

MAKING COMPLICATIONS FROM EXCESS WEIGHT (CEW) CLINICS WORK FOR CHILDREN YOUNG PEOPLE AND FAMILIES

Messages from engagement and
recommendations for practice

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ABOUT THE IMAGES IN THIS REPORT

The drawings of young people in this report were designed by young people. They have been created to show different ways that excess weight can look AND importantly to be positive non stigmatising illustrations of young people. We have also used drawings of paper airplanes as they highlight the importance of using creative methods when working with young people particularly young people with neuro diverse conditions and / or learning disabilities.

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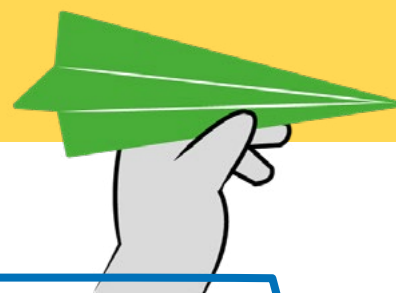
INTRODUCTION

Understanding the perspective of children, young people and their families attending specialist complications of excess weight (CEW) clinics is critical to getting the model right. To inform the development of new NHS clinics the Association for Young People's Health led a programme of patient and public voice work.

In total 62 children and young people and 101 parents took part in a range of participation activities. This included engagement events with a CEW clinic in each NHS region, an online survey and a small group of youth expert advisors who were recruited to work with AYPH throughout. All children, young people and parents involved in the engagement events were CEW service users and our youth expert advisors were either CEW service users or eligible for CEW services.

The majority of the participation work took place in 2023. The first stage focused on the clinic environments and highlighted the importance of making young people and families welcome and having both in person and online options to engage with clinics. The second stage focused on the role of staff within CEW clinics and how children and young people could be supported to engage in participation activities.

The value of young people and parents engaging with each other has been highlighted throughout this work as well as the need for more support for staff in relation to how to engage with young people and parents effectively. This report sets out recommendations from young people to support this work.



ABOUT THIS REPORT

This report brings together the themes from all the participation activities including six face to face workshops, one online workshop, regular online sessions with the CEW youth advisors and an online survey. You can find reports from AYPH's previous work here.

We share recommendations from young people for practice and some patient stories created by young people.

The report is designed for all CEW clinic staff. It summarises what children, young people and families told us. We hope it can help increase understanding of children, young people and families' perspectives and can be used in training and development conversations.

At the end of the report there is some advice from children, young people and families for other children, young people and families thinking about attending CEW clinics. This is designed to be given to children, young people and families where appropriate to support their journey with CEW.

Engagement not research

As engagement rather than formal research the aim of this work was to get a sense of the range of views held by the children, young people and families using the clinics, and to allow them a voice in the debate around all aspects of the CEW clinics. Their views will not necessarily be representative of all those attending clinics, but they ensure we do consider provision from their point of view as the clinics evolve.

WHAT CHILDREN, YOUNG PEOPLE AND FAMILIES TOLD US

Messages for CEW from engagement with children, young people and their families

These ten messages summarise the things that children, young people and families told us was important for CEW clinics to do. Cutting across all these messages was the importance of children and young people feeling understood and listened to.

- 1 Create a welcoming and comfortable clinic environment
- 2 Provide a clear service offer with in person and online options to engage and a young person and family friendly welcome pack
- 3 Ensure support is in place to help young people and families manage the complexity and cost of getting to and managing multiple appointments
- 4 Provide opportunities for young people and parents to engage with each other
- 5 Provide access to a multi-disciplinary team including mental health support and youth or family workers
- 6 Build a relationship with young people and family members in order to provide compassionate, non-judgemental care.
- 7 Link with schools and colleges to help understanding of excess weight and make referrals to other services when needed
- 8 Ensure regular contact with young people and families and a consistent and reliable service
- 9 Give detailed practical advice customised to children, young people and their families with realistic actions for them to take
- 10 Recognise the important role families play in supporting children and young people and increasing their independence

“Understand me, my family and my life... school, friends and hobbies.”
Young Person

ABOUT THE ENGAGEMENT

ENGAGEMENT SESSIONS

7 sessions – one in each NHS region
45 children & young people
43 parents / carers

ONLINE SURVEY

Circulated to all CEW clinics
17 children & young people
58 parents / carers

YOUTH EXPERT ADVISORS

Four young people with lived experience
Advising on content of the engagement
Creating resources to support other young people

WHO WAS INVOLVED?

