

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

Themes from engagement work



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

### *Key messages from engagement with young people and families, December 2021*

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### Executive summary

The Association for Young People's Health (AYPH) led a programme of engagement work with young people and parents living with obesity and excess weight. AYPH was commissioned as part of the Young People's Health Partnership to deliver the engagement. The work was specifically linked to the establishment of new NHS clinics to treat complications related to excess weight (CEW clinics) and a Delphi consensus process being undertaken to identify the outcomes that were most important for these clinics. We worked with SHINE (Self Help Independence Nutrition and Exercise), a community based service in South Yorkshire, and supported a group of young people and parents to have their views heard in sessions from November – December 2021. In total six young people and six parents were involved. Themes from the sessions were fed into the Delphi process. This report sets out those themes and the other main messages from the young people and parents.

Improving mental health and wellbeing was unanimously held by the young people we spoke to as being the most important thing for the clinics to focus on. It impacted their motivation, which they saw as key to making positive changes. Poor mental health was a barrier to many things in their lives including doing sports and other activities.

*"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*

Good communication with healthcare staff was also key. Young people wanted doctors who explain things *"in a way I understand"* with an empathic approach. They needed a safe place - to exercise, to do fun physical activities in groups and to learn to cook together etc. They shared stories of stigma and bullying which affected them every day. They also reflected on the positive support they got from their peers facing the same issues as them in a safe community setting.

Parents also ranked mental health improvements as one of the most important outcomes from clinics, but felt the other two top line outcomes (physical health and weight loss) were important. They noted the need for holistic and responsive services that are patient centred. Continuity of staffing and a non-judgemental approach were key together with the potential for the development of positive peer relationships. Parents also shared the stigma and judgement they faced from healthcare staff and others.

Whilst there were some differences in the issues that young people and parents raised there were many similar themes pointing to action that the new clinics and other healthcare settings could take. The young people and parents enjoyed having their views heard and wanted to be involved in improving services. In order to do that safely there is a need for expert support from staff with experience of youth participation who are trusted by young people and families.

## 1. About the engagement

### Background

Trends in childhood obesity show rising rates of children and young people living with obesity and excess weight with significant inequalities between young people in the most and least deprived areas<sup>1</sup>.

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 Plan,<sup>2</sup> these services focus on treating the "complications" related to their excess weight. Involving service users in the design of new services is critical to their success<sup>3</sup>. There is increasing evidence that the circumstances and experiences of patients influences their engagement with treatment<sup>4</sup>.

As a result, as part of the development of new clinics for treating 'Complications related to Excess Weight' (CEW clinics), NHS England and Improvement funded the Association for Young People's Health (AYPH) and the Young People's Health Partnership to seek the views of young people living with excess weight and obesity and their families.

The consultation with young people and families was run alongside discussions with practitioners and commissioners. All of the engagement work was shaped by a Delphi consensus process to which the various experiences and perspectives of participants contributed, including those of the young people. The Delphi method is a form of interactive decision making that was used to determine which outcomes the NHS may want to measure. Participants responded to two rounds of questionnaires, the responses were aggregated and shared back with the group after each round for more discussion. During this process, the range of answers decreases and the group converges on a shared 'best' answer. The method is commonly used in health research<sup>5</sup>.

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### References

<sup>1</sup> NHS Digital (2021) National Child Measurement Programme England 2020/21 School Year. London: NHS Digital <https://digital.nhs.uk/data-and-information/publications/statistical/national-child-measurement-programme/2020-21-school-year>

<sup>2</sup> NHS Long Term Plan

<sup>3</sup> Bombard, Y., Baker, G.R., Orlando, E. *et al.* (2018) Engaging patients to improve quality of care: a systematic review. *Implementation Sci* **13**, 98

<https://implementationscience.biomedcentral.com/articles/10.1186/s13012-018-0784-z#article-info>

<sup>4</sup> Public Health England (2015) Local action on health inequalities: Improving health literacy to reduce health inequalities. London: PHE

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/460710/4b\\_Health\\_Literacy-Briefing.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf)

<sup>5</sup> Mead D and Moseley L (2001) The use of Delphi as a research approach. *Nurse Researcher* 8(4) 4-23

## **Aims of the engagement**

The engagement had two main aims. The first was to find out what was most important for the clinics to do or to achieve. The NHS was keen to understand what 'good outcomes' would look like for children, young people and parents / carers who might attend them.

