their parents when engaging with excess weight services are:

- The quality of their experience – whether they feel ‘seen’ and ‘heard’.
- An appreciation of and response to the mental health elements of their experiences.
- An acknowledgement and understanding of the negative experiences all young people and families will have experienced by the time they get to this stage, and a willingness not to perpetuate this. This includes the need to recognise and involve parents and carers alongside young people without blame, judgement or stigma.
- An appreciation of – and compensation for – the awful social impacts they have all undoubtedly experienced, including difficulties socialising with other young people of their age. Services should consider providing supportive peer group activities to rebalance their experiences of bullying and stigma and promote positive social contacts.
- The need for holistic approaches that recognise the whole child and the way in which their needs and issues are all linked and need addressing as a whole.

“I think its good that we got a say in all of this, we actually get our ideas into something”

Young Person

Finally, the young people and parents enjoyed having their views heard and wanted to be involved in improving services. Engaging young people in service planning and delivery is likely to improve effectiveness. However, as we noted at the outset, this is a highly sensitive topic. In order to promote effective and safe engagement there is likely to be a need for expert support from staff with experience of youth participation who are trusted by young people and families.

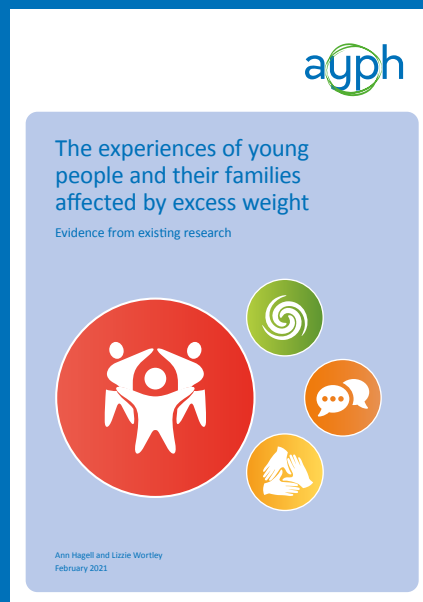
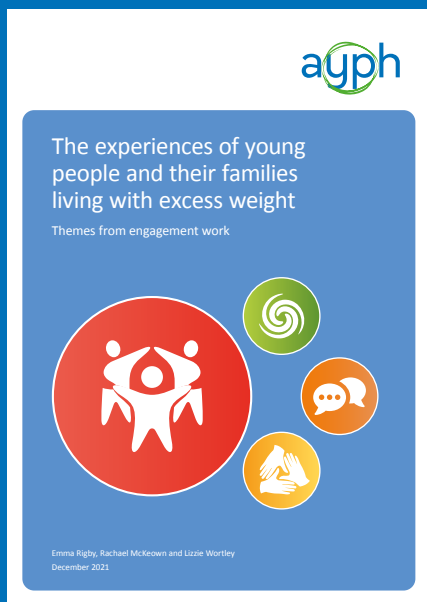


About the organisations leading this work

The Association for Young People's Health works to understand and meet the particular health and wellbeing needs of 10 – 25 year olds.

The Young People's Health Partnership is a partnership of seven organisations with voluntary and community sector networks across England from the youth and young people's health sectors.

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