

Children and Young People's THRIVE Emotional Wellbeing and Mental Health Framework

New provider principles Parent/carer/young people survey results

June 2023

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Introduction

As part of the NHS Long Term Plan, Lancashire and South Cumbria Integrated Care Board (ICB) is continuing to invest in expanding access to community-based mental health services to meet the needs of more children and young people.

Following on from previous work with partners, including NHS organisations, local authorities, children, young people and parents/carers and representatives from the Voluntary Community, Faith and Social Enterprise (VCFSE), a new model of delivery to improve services supporting the emotional wellbeing and mental health of children and young people aged 0-19/25 was co-produced.

To understand what values a child, young person and parent/carer would like to see in any new provider of mental health support services, a member of the ICB's engagement team was asked to develop a survey.

This survey, alongside a poster, was co-produced by a team of children, young people and parents/carers and led by two members from Children's Services Commissioning Team at Blackpool Council.

The survey and poster were shared directly with targeted partners, organisations, young people services, schools and members of the public via direct email and social media. It ran from 30 May 2023 to 25 June 2023.

Executive summary

A total of 314 responses were received: 179 (57 per cent) were from a young person and 135 (43 per cent) from a parent/carer.

Of the 179 young people: 75 per cent of these were aged between 13 and 15; 55 per cent female, 38 per cent male, and 4 per cent non-binary - 8 young people indicated that this was not the same gender they were given at birth. The majority (84 per cent) of young people who responded were white whilst 7 per cent were Asian or Asian British.

The survey was split into a section for parents/carers and a section for young people. Whilst the questions were broadly the same, they differed slightly in the language used.

The survey asked each of the two groups four questions: what is important (in terms of values) from a member of staff running a group or activity; what makes you want to keep going back to a group or activity (young people); what does an organisation need to do to ensure you feel your child is going to a supportive, safe and nurturing environment (parents/carers); what make a group or activity inclusive; and, what type of mental health support do you think would best help.

Respondents were given a list of choices (with the option to tick more than one answer) as well as the opportunity to add any further comments.

Whilst young people want any group or activity they access for mental health support to be fun and/or interesting they are less bothered about being able to see the same support worker. It is, however, important that staff are friendly and don't judge but listen to the young person.

The young people don't want any to be made to feel differently to anyone else, and that everybody is given the opportunity to have their voice heard.

The mental health support the young people say they would value the most is someone to talk to who will listen to them; this could be through either one on one sessions or in a group therapy session. They also want to be able to manage their stress and anxiety in addition to more help to deal with self-harm and eating disorders.

For parents/carers communication is crucial; both with them and with the young person. It is important that the family's expert knowledge of their child is listened to, and that services don't give up on their child but work with the family.

They want staff to be understanding with specialist skills and knowledge, and that support is person-centred flexible to the needs of the young person.

An important requirement is that support is timely when needed and easy to access, available at evenings and weekends and is outside of a clinical setting. They also want different types of support available such as counselling – both group and individual and play therapy.

Overall, it is important to recognise that one size does not fit all. Services have to be personcentred and tailored to the needs of the young person. Early intervention is key so it is important to have easy access to support when required and preferably to include evenings and weekends and be outside of a clinical setting.

Staff have to be understanding, friendly, welcoming, non-judgmental, skilled and qualified - preferably with lived experience. They need to actively listen to both the young person and their parent/carer and understand the needs of the young person.

Responses – young people

Of the 314 responses received, 179 (57 per cent) of these were from a young person. The responses are as follows:

When you meet a member of staff who is running a group or activity, what is important to you?

Of the 179 responses received from a young person, 173 (97 per cent) young people answered this question.

As indicated in the results shown below, staff being friendly and non-judgmental are two of the most important factors to a young person.