The second aim was to find out more about the broader perspectives of young people and parents. What would an 'ideal service' for managing excess weight look like? This includes understanding the challenges and barriers that need to be overcome.

## **2. Methods**

Excess weight is a sensitive and difficult topic for young people to discuss. This engagement exercise was also commissioned within a tight time frame. For this reason, we worked with an existing support service for young people affected by excess weight. Given the stigma faced by young people and families, we needed to engage with an existing group rather than recruiting new young people for the purposes of this project. This was important, as it meant the young people and their families already knew and trusted each other and the support staff. Fundamentally, it also meant that they had a form of support in place if the discussions led to more concerns or anxiety. Safeguarding young people and families involved in the engagement was of paramount importance throughout. The service we worked with was SHINE Health Academy and is based in South Yorkshire. It is a community based, not for profit service for young people aged 8-17 with excess weight and complex needs.

AYPH was happy to work with other services working with groups of young people affected by excess weight. NHS England contacted all regional leads for the CEW Clinics providing them with AYPH's contact details. AYPH spoke to two regions who expressed an interest. Whilst both were keen to be involved neither had established groups of young people affected by excess weight in their patch. In conversations with both regions the challenges of engagement with young people affected by excess weight was raised. In one region, plans for broader engagement with any young person in relation to weight and obesity was being planned. There are clearly constraints to working with one service. However, without the support in place for young people and families the engagement would not have been safe.

In the process of designing the engagement tools we were clear about the difference between asking a question of young people as part of their clinical care and asking the same question in an engagement setting.

All of AYPH's engagement work is underpinned by [a set of principles](#) that can be viewed on our website and includes our approach to confidentiality, consent and communication. For this engagement exercise we also emphasised that we were not asking young people to share their personal experiences, but to draw on these to tell us about what they thought were the most important considerations in setting up new services for other young people.

## Engagement sessions

The engagement with young people and families took place over three structured workshops; two online via zoom and one in person:

1. Online introductory workshop to identify the top objectives for the CEW clinics, and a discussion around what the perfect clinic might look like. This included an adapted stage one of the Delphi process.
2. Second workshop in person, to 'vote' on the objectives identified by the other stakeholders in the Delphi process (included completion of Delphi questionnaires see Appendix 1)
3. A final online workshop, to undertake a 'validation' of the main messages and conclude discussion

The lead staff member from AYPH attended the separate Delphi decision making meetings to share the themes from young people and parents. These meetings involved staff from NHSE and the clinicians and specialists taking part in the Delphi. They took place after session one and session two. The messages presented to these meetings were then taken back to the young people and parents at the final session for further validation.

Participants were provided with an introductory sheet in advance of the first workshop, and were given a short, user-friendly presentation about the Delphi process so that they understood how their perspectives were being fed into the process. The host organisation also ran a session with young people and parents to answer any questions and ensure that the technology being used worked for participants. Standby emotional support was accessible throughout for young people who experienced emotional responses to issues raised within discussions.

All sessions were facilitated by two staff members from AYPH and supported by one or two staff members from the host organisation. NHS representatives also attended as appropriate. The NHSE Clinical Director for Children and Young People attended the first session for a short while to set the context and explain the idea for the clinics and attended the face to face session in full. A project manager from NHSE attended the first online session and the face to face session. Apart from introductions and endings, parents and young people were split into two separate groups for discussions. This enabled us to distinguish views of young people and parents / carers and avoided some inhibition to contribute particularly for those young people and parents who were related.

AYPH designed all of the engagement sessions working alongside NHSE colleagues leading the Delphi process and the host organisation. Plans for all the sessions were agreed with NHSE and the host organisation and adapted as needed based on discussion. We designed the process so that we could have in depth conversations with young people and parents that were appropriate to a Patient and Public Involvement process rather than a clinical conversation.

All participants involved in this work were offered vouchers to recognise the time and commitment they brought to this work. All participants were offered support pre and post each session from SHINE to support emotional wellbeing.

## About the young people and parents involved

**Numbers:** Overall, the engagement included six parents and six young people. It is important to keep the small numbers in mind when generalising from the findings. The perspectives shared by the young people and their parents are illustrative and important, but not necessarily representative; this was a piece of engagement, not research. However, as we comment below, the messages from the young people resonated strongly with the messages arising from our parallel scoping review<sup>6</sup> on young people's views, and with messages from other young people we have worked with over many years. As we note in the scoping review much of the existing work with young people and their families affected by excess weight includes relatively low numbers of young people.