A broad range of children, young people and families were involved. All those involved in the engagement sessions were recruited via CEW clinics working with CEW staff. The Youth Expert Advisors were recruited via youth organisations working with young people affected by excess weight.

We spoke to young women, young men and non binary young people. Most family members involved were mothers but we also had grandparents, fathers and siblings sharing their views. Whilst the majority of those involved identified as White British those attending sessions and completing the survey came from a range of ethnic groups including Asian, Black African, Black British, Black Latin American, Mixed ethnicity and other White ethnicities. Attendees had a range of access needs. Interpretation was required in two of the sessions, a number of the young people were neurodivergent or had learning difficulties or disabilities, some attendees had restrictions to their mobility and some experienced anxiety. Many of the young people had experience of using multiple health services either in relation to their weight or other long term conditions and many of the families were managing complex interactions with health services, schools and other services.



WHAT CAN HELP CHILDREN AND YOUNG PEOPLE WITH EXCESS WEIGHT TO BECOME INVOLVED IN ENGAGEMENT WORK?

The importance of engaging with young people with excess weight has been highlighted throughout our patient and public voice work. Understanding young people and parents perspectives is vital if services are to provide care that meets their needs which are often complex and multi-faceted.

However, there is a lack of confidence from services to do this work and young people and families worry about becoming involved – often due to the stigma, bullying and negative experiences they have experienced. For many young people and families we spoke to this was the first time that they had had the opportunity to meet together with others going through the same experiences as them. The feedback at the end of sessions about whether they enjoyed meeting with other young people and parents was overwhelmingly positive.

This is challenging engagement work and needs skilled participation staff, support staff who are known to the young people and sufficient time to recruit and support those invited to attend. With these supports in place safe participation work can take place leading to rich and powerful reflections from young people and parents.

Patient stories

Our work with youth advisors during the project focused in part of the things they found helpful when being engaged and the things they would find more useful to support their interactions with services. They agreed together four priority areas:

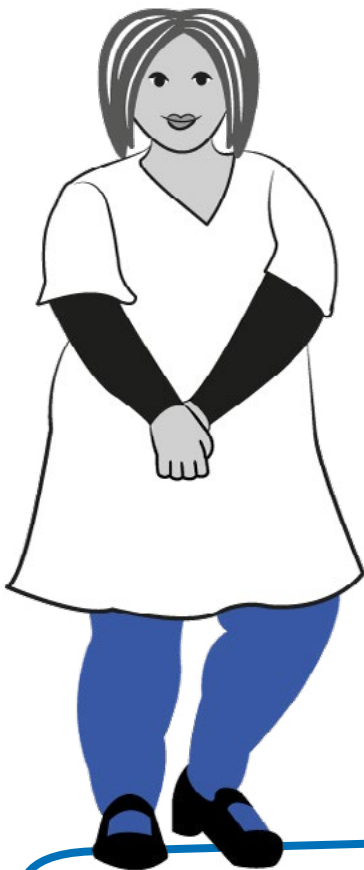
- **Increasing understanding of weight related issues/conditions**
- **Focus on providing an inclusive service**
- **Efforts to reduce stigma**
- **Helping young people set and achieve their own goals**

To explore these in a more detail they have created four characters who through their stories highlight the things that are important to young people. We have brought these together in this report as a resource for CEW clinics to highlight the importance of participation work with young people and to support participation practice moving forwards.

INCREASING UNDERSTANDING OF WEIGHT RELATED ISSUES/CONDITIONS

ARFID stands for Avoidant/restrictive food intake disorder where people avoid eating certain foods, or restrict their diets.

Lipoedema is a chronic condition that leads to a build up of painful fat and swelling in the legs and/or arms.



Hello my name is Taylor. I am 14 and I live with my Dad. I have conditions called ARFID and lipoedema – my lipoedema affects the way I look and means my body doesn't respond in the same way to diet and exercise. ARFID means that I am only comfortable eating a small number of foods.

I have been looking for support with losing weight for a while but I only just started going to the CEW clinic. At 12, a lot changed for me - most obviously the size of my legs tripling almost overnight. I was already struggling to deal with ARFID and I just felt like my entire world had been flipped upside down.

My Dad helped as much as possible, trying to give me a healthy diet. But it's difficult on such a tight budget and around his work. My ARFID was making meal times difficult anyway so we were eating more and more microwave meals.