Ans	Answer Choices		Response Percent	Response Total
1	They are friendly		80.92%	140
2	They listen to me		74.57%	129
3	They don't judge me		76.30%	132
4	They show interest in me		54.34%	94
5	They make me feel safe		70.52%	122
6	They include me		67.05%	116
7	They don't shout at me		61.85%	107

The young people were also invited to provide any other feedback. Comments received include:

- They ensure my opinion is taken into account
- They understand my culture and faith sensitivity
- They are welcoming, especially when feeling anxious about a new environment
- Don't make me feel small or stupid
- They are comforting
- Supportive and ask questions to understand better the service user
- Provide alternative support if needed and be there to help guide them through until they are where they need to be
- Don't give up on service users
- Be on time and flexible
- They are engaging
- They understand if I am struggling with anxiety due to being in a group of new people
- Don't go to them because they are mean and shout
- Trust them
- They give you individual time
- They don't belittle my problems
- They take ideas from children for future lessons/activities
- They don't make me feel guilty of what I say
- That if I have a bit of feedback they take it into account
- They don't tell anybody else what I tell them
- They understand the intellect of young people and let them allow young people to express themselves while the teacher can freely say the opinion to the child without a consequence and punishment. This makes trust and bond with the child instead of children having inauthentic interactions with their teachers

What makes you want to keep going back to a group or activity?

Of the 179 responses received from a young person, 173 (97 per cent) answered this question.

As the table of results below indicates, being able to see the same support worker received the fewest responses and it doesn't appear that this is an important factor to the majority of them. They do, however, want the group or activity to be interesting and/or fun.

Answer Choices		Response Percent	Response Total	
1	It is interesting		71.68%	124
2	I get to see the same support worker		36.99%	64
3	They communicate well with me		48.55%	84
4	It helps me		47.40%	82
5	It is fun		72.83%	126
6	I trust them		52.60%	91

The young people were also invited to provide any other feedback. Comments received include:

- More practical inclusiveness and less paperwork
- At current I don't think the staff understand my needs to me and my friends are reluctant to attend
- It gives me an escape from home
- They show the really care and are not going to leave after opening up. Even if they are 18, still have support put into place and be guided from a child to a young adult services.
- I enjoy the experience and feel comfortable
- It provides a mental and physical break when you are having a particularly difficult time at home
- Someone I am close with goes there
- They are really nice
- I enjoy it
- That the space looks appealing
- I feel encourage to go back and boost confidence
- I have nothing else to do
- It is something to do
- If it's about my future in entrepreneurship

What do you think makes a group or activity inclusive?

Of the 179 responses received, 172 (96 per cent) young people answered this question.

This question doesn't appear to have resonated with the young people, however, everybody having the opportunity to have their voice heard and nobody being made to feel different are important.

Answer Choices		Response Percent	Response Total
1	Nobody is separated	52.33%	90
2	The space is accessible for everyone	63.37%	109
3	Everybody is encouraged to join in	63.95%	110
4	Nobody is made to feel different	67.44%	116
5	Everybody has the opportunity to have their voice heard	66.86%	115
6	Nobody is discriminated against	63.37%	109

The young people were also invited to provide any other feedback. Comments received include:

- You aren't forced to do anything you don't want to
- The smaller the groups, the better it is for communication to happen as some people struggle with group stuff because of social anxiety.
- Allow people to add ideas/ improvements so it's accessible for everyone
- People are aware and understand if other people may need extra time to complete an activity or may require additional help or struggle socialising
- Everyone is judged they act like they don't when others are in the room
- Picking who to be with
- No one feels left out
- Banter and tough love, should respect dreams of their peers

What type of mental health support would best help you?

This was an open-ended question. Some of the suggestions provided were duplicated but these include the following:

- Being checked on every once in a while and having someone to talk to
- Personal and professional development in careers etc
- Managing the stress of college exams and balancing school, social and work life against expectation
- One on one
- ADHD
- More specialist mental health support within medical teams. Mental health and physical health are very separate and need to be seen together. Especially in the case of long term conditions or traumatic events that end in hospital
- Therapy
- Having someone to talk to
- More help with self-harm
- Social worker
- A 5 minute check-up when needed by somebody who cares
- Private and confidential
- I'm not sure but probably someone to just listen and not shove impersonalized and general 'cures' that don't even work that well
- Anxiety support and autism support