**Demographics:** Of the six young people, three were young men, two were young women and one was gender fluid. Four of the young people lived with both parents and two of the young people lived with one parent. Two young people were from minority ethnic groups and four were white British. They ranged in age from 13-17 years and had BMI z scores of between +3.19 and +4.28 making them all eligible for CEW clinic support according to NICE guidelines. Co-morbidities across the group included insulin resistance, Type 2 diabetes, polycystic ovarian syndrome, hypertension and fatty liver disease. All the young people had mental health issues including anxiety, depression, low self-esteem and two were self-harming. Two of the young people were not in school due to anxiety. Two of the young people had a diagnosed Autism Spectrum Disorder.

Four parents involved were related to one of the young people involved and two were not. Five mothers and one father took part. Two of the parental group were from minority ethnic groups and four were white British. Two were separated and four married. Four of the families were affected by poverty and two were more affluent. Two of the parents were unemployed, one was a carer and three worked. Three of the parents had their own weight problems and three were not affected by excess weight.

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<sup>6</sup> Hagell A and Wortley L (2021) *The experiences of young people and their families affected by excess weight: Scoping the evidence: Outline of emerging issues*, April 2022 London: AYPH

### 3. Themes from the Delphi process

#### Views on the top level outcomes for the clinics - What is the most important thing these clinics could do?

In the first engagement session we asked young people and parents about the three potential top level outcomes for the new clinics. These were:

- To treat the physical health problems and complications that can happen with excess weight
- To help young people lose weight
- To help improve mental health and wellbeing

Young people and parents were asked which they thought were the most important. Although there were some similarities across the two groups, there were also important differences.

#### Young people's views on top level outcomes for the clinics

Young people unanimously said that helping to improve mental health was the most important thing for these clinics to do. They said that poor mental health was a barrier to doing sports and other physical activity. This was both because they needed to be in the “*right mind*” to take part in sport / exercise but also related to the stigma of exercising with others. As one young person commented, “*Doing sports around people who are physically healthier than you can cause a lot of anxiety and it takes a lot of help to get rid of that anxiety*” and “*It takes time and a lot of work too*”.

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.

Young people also identified some times in their lives that were particularly difficult in terms of mental health, including the transition to secondary school and doing GCSE's. They spoke both about bullying, the fear of bullying and comparing themselves to others at these particular points in time. Thus, for example, “*during important transitions it's hard (primary – secondary school) because you don't know people and you might have had hard times in the past with bullying .... I know for me I started binge eating for comfort*”, and “*with GCSEs and mocks for people who have other issues to deal like weight .... it's easy to give up and say I can't do it when I compare myself to other people*”.

Motivation was absolutely key to the young people and getting support from peers experiencing the same things as them as well as support staff really helped. For example, “*I think the thing that stops a lot of us from taking the next step is motivation – like a lot of us are in the mental block where we don't want to change cause it's too hard, we need motivation .... To do it alone and without support can mean we go back into our old ways*”. The company of others contributed to motivation; “*I've found the difference for me is being surrounded by people who are like me and not judging me for what I am doing*”, and “*Being able to see what others can do and that I can do it too if I try hard enough*”.

#### Parent views on top level outcomes for the clinics

Parents agreed that all of the proposed priorities for the clinics were important and felt that the whole point was to have them all together, so a holistic approach was what they needed, more than

any single outcome. They felt that any service needed to be responsive and patient centred. What was the most important would depend on the child so clinics should be able to tailor their approach. In the discussion parents agreed that treating the physical and mental health problems associated with excess weight were more important to parents than losing weight.

In the discussion parents spoke about their awareness of obesity as a societal problem and its costs to society as well as issues in relation to access to affordable healthy food, good education on nutrition and healthy eating. They had a clear understanding of its links to other health issues but also felt that sometimes assumptions were made that all health problems were related to their child's weight e.g. a physical disability that affected walking is often presumed to be because of their weight.