When I turned 14 I finally got a diagnosis of lipoedema (stage 3) and was referred to a CEW clinic for my weight. I have had a few bad experiences in the past which made me quite apprehensive. Also the appearance of my legs is quite shocking to me and I find it really hard to talk about. But my first appointment was good and the people I spoke to were lovely and very

understanding. I just know managing my health conditions and diet is difficult and it still worries me. I want to set goals which feel achievable. Like being able to eat with my friends, feeling healthier overall and having a better mindset about my appearance.

Despite feeling really anxious I really hope I will be able to start progressing in my health journey.

Young people would like....

- Knowledge about weight conditions that can cause weight gain
- Understanding about how other health conditions could affect their ability to lose weight
- Understanding about their previous experiences and their ability to exercise and change diet
- Knowledge about all types of eating disorders and what can trigger them – e.g. calorie counting or obsessive weighing
- To educate other professionals they see outside of CEW about these issues as part of a care plan - with their consent
- Understanding that scaring or shaming a young person is not a good way to work with them

The CEW clinics have really understood my other health conditions and helped me to understand them better to. It's really important to me that weight loss is not the only goal people should aim for – having a healthier lifestyle and diet can also be good goals to set.



AN INCLUSIVE SERVICE



Hello I'm Leo. I'm 17 and I live with my mum and dad. I identify as non binary and this has been something that has really affected my access to help generally and with my weight. I have often felt too anxious to go to the doctor's due to past negative experiences with them not respecting my gender identity. I was referred to the CEW clinic through CAMHS, who I was seeing due to my anxiety and depression. I have had a positive experience with the CEW clinics. The welcoming vibes helps me connect with the staff and speak honestly with them about my problems. This has helped me make an effective plan with the help of the staff.

A service that respects me and my identity is so important and has helped me get the support I need and be on the path to meeting my goals.

Young people would like...

- Recognition of their personal goals – some young people may want to lose weight, others may want to improve their health or get better at managing other health conditions
- Individual recommendations about what food to eat – paying attention to cultural diversity and any history of disordered eating
- To not have assumptions made about what they are eating – there will be a range of diets and cuisines
- Understanding about their daily life and routine e.g. water drinking recommendations don't take into account how difficult it is to get to the toilet at school
- Understanding about their family / eating context – things like siblings, who cooks, how much time there is to cook etc.
- Understanding about any food issues related to other conditions – i.e. food textures for neuro diverse young people
- Understanding that cost can be a big challenge when trying to eat a healthy food
- Respect and proper use of their names and pronouns – these can change so it's good to check in regularly



REDUCING STIGMA

Type 2 Diabetes is a common condition that causes the level of sugar (glucose) in the blood to become too high. Being overweight increases your risk of having Type 2 Diabetes.

Hi I'm Ben. I'm 12 and I live with my mum, step dad and 3 brothers and sisters. I have been with the CEW team for about 9 months.

Before starting with CEW I thought that the professionals were going to be judgemental about my weight. I find secondary school very difficult due to bullying about my appearance I get called names as well as being physically attacked. This really affected my self-esteem and self-worth. I became very angry and would misbehave so I could get out of class. My attendance dropped and eventually I stopped going to school. I had little to no social life or friends. I felt isolated and too scared to go out in case I would see the people that bullied me in school. Due to this I spent my days struggling to get out of bed and eating at various times craving unhealthy foods and not being very active.

As both of my parents work, I would stay at home with my youngest brother Frankie and look after him. I started to feel unwell and that was when I was diagnosed with Type 2 Diabetes. This left me feeling even worse about myself.

Due to my health complications I was asked if I would like to be referred to CEW. I was very nervous, but with mums' encouragement I accepted the referral. My first encounter was at a home visit, which I was glad about as I did not like going out. It lasted around an hour and half, but it went quickly as the specialist



Young people would like...

- Encouragement to talk about health and emotions so they can get the help they need
- Someone to listen when they talk about their health issues – and not assume it's always about weight
- Someone to listen when they talk about emotional issues – again its not just about weight!
- Understanding about their individual experiences with weight, food, eating and emotions
- Health professionals who realise that what works for one person may not work for another.
- People who accept them for who they are – body shape and size is part of human diversity
- Recognition that they make have had a difficult time and increased kindness in their interactions

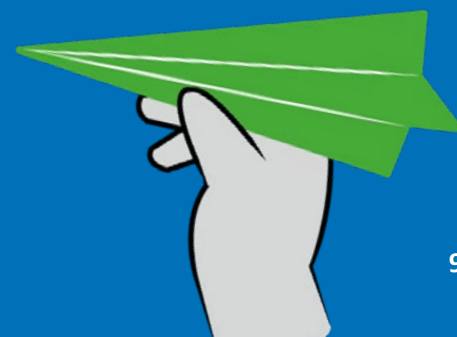
nurse and youth worker were asking about me, my life, my hopes, my barriers etc.