- Something that helps with intense anxiety
- All types of mental health should be treated equally
- Anxiety depression self-harm suicide
- Somebody that listens when I am talking and doesn't stop me to talk about their problems
- Eating disorder help
- Community based, like we have accessed locally in Blackburn. Youth Connect programme at Eanam Wharf
- More counselling options available
- Not taking therapy
- Better access to 1-1 or group therapy sessions and understanding people do struggle
- 1 on 1 with someone face to face in a quiet place where no one can hear us
- Early intervention schemes. Stop trying to solve a problem when a young person is literally in crisis. I have known people who've died as young as 13 years old because they weren't "sick enough" which drives lots of young people into self-harm and similar externally noticeable issues to be validated by those who should have already cared. Teach primary school children about how to take care of their minds in the same way we teach healthy eating plans and exercise.
- Maybe group support sessions with people who have similar issues so I feel less lonely
- Honestly, I don't know. I don't know the support available or anything. I was with CAMHS/ ELCAS. But because I was leaving high school, and they said to me "there is not enough time to do CBT with you." And discharged me. I now receive support from a college counsellor, and pretty much every other day, I'm speaking to helplines like SHOUT, YOUNG MINDS, Childline and Kooth
- Support for anxiety and spiralling negative thoughts
- Anger and worry

Responses – parents/carers

Of the 314 responses received, 135 (43 per cent) of these were from a parent or carer. The responses are as follows:

When your child is getting support from a service what values are important to you from the staff?

Of the 134 responses received, 131 (98 per cent) parents/carers answered this. As the table below indicates, not all parents/carers ticked all answer choices.

Ans	wer Choices	Response Percent	Response Total
1	They treat me and my child with respect	92.37%	121
2	They get to know my child	88.55%	116
3	They listen to my child	90.08%	118
4	They are non-judgemental	88.55%	116
5	They make sure my child is included	81.68%	107
6	They are approachable	85.50%	112
7	They are honest with me and my child	88.55%	116
8	They listen to my knowledge of my child	91.60%	120
9	They don't give up on my child	83.97%	110

Comments received include:

- All of the above. Plus none of the above are worth anything UNLESS the first appointment is timely. A 6+ month wait for an appointment makes the service virtually worthless. The young person has either recovered, got much much worse (making your work much much less effective), or has taken their own lives.
- They are accessible 24/7 for emergency support or means of communication is flexible email/text rather than having to ring between core hours
- continuity of support staff
- They are open minded (to diagnosis, differentiated treatment options eg for ND kids)
- They train and upskill on autism and learning disabilities
- The setting is non-clinical, warm, cheerful and welcoming run by people from the community who understand needs and qualified in additional needs and children's and young people's mental health (lived experience)
- Accessible, timely and available
- Caring and compassionate
- Clinically excellent knowledge and skills
- Continuity of care I want to build a relationship with professionals I can trust
- Organised: they do what they say they will, when they say and communicate if things change
- They take 'ownership' of a case they don't just work to the limits of their particular team but 'handover' to the appropriate skilled clinician not 'handoff'
- Outreach into schools, homes and communities non-engagement is a system failure not a patient failure
- They provide timely access, easy access and don't refuse referrals
- We are informed on waiting times and give realistic expectations
- Make adjustments for children with disabilities and not just say everything is severe learning disability
- They have knowledge of autistic burnout, PDA, masking
- Taking parents seriously would be nice. Listening to their concerns and not replying with "well they're not 6 so there's nothing we can do yet"

- They are highly knowledgeable about specific mental disorders which affect my child and are not generic in their approach
- It feels like services are always looking for reasons why a young person doesn't need support. Usually due to staffing shortages and not the young person's needs
- Treat my child as the expert of their own lived experience
- Understand behaviour issues
- All staff are approachable
- They allow enough time to really listen to and understand my child. They are knowledgeable about other local support services. They are clear right from the start what the service can and can't do
- I'd make sure they don't talk down or shout seek help , then in my experience of group my child's faced just as bad treatment as they received at school which triggered them
- Never force a young person to engage
- Never force a neurodiverse child to participate, or change the format raise voices be aware of sensory processing unfortunately professionals don't seem to take it as seriously as it needs to be taken
- Never threaten a young person if they don't participate they'll have to leave
- Acknowledging a child's gender, pronouns
- Listen to their parents
- They acknowledge n respect religious beliefs of family and child
- Understand the cultural issues of the individual. Need more staff recruited from the diverse communities we serve. Needs to be needs based treatments and with considerations of those with mental health ad families and friends close to the patients. Needs to be holistic and inclusive treatment plan .Not all size fits all.
 NATURE AND TIME TO HEAL IS NEEDED .UTILIZE NONE MEDICINAL APPROACH DO NOT RELY ON MEDICINE ONLY PLEASE. People from all backgrounds at decision making process especially commissioning service
- The most important is not giving up. There are a lot of services that say two non attendance and you're out. If you are dealing with young people who have mental health there needs to be extra hand holding and time
- They listen to us, if we feel there is something not quite right, to not just ignore us, and to work with us. We know our children more than anyone, and these days we all get fobbed off, and this is so frustrating for parents/carers. Which makes us not want to go to these services again, which can miss all sorts, and cause many problems later on in life
- My child has some anxiety and they help her relax and feel comfortable
- Clear advice or guidance provided, rather than just signposting to a website/app/phone number
- Sessions are child centred
- They are well qualified and experienced
- Not waiting too long to be seen
- They take my child's difficulties in consideration, not forcing to have a blood test, dental appointment etc if the child is not ready. So the child knows he can trust the staff
- Listening to carers and family members is so important. There should also be support for them
- Awareness of current difficulties that make it difficult to engage initially eg. Anxiety
- They understand and take interest in wider family & friendship dynamics and don't look at my child in isolation
- They empower my child rather than disempower