When discussing losing weight as a key priority parents spoke about the need for access to facilities to help to lose weight. Being outside was very positive for some young people. Using facilities like gyms was more complex. Parents spoke about overweight people needing confidence to use facilities. A space where all young people are going through the same thing helps with confidence for example a dedicated facility or sports centre. Building up the confidence to do exercise takes time. In addition, parents spoke about the importance of having strategies to support their young person to lose weight including a combination of restricting / cutting down food and making them more aware of issues such as the food they can eat if they have burned off calories. Encouragement and taking it at their own pace was also key. As one commented, *“Doctors give unrealistic weight loss goals but it doesn't come off that quick – the kids didn't choose to put this weight on – need to encourage them to take on at their own pace, more likely to achieve”*.

The priority of helping to improve mental health and wellbeing was central for parents. Parents described a vicious cycle between mental health and weight with their young people struggling with issues such as emotional eating. They spoke about the links between good self-esteem, happiness and losing weight as well as the links between trauma and weight gain.

Acknowledging the interactions between the priorities, parents recounted powerfully the traumatic experiences their children faced while being overweight which impacted their mental health. Young people felt humiliated at school, were bullied, frightened to go out and labelled as *“the fatties”*. For some young people this was leading to self-harm after coming home from school. For others where school support was better there were still points in the day – lunch time – where they were bullied. Parents themselves felt labelled and judged by health professionals before they walk into the room and spoke about the need for compassion in communication with doctors. They also questioned why eating disorders could be recognised as mental health conditions, but being overweight is mostly not seen as the same. Finally, the struggle to get a mental health diagnosis and long waiting lists for mental health services was highlighted.

### **Views on second level outcomes for the new clinics - What are the next most important things these clinics could do?**

In the face to face meeting young people reviewed and voted on the second level outcomes being considered for the clinics. These had been identified via the iterative Delphi process with clinicians that was happening in parallel (see Appendix 1). The young people and parents' responses to the first level metrics had been fed in to this process and there was an opportunity to reflect on the next most important things the clinics could do.

The second level metrics were voted on by young people and parents following an explanation of all the terms. Rankings were made on the basis of a series of options presented to the group.

- **How the clinics should work:** Young people ranked highest that *Doctors and other staff have involved children, young people and families in decisions* and that *Children and young people like and trust the staff team*. Parents ranked all four suggested metrics as very important and there was unanimous agreement that *Children and young people like and trust the staff team* was particularly important.
- **Physical and mental health:** This was the longest of the Delphi questionnaires and asked about the particular conditions, complications and other physical and mental health issues which the young people and parents felt were most important for the clinics to look at. Young people ranked two metrics as being most important that *The changes that are made last as long as possible* and that *Children and young people feel less anxious and/or depressed*. The next most important thing to young people was *Improvement in managing other long-term conditions - such as diabetes*.

Parents also ranked *Children and young people feel less anxious and/or depressed* as most important as well as *How much fat there is in the blood*. Parents said the next most important things were *Reduced fatty liver disease*, *The changes that are made last as long as possible*, *Children and young people have improved self-esteem* and *Fewer problems with breathing when sleeping*.

The importance of a focus on improving mental health as well as the sustainability of improvements was highlighted by both young people and parents.

- **Other areas of young people's lives:** Young people and families were also asked how the clinics could most usefully have an impact on school, friends, exercise etc. Young people ranked *Children and young people are more active (e.g. everyday activities)* and *Children and young people are making healthier choices about food and drink* as being the most important to them. Parents also ranked *Children and young people are more active (e.g. everyday activities)* as the most important. Followed by *Children and young people are attending school more*.

In discussion about these second level metrics we talked about the cause of a young person's weight problems being better understood. Young people highlighted the link from this to better societal understanding.

Parents highlighted the need for an understanding of how parents feel. They can experience criticism from their young people and the medical team. Some never leave appointments feeling good or reassured, and constantly feel that they face stigma. Clinics asking parents large numbers of questions about themselves can make them feel extremely criticised. Parents highlighted that no element of the questionnaire focused on how parents feel.

#### 4. Main themes from the engagement overall

In all three engagement sessions young people and parents spoke about the challenges they faced and the type of care they would like to see. Their comments and thoughts have been grouped into ten themes that could inform the work of the clinics more generally. All of these themes were important to young people and parents. However, the first five themes in relation to communication, consistency, peer support, recognising stigma and holistic approaches were the themes which were most regularly discussed.