After the visit I started to work with the youth worker and clinical psychologist regularly. The youth worker met me at home, and we worked towards getting out of the house and going for a walk, over time this progressed to booking low cost swimming sessions and gym sessions which are FREE.

The clinical psychologist saw me at a local clinic, so I did not have to travel too far. I would also go up to the hospital regularly for my diabetes. Through education around food, routines, encouragement, emotional and physical support I was able to make changes to my lifestyle and have now reversed the diabetes.

I now attend school again – something I could not see myself doing 12 months ago. The support I have been provided within this service has increased my confidence and I feel my voice is being heard. My social peer group has increased and I've made friends with people my own age within CEW.

I hope my story can help other young people have the confidence to seek help and have someone to listen to you about your health concerns whatever they may be, as well as finding out what you enjoy doing and supporting you in accessing this.



HELPING YOUNG PEOPLE SET AND ACHIEVE THEIR OWN GOALS

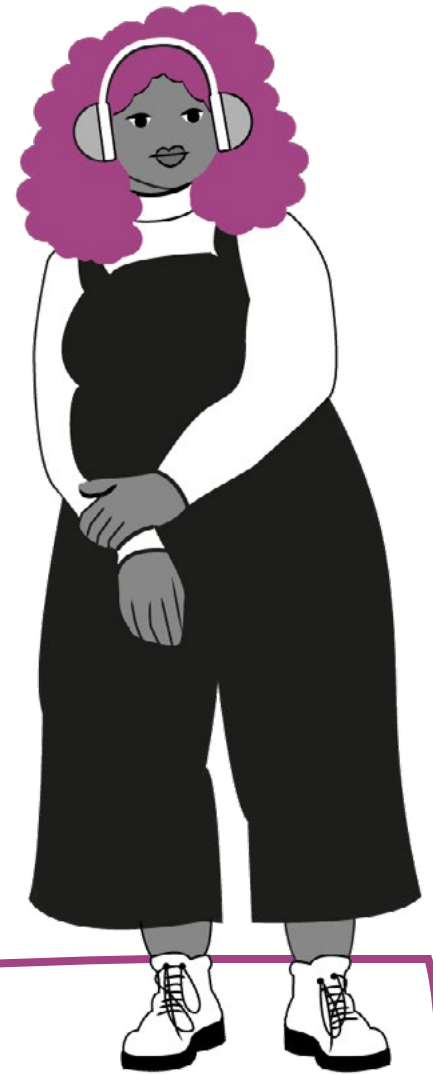
Hello I'm Alexandra, I'm 16 and I live with my mum, brother and sister. I have autism and struggle with the texture of certain foods. I also find changes to my schedule and meals really difficult to cope with.

When I started at the clinic I didn't really know anyone and it took me a while to build up a relationship with people. I found it really hard to set goals for myself that involved change. My family really helped me by giving me courage and motivation. My doctor also helped me by giving me information and small steps that I was able to follow. The CEW staff also checked in with me to see if the goals we set still fitted which was helpful. I really liked that the staff spoke to me like an adult and let me make my own choices, which made it much easier to keep going.

Together my family and the CEW doctors and staff helped me get my own motivation and it was that which kept me going. I'm worried about my time at the CEW clinic ending and want them to help me set new goals for when I leave.

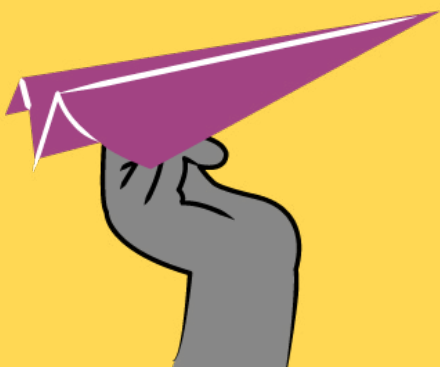
I still don't feel confident about seeing anyone else because I will have to get to know them before trusting them and I think I will have to be introduced to my new doctor very slowly.

Setting smaller, more achievable goals to keep feeling successful can help promote positive feelings. I would really like the CEW clinic to work with me to create new goals that can help me during my transition to a new support service and see if they can check in with me.



Young people would like...