- They are not stigmatised towards mental health and do not use stigmatising language. They recognise my child is an individual. They do not make assumptions about other conditions or behaviours that are outside their remit or field of expertise. They do what they say they will do. They own their mistakes. They do not use you as a go between for other NHS mental health services. They do not demonstrate professional snobbery to other mental health services. They treat you like a customer and not a number
- They don't rush my child

What does an organisation need to do to ensure that you feel your child is going to a supportive, safe and nurturing environment?

Of the 134 responses received, 131 (98 per cent) parents/carers answered this. As the table below indicates, not all parents/carers ticked all answer choices and it appears some of the answer choices were not as important to parents/carers than others.

Ans	Answer Choices			Response Total
1	They communicate well with me		94.66%	124
2	There is a consistency of support worker		80.15%	105
3	The physical environment is welcoming		70.23%	92
4	There is no shouting		67.94%	89
5	There is honesty		78.63%	103
6	My child is met with positivity and understanding		90.08%	118
7	There is consistency		86.26%	113
8	There are clear boundaries for everyone to follow		77.10%	101

The parents/carers were also invited to provide any other feedback. Comments received include:

- All of the above. Plus none of the above are worth anything UNLESS the first appointment is timely. A 6+ month wait for an appointment makes the service virtually worthless. The young person has either recovered, got much much worse (making your work much much less effective), or has taken their own lives
- Staff have basic human kindness
- Staff have up to date CPD
- Staff accept the young person's experience of the world and don't argue with it (ie they are person centred, rather than glued to the medical model)
- The MOST important thing is having the same care worker throughout! This does not happen at present
- They read and understand my child's needs, be non-judgmental and acceptance of who they are
- There are no ulterior motives and no pre-conceived ideas about the child or the carer of that child. Every child is different. Comments like, 'She's not ADHD because she's not like the other children I've seen with ADHD' made to us by a consultant paediatrician

- Use familiar, non-medical, environments homes, schools, community centres, cafe e.g. Cornerstones, libraries, Churches, mosques etc
- They provide timely access, easy access and don't refuse referrals. Just be helpful and don't push the child back and forth from pillar to post
- Need to be flexible to the needs of the child / young person
- Having knowledge of the strategies needed when working with PDA
- Taking parents seriously would be nice. Listening to their concerns and not replying with "well they're not 6 so there's nothing we can do yet"
- I understand that it isn't always possible to have a consistent support worker but what is important is that support workers are introduced to my child and communication between support workers is effective so that there is consistency no matter who my child sees. The environment also needs to be child friendly, as well as welcoming. I'd also want to be confident that recruitment processes for support workers are robust and that the most appropriate and qualified people are being employed to support my child.
- Boundaries are important but please be aware these you p people are so vulnerable and will make mistakes some are terrified, some are in desperate crisis for years due to the mess after covid
- Community venues used, so that they are familiar with would be beneficial and easier to get to. Linking in with other services to use their buildings.
- Reasonable 'person centred needs' accommodated.
- Suffering with anxiety or fear or meeting new people, especially in large groups
- Same time same place each week
- They communicate well with the child
- Friendly
- Positivity

How do you think a service can be more inclusive?