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

Young people stressed the need for good communication and staff who are understanding and empathic. Some doctors the young people had met with in the past hadn't explained things clearly. Young people wanted to understand the health issues in relation to their weight and how they might have an impact. Explaining this, one said, *"For me when I went to the doctor about diagnosis and stuff they didn't really explain so I didn't really know what it was... I didn't know it had an impact ... so I went online and did some research and realized that it was a big thing ... that's when I took notice ... but the doctor didn't do that"*.

In order for services to be effective, the young people felt that it was important that communication was directed to them not just their parents and it was also important that healthcare staff recognise the emotional barriers that young people face; *"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 people spoke about the importance of getting the communication balance right. They wanted doctors to break up information when they share it and provide reassurance. Instead their experiences had often been that *"they just chuck it on you"* saying things like *"you might need a transplant... why would you tell me like that...it was overwhelming"*.

Young people said they needed *"time to comprehend so you don't get overwhelmed"*. They recognised that they needed to know that this was a very serious health condition but that the communication needed to be sensitive and empathic. They wanted doctors and other staff to be honest and consistent. They also wanted them to explain the words they use.

Parents also highlighted the importance of a good relationship with the professional including the importance of staff understanding the challenges of living in a bigger body. They also spoke about feeling judged as parents and feeling that their children were being judged. One parent had been told, *"I didn't think you would look like this"* by healthcare staff who had expected them to be overweight – other parents had been told that staff had not expected that they would have a job.

These experiences underline the fundamental importance of how doctors talk to young people and parents, and the importance of building this into clinic design. Parents said that if you get it wrong there is a danger of young people and parents not re engaging which was particularly important at points of transition between services. Parents spoke about children being down hearted after appointments or worse and wanted staff to treat the patient not the condition. As one noted, *"One hospital appointment made my child feel set for self-destruction"*.

Parents described a young person centred approach as being particularly helpful in supporting attendance at clinics and adherence to advice. This included identifying what it is that is important to the young person and when needed allowing young people to take time out of a clinic session. Parents felt that their young people needed to be able to identify progress and feel that their individual needs were being taken into account. Without this approach, persuading young people to leave the house and go to a session could be a constant challenge.

### **Consistency, continuity and follow up**

Parents said that young people and families want to feel known by services, and not just a number. They wanted staff who knew them so they didn't have to explain their medical history every time. Participants reported that seeing a new face can be overwhelming for young people especially for those with anxiety. Change often worsened anxiety for their children and affected attendance at appointments. This included the importance of being able to go to the same place for appointments or sessions. The importance of sharing patient records between providers was also mentioned by one parent.

Young people focused more on the need for consistent check ups between hospital appointments. They wanted these to push them as they were aware that doing things independently sometimes led to them relapsing. Their view was that the follow up in between hospital appointments is really important and keeps young people going. This could be via a family support worker or another service. This kind of support also made young people feel less isolated and alone. Parents also said that there was not sufficient communication between appointments – it was not always clear if they are in the system or not, and its particularly challenging in the transition to adult services.

Young people and parents participating in the engagement felt strongly that some of this directly impacts treatment. Young people reported that they felt they were weighed constantly with the same process always being repeated. Parents and young people understood the need for being weighed but stressed that the impact of measurements on children and young people needs to be considered and systems for recording measurement centralised so they don't have to be taken repeatedly by different professionals.

### **Peer support**

Young people involved in this work had experienced working in peer groups and having peer support and this was fundamentally important to them, and something they felt should be considered in the development of new services. They talked about the importance of friends in the group and how peer support had increased their motivation to do the things they needed to in relation to their weight. If they saw everyone else doing something they wanted to join in.

*As one shared, "my doctor told me if I continue eating with my fatty liver I could die .... To be fair with you I did cry because it was really hard to hear but the Dr put me onto Shine and I've made friends and I've really done good for myself and I've started to work harder and reverse the fatty liver diagnosis" "it's good to have friends somewhere so you got someone to try and help you and give you a big push to carry on" "I don't think I would have carried on if .....my friend ... wasn't there".*

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. This was opposite to the positive experience that their young people had had with

their peers also experiencing weight loss. Being able to meet other children who know what you are going through and be supported was really important and reduced the loneliness some young people experienced – *“somewhere to belong”, where they “don’t feel different”, and young people are “excited to get up and go”*.