- Staff to understand who is already in their support network – friends, family, youth workers, sports coaches etc.
- To identify someone in their network to help when things get difficult
- Clinic staff to develop a trusting relationship before setting goals
- Someone who can provide extra support, like a youth worker who can just chat or get them out of the house
- Someone who listens to what they enjoy doing to stay active
- Regular check-ins about goals – they can change over time or young people develop their own ideas
- Staff who make appointments that work for me e.g. so I know beforehand who will be in the room, and I'm not asked too many questions.



CONCLUSION AND RECOMMENDATIONS

The honest feedback we received highlighted the importance of an approach to delivering CEW clinics which is person centered with ongoing structures for youth and family participation built in. Young people and parents are clear that having warm, supportive and friendly staff is essential. The positive relationships young people were able to develop with youth / family workers was particularly appreciated. Building trusted relationships with staff in the clinic and supportive peer relationships with each other seems key to CEW interventions and ongoing access to health services.

A number of specific, practical recommendations for the consideration of the CEW clinics arise from this work.

- 1 Create simple and sustainable ways to run participation work with children and young people.** This could be CEW dedicated sessions or sessions linked to a generic hospital youth service. Training is available to support effective participation work with young people and there are lots of good models being tested in CEW clinics. It is important to ensure staff feel confident and supported in this work.
- 2 Provide clear and simple youth friendly information about CEW.** This should include a welcome pack, information about youth participation sessions, goal setting and any treatment they are receiving. Where possible co-designing or checking information with children and young people is the best way of ensuring it makes sense. Leaflets are not always the most effective – other creative content can be great for supporting children and young people's understanding.
- 3 Understand the child and families context and how this changes over time.** This should include understanding about how well each child (and their family) are engaging with school or college, how the needs of young people change over time, how families want to be involved and whether parents and carers need to be signposted to support themselves.
- 4 Understand how young people and families prefer to engage with the clinic and how they can be supported to attend.** In early sessions a survey or a conversation can help to understand the young person and families preferences about how they engage with the clinic including online V in person, best appointment times, how far they have to travel, how they travel, cost of travel. Considering online and other tools that can help families and young people manage appointment times and provide some choice and flexibility is also important. There is a cost to families of attending clinic appointments and clear guidance about how to claim for travel expenses is really important.
- 5 Advocate for young people and families affected by excess weight.** There are many misunderstandings about how excess weight affects young people. Helping schools and colleges understand how excess weight affects children and young people from your clinic is really important to support young people attending appointments and to reduce some of the barriers they can face to attending school. More broadly a better understanding of the psychological impacts of excess weight is particularly important to young people and families.

ADVICE FROM YOUNG PEOPLE, PARENTS AND CARERS FOR THOSE NEW TO CEW

We collected feedback from over 60 children and young people and more than 100 parents and carers using CEW clinics. We asked what advice they would give to other children, young people or parents and carers. This is what they said ... we hope it can help support other children, young people and their families attending CEW clinics.

Ask for help, take help that is offered and try not to see it as a failure or criticism.

"To fully embrace the service. It's not a criticism of your parenting but a helpful service" Parent

"Please ask for help and take everything that's offered. Easy to feel guilty as parent of obese child but that doesn't help them." Parent

"Don't be afraid to ask for help even if you feel silly for asking for it" Young Person

"I would recommend CEW to anyone that is struggling" Parent

CEW staff are there to help and support you to meet your goals.

"The CEW are willing to help and will support you" Young Person

"Work together, don't feel shy to ask questions. Make sure the team can understand your feelings" Young Person

"You can always push towards your goals. And all of the youth workers are down to chill" Young Person

"Don't worry CEW staff don't judge" Young Person

Engaging as a family with the team of experts is important

"That tackling weight issues is best done as a family unit, nobody is assigning blame for increased weight."

Young Person

"Managing your child's weight is so much more than just diet. CEW gives access to a team of experts to support the journey."

Parent

If you are starting on this journey of attending CEW clinics you are not alone

"You're not on your own there are people out there to help"

Parent

"You are not the only ones struggling!"

Parent

"Give it a go!"

Parent

Manage your expectations – weight loss and behaviour change doesn't happen quickly but small steps are important.

"It's a journey ... It is a bumpy ride. There will be ups and downs you just have to keep going"

Young Person

"Manage your expectations to be patient and mindful"

Parent

"It's not a short fix"

Young Person

"It can be done but in smaller steps little changes go a very long way."

Parent

"Worth it. Stick with it – it's a long term thing"

Parent

About AYPH

The Association for Young People's Health works to understand and meet the particular health and wellbeing needs of 10-25 year olds. For more information email info@ayph.org.uk

ayph.org.uk @AYPHcharity



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