Of the 134 responses received, 130 (97 per cent) parents/carers answered this. As the table below indicates, not all parents/carers ticked all answer choices.

An	Answer Choices		Response Percent	Response Total
1	The physical environment is accessible for everybody		75.38%	98
2	They communicate in ways that everybody understands		84.62%	110
3	Inclusive language is used		68.46%	89
4	Everybody is given the opportunity to be involved		83.08%	108
5	Having a flexible and adaptive approach		87.69%	114

The parents/carers were also invited to provide any other feedback. Comments received include:

• CPD for staff in LGBTQ+ issues - please keep up with the kids

- CPD on neurodiversity issues, please keep up with neuro affirmative language and thinking, get your CPD from adults with lived experience
- Accept PDA exists and learn about it
- Be led by the child, meet the child where they are and do not have prior expectations
- Baby steps; not too much too soon. Work on building positive rapports
- Multilingual, multicultural materials and access to interpreters including BSL
- Peer support groups hosted in the same setting
- Regular feedback from service users
- Outreach end the culture of 'not my team': e.g. our local mental health services 'don't do autism'
- They think about the service being offered from the service users point of view
- They use common sense
- Having meeting rooms that are a good size not like a match box
- Rooms with no clutter / lots of equipment
- Flexible to the needs of the child
- Flexible and adaptable is key, appointments on line if needed, meeting one autistic is meeting one autistic, everyone is as unique as your finger print so please don't have an approach that is generic
- Taking parents seriously would be nice. Listening to their concerns and not replying with "well they're not 6 so there's nothing we can do yet"
- Ensure rooms are inviting and comfortable, no so hospital like or formal
- Time is crucial pre-appointment diaries that the parent/carer/young person are able to fill in will enable a better understanding of "impact" rather than having to rush through in a consultation
- Being available on evenings and at weekends. Being offered outside of clinical settings at places where young people are, e.g. at a youth centre where they might already be attending for other activities. Having a remote option so that a child can access support from home. Ensuring feedback is regularly captured from people who use the service and is acted upon to make improvements
- Again being inclusive but not pushy
- Don't do ice breakers for people with asd , selective mutism these are unbearable
- My child struggles to verbalise remember never push communication
- Adapt ... educate the other young people if possible
- Find resources to support those that struggle with communication
- A non-judgemental approach
- Diverse and trained staff as well as customer care and staff with lived experience to advise and enhance the service
- The physical environment and language used is adapted to include children who are neurodiverse.
- Using technology for young people. What's app video or photo to be sent to introduce the practitioner. Breaking down barriers from the onset
- Support involvement not just make it available
- Reasonable 'person centred needs' accommodated
- Suffering with anxiety or fear or meeting new people, especially in large groups
- Easier to access help when needed as there seems to be very long waiting lists. This then means some slip through the net and are missed
- Build a relationship with my child at their pace
- Staff should be trained for PTSD
- Lots of communication and opportunity to talk with parent carers as well

- They do not stigmatise mental health, nor the parents/child
- Different communication methods utilised

What type of mental health support would best help your child?

This was an open-ended question; 77 parents/carers provided a response. These are as follows:

- Support that is delivered when it's needed NOT months later
- Firstly it needs to be timely- 18+ month wait for a psychologist when a child is in crisis is appalling. Secondly a recognition that autistic kids need mental health support too- not to be turned over to the autism service, which can offer very little. Neurodivergent adapted 3rd wave CBT type approaches rooted in a person centred philosophy. (Adapted DBT ACT CFT etc). EMDR. Systemic family therapy. Consider some radical thinking- gaming therapy, Lego therapy, animal therapy etc. Joined up thinking with autism service so that practitioners can offer neuroaffirmative psychoeducation embedded into therapies. The option if the child can't engage- to have appointments on zoom, and the option (again if child can't engage), for the psychologist to work directly with parents during the child's appointment slot to resource parents with skills to better manage their child's condition at home, rather than just discharging with no support
- Consistent understanding and empathy. We currently have to ask for things that we see elsewhere. These should be promoted to us
- They understand what the child needs and how to support them
- Mental health support which acknowledges that if you are autistic, you may need adapted and flexible approaches. A CAMHS service that accepts that autistic anxiety is not just inevitable, but does need a distinct and potentially differentiated approach to mental health support
- A specialist trained autism team, including understanding of the pda profile
- Support that helps the child and family move forward
- One to one with a counsellor
- Lived experience, qualified in the child's specific needs, non-intrusive, softly softly but firm, outdoor activities, working to the child's interests i.e technology, numerical and scientific (kinaesthetic)
- In school, positive activities, clubs and societies to join. Counselling, PWP access in schools
- Coping with anxiety and managing emotions
- At the moment the lack of available clinicians via CAMHS means that any support from them would be welcomed
- Seeing someone when needed
- Functional medicine doctor, tests for supplements and nutrition. Tests for retained reflexes, audio therapy, Understanding the root cause, not just giving the option of medication without any tests or talking therapy without knowing if the person can deal with that first. Do they need supplements first. Look at their methylation
- Counselling
- More access to CAMHS. Maybe CAHMS could go to special schools to see more pupils and in a more friendly / safe (familiar) environment
- Activities, lots of Counselling to help child go through studies pressure, bullying, anxiety
- Support for families when in autistic burnout, PDA, appreciate when a child is masking. Not having to wait 3 years for an autism assessment. Autism to away from