As with positive mental health, young people and parents identified how positive peer group relationships and socialisation supported their motivation.

Peer support for parents is also important. Chatting to each other, not feeling judged and having support was really important to the parents and reduced the isolation they often felt.

### **Recognising and responding to experiences of stigma**

Both young people and parents spoke about the stigma they had faced. They said that being overweight leads to blame and stigma and suggested this needs to be considered in new service design. Parents themselves often feel blamed and criticised in their parenting and they want understanding from services. Supporting this, they shared comments such as *“I felt that as a person I am rubbish”, “Living with (someone who is overweight) is like living with an addict”, and “From the moment I wake up in the morning I think what’s the point”*.

Parents highlighted that young people are not just what they weigh. Other illnesses can make young people inactive or feel anxious. Young people are often labelled ‘fat’ but it does not mean that their fitness levels are always low. They felt that these kinds of views contributed to stigma.

Parents spoke about *“avoiding the domino effect”* when sharing the impact that one issue can have on another. Young people’s anxiety about attending appointments can make parents feel anxious which can have a domino effect throughout the family on siblings etc.

Young people really wanted to be involved in how things can be improved highlighting the importance of young people’s engagement in service development for many reasons including reducing stigma.

### **Holistic provision with access to activities and exercise**

Young people talked about having a space to exercise that is safe and fun and physical activities in groups. Gyms and exercise spaces that were not noisy was important for some of the young people as well as fun action packed activities. As one said, *“We went on a swimming course thing like an obstacle course on the water and it was amazing .... No questions asked I’d do it again ... it was so fun”*.

Learning to cook together with peers and socially interact over food was also important: *“we cook healthy meals ... how to take our time so we get full easier.. I’m really picky about who I eat with but it’s nice to eat together and have some social interaction”* and *“I can cook quite well....we’ve started making everything from scratch at home because we’ve found its healthier than eating from a jar”*.

In terms of service development, parents stressed the importance of bringing everything together and being able to access all services including exercise facilities in one place. Community services were also key to avoid having to go to hospital all the time. Finally, the cost of activities, after school clubs and healthy food was highlighted by parents. It is a barrier to access for some families and should not be forgotten.

### **Trusted and accessible location**

Young people we spoke to said that the help they get needs to be somewhere they trust and would be happy to go to. They felt it should probably be outside of school as they experienced so much stigma in school.

Getting to any service easily was really important and particularly pertinent for one young person who had to travel further to access the services currently. Emphasising this, one young person commented, *“Location is definitely important ... I can only come once a week ...travelling takes a really long time and I am so tired....location and access to stuff is really important”*.

Parents spoke about the ideal service not being like a hospital. They spoke about the importance of a positive and consistent environment. Young people also spoke about the importance of getting help when they needed it with the option of drop in / open access services.

### **Understanding the impact of school life**

Young people involved in the engagement had a range of experiences in school. Some were not attending school but others had a much more supportive relationship with their school in place. It was clear that without the right supports school can feel unsafe. Young people shared many experiences of bullying linked to school but which often took place on the way home or online after the school day. There are some good school models like a pastoral manager and mental health lead having weekly meetings with young people. The option of college was proving better for one young person with more freedom and choice. These experiences highlight the need for clinicians to understand the social pressures young people are facing and how these impact on them so that interventions have a greater chance of success.

Parents stressed the need for early preventative work to happen in school. They recognised the links between health and education and how each affect the other. They also felt that teachers often don't have the right expertise to manage the weight issues their young people face. This is in part in relation to the recognition of the impact of anxiety and mental health and how severely this can affect their children. A positive and constructive relationship between schools, young people and families felt really important and was not in place for most of this group.

### **Getting good sleep**

Young people said that getting enough sleep was really important to their health, and that this was an important issue as a context for excess weight clinics. Without sleep, one young person said *“I can't work and I can't talk ... just too tired”*.

Parents agreed that good sleep makes a difference particularly affecting mental health. One parent whose child has PTSD described how they can't sleep in the night, only in the morning when they know their mum is awake, which means that they don't have a routine or set meal times. Again, understanding this context is important in communicating with young people in these situations.

### **Thinking about gender**

Young people talked about the importance of gender to how they think and feel about themselves and their weight and how they respond to services. One young person who was gender fluid talked about doctors not using their chosen name, which made them *“not care about what they say”*. The young person would have liked the service to understand which pronouns and name they preferred to be used. They understood that their legal name would also need to be in their record but it was key that this was not the name used when communicating with them.

The fact that BMI charts are blue and pink seemed old fashioned and inappropriate to the young people.

### **Managing dual diagnosis**

Parents posed questions about how the clinics would manage young people with dual diagnosis for example learning disabilities and autism spectrum conditions. Some parents had received a CAHMS diagnosis for their child of PTSD and autism alongside managing excess weight but they were not receiving any mental health support for their child. For others young people had attended a 12-week mental health intervention but received no follow up.

## **5. Reflecting on the experience of engagement**

There was overwhelming positive feedback about the experience of being involved in the engagement sessions as well as a wish for young people affected by excess weight to be involved in service development and improvement moving forward. Participants suggested, for example, *“I think it’s good that we got a say in all of this”*, and *“we actually get our ideas into something”*.

Parents said that it was good to meet and share experiences and views and learn from each other. They also said it was nice for people to listen for a change when they were normally fighting for support. They welcomed the move to set up the clinics and were interested in seeing the results from the research.

Parents, young people and their support service were sent the draft reports to make sure that they represented their views.

## **6. Conclusions and recommendations**

To some extent it does not matter how the question is asked; whether it is an open ended question, a Delphi metric or a ranking. The responses are remarkably consistent across different methods. The various parts of the engagement all 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 judgemental experiences that all the young people and families will have experienced by the time they get to this stage, and a willingness not to perpetuate this
- An appreciation of - and compensation for - the awful social impacts they have all undoubtedly experienced. For children and young people this has usually included difficulties socialising with other young people of their age. Services should aim to provide supportive peer group activities to rebalance their experiences of bullying and stigma.
- The need to respond to young people's individual needs - including autism, learning difficulties, PTSD etc.
- 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.
- The need to recognise and involve parents and carers alongside young people without blame, judgement or stigma.

## **Acknowledgment**

We would like to thank the young people, parents, carers and staff at SHINE Health Academy for their involvement in this work.

## Appendix 1: Delphi forms used in second engagement meeting

### How to fill in these forms

For each of the statements you just need to tick whether it is

*1 Not important*

*2 Important*

*3 Very important*

You can also tick *I don't know* – you can ask someone while you are completing the sheet what something means if this will help but if you still don't know if it's important or not that is fine.

**Remember this is all confidential – your name is not on this form so there is no way we can link what you say back to you.**

### Section 1 – How should the clinics work?

This section is about what skills the doctors and other staff should have and the kind of treatments that should be available to children and young people.

Doctors and other staff have involved children, young people and families in decisions	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people like and trust the staff team	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people can access other support in their local area	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people see the same staff and feel known by the clinics	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>

### Section 2 – Physical and Mental Health

This section is about what physical and mental health problems it is most important for the clinics to focus on. After our first meeting it has already been decided that physical health and complications and mental health and wellbeing will be priorities for these clinics – this is just a bit more detail about the part of that which is most important to you.

Improvements in how the body copes with sugar (e.g. insulin, type 2 diabetes)	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Improvements in measurements like BMI	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
How high blood pressure is	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
How much fat there is in the blood	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>

Reduced fatty liver disease	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Fewer problems with breathing when sleeping	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Improvement in managing other long-term conditions - such as diabetes	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
The cause of a child or young person's weight problems are better understood.	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people feel less anxious and/or depressed	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people have improved self esteem	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people have a better quality of life with improved wellbeing and happiness	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people can manage their care and their treatments better themselves	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
The changes that are made last as long as possible	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>

### Section 3 – Other things in your life

This section is about other things in your life – school, friends ... what is it important the clinics have an impact on?

Children and young people are attending school more	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people are making healthier choices about food and drink	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people are exercising more.	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>
Children and young people are more active ( e.g everyday activities)	<b>1</b>	<b>2</b>	<b>3</b>	<b>Don't know</b>

## About AYPH

The Association for Young People's Health (AYPH) is the UK's leading independent voice for youth health. We work to improve the health and wellbeing of 10-24 year olds. For more information about our work email [info@youngpeopleshealth.org.uk](mailto:info@youngpeopleshealth.org.uk) and visit our website [ayph.org.uk](http://ayph.org.uk)

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