CAHMs. Support, post diagnosis, to have staff that are autistic themselves, support when they cannot leave the house, helping them get a hospital passport uploaded onto the hospital system so that staff know about difficulties when they come to hospital. Having staff with up to date training, lots of stereotypical old fashioned training is used within the NHS

- Taking parents seriously would be nice. Listening to their concerns and not replying with "well they're not 6 so there's nothing we can do yet"
- Home visits, support for ASD children coming to terms with diagnosis
- One that is inclusive, non-judgemental, has good understanding of the wider impact of mental health difficulties on young people for example not being able to go to college or work is not a choice it is because my child struggles with their mental illness.
- One that takes into account neurodiversities
- Massive gap in service around impact of developmental trauma on mental health
- Support/diagnosis for neurodiversity without waiting several years
- CBT and talking therapies 121, in person
- Confidence and resilience pro-active support built into curriculum throughout the school years
- Support with anxiety and behavioural issues
- My child has an asd with pda profile diagnosis, I am completely unaware of what support is available for her or us as parents
- Weekly longer term support
- I was advised following his appeal from his section that he should receive ceryain medication, and talking therapies, 2 years on I have been listened to over his meds and still waiting for therapy. Too many failings and inconsistency in his care has been a major issue
- Socialisation work and EBSA support
- Early intervention to stop the situation escalating. Still waiting for CAMHS 21 + weeks after a referral. This cannot be seen as an emergency service but an emergency service is required. There are not enough soft touch services. My son has gone from anxiety to self-harm to school refusal. Would have been great to have got some support at stage 1
- Anxiety
- Support them to understand their mental health, to learn how to look after their mental health, to know how to access extra support when they need it and for the support to be available straight away so they are not waiting and becoming more unwell. Support should be tailored to my child, taking into account what they are experiencing and how they want to be supported and to plan this with them rather than for them. It would also be useful for me to learn more about mental health so that I can better understand and support my child and know how to spot signs of someone being mentally unwell
- Positivity and challenges
- My child is struggling massively, we are awaiting service involvement. I think shorter waiting times and school teacher education needs improving
- CBT
- Face to face with the same person each week
- Managing emotions
- Targeted group purely for asd doing art therapy or something creative they struggle with trauma too so working with animals or veterans in community, anything to break through. They need long term group that aren't colicky full of bullies and staff that

shouted at them changed the format to school like activities forced one to one's that would be a start. Start supporting these kids early, train teachers. Change the narrative within schools normalise support. Access to regular long term sen trained mental health support

- Help with dealing with anxiety and panicking ie exam times. Dealing with parental split up, knowing she can have a relationship with both and how to have a healthy relationship with her father who can be quite controlling n negative. Helping increase her confidence
- Eating issues
- 24/7 online help available, which Kooth is great at, but algorithms mean that unfortunately my child is ignored if not deemed high risk
- A human approach with understanding more reliant on alternative to medicine rather than medicines. More help for families take their opinions into consideration as they live with them. PLEASE MAKE A WAY TO GET HELP TO CHILD EVEN IF THE CHILD OR ANY INDIVDUAL REFUSES TO ENGAGE. Find WAYS TO DO SO. NOT ALL SYSTEM ARE APPLICABLE TO ALL. My child who is 28 still is my child but can't access help for him because he's too old according to your systems. As a parent I feel helpless and upset can't help my own child even though I work for health
- At present the only service available to my son (who is both autistic and struggling • with his mental health) is CBT, which he is not able to engage with. We have been advised that he does not meet the criteria for the higher need ELCAS service (as he is not at immediate risk of harm). There is no other mental health support available to him. Counselling has been recommended (provided by charities who have long waiting lists), but he is not able to engage with that either. This has left us doing our best, without any external support, to do our best to support our child on our own. Support needs to be adapted to meet the needs of autistic children and be more flexible. Mental health services need to be accessible to autistic people. This could look like 1:1 coaching instead of counselling / CBT, art therapy, animal therapy (such as equine therapy). It needs to be more creative and flexible. It is not ok that families like mine are left with nothing, until our children's mental health deteriorates to the point where they do meet the criteria for the higher level ELCAS. Recovery is much more challenging for children when they have become so seriously unwell and is more costly than support that starts when they first begin to experience difficulties.
- Emotional support
- My child should feel comfortable and understand the benefits of mental health support system
- Support around anxiety, how being online affects your mental health and well-being. Anger and how to deal with it. Self-harming and low self esteem
- More knowledge, understanding, patience and empathy. Each child is individual, what works for one won't for another. To work best with each child to their own needs

 not in general - what they think works for all, or what the organisation thinks work, as this is not the case with many. And can even make children worse off, if they're not being listened to or dealt with as an individual/unique
- Just having a one to one person that's just for them
- Groups to support their needs and to share experiences with children who have been through similar things.
- Support that is timely
- CBT and to learn it's ok to worry sometimes but don't allow it to control you
- Angry issues, depression, ADHD
- Cognitive behaviour therapy, eating disorder

- Person Centred Counselling. Age appropriate supervised fun social events/activities. Understanding 'no self-blame or guilt or too much responsibility' as a Young Carer. Practical tips on managing role as a young carer
- One to one not good in group setting and a male if possible
- Anxiety, worries
- Support
- Developing ways to regulate emotions and build resilience
- Understanding emotions, talking through times they have felt tricky, problems solving, all emotions are ok
- Resilience to deal with everyday life. Someone to talk to if they have any worries
- Ongoing coaching and community groups
- Nothing specific needed for my children, however teaching awareness of feelings and how to deal with them, when to speak to a trusted person and get help etc
- Through games, talking
- Emotional development
- Play therapy
- Something that puts them at the centre and is inclusive of their needs making sure they are comfortable with the format and don't have to fit in someone else's idea of support that doesn't work for them
- Access to a psychiatrist and health professionals who are specialists in trauma and the impact
- Timely support when needed. Early intervention
- Outside of a clinical environment
- Someone with experience, consistency, access to psychiatrists
- 1-1 person centred, group CBT, management of own anxiety
- Anxiety workers for them but he's already got 3
- Support that is accessible when it is needed, and not months after presenting with a concern or problem
- Lower waiting lists. Provision of assessments. Talking to and referring into other services without the parent having to do everything. Recognition of the challenges of mental health and neurodiversity and not just fobbing it off as neurodiversity and nothing can be done. Not telling you you can get something from school that you can't get from school (misinformation) so fobbing it off in someone else.
- A relevant one. Not a 'one size fits all' method
- Counselling

Equality monitoring – young people

This section applied only to the young people. It was specified in the survey at the start of this section that these questions didn't need to be answered but it would be helpful so we could understand who we were reaching.

1	10. What age range are you in?			
A	nswer Choices	Response Percent	Response Total	
1	13 - 15	75.14%	133	
2	16 - 18	16.95%	30	
3	19 and over	7.91%	14	
		answered	177	

1	11. How would you describe your gender?					
A	Answer Choices Response Percent					
1	Male	38.55%	69			
2	Female	54.75%	98			
3	Non-binary	3.91%	7			
4	Prefer not to say	2.79%	5			
		answered	179			

1	13. What is your ethnicity?				
A	Answer Choices Response Percent				
1	White	84.36%	151		
2	Asian or Asian British	7.26%	13		
3	Black or Black British	0.56%	1		
4	Mixed	2.79%	5		
5	Prefer not to say	5.03%	9		
		answered	179		