



YOUNG PEOPLE'S EXPERIENCES OF HEALTHCARE

A lived-experience report from SEND young people across
Yorkshire and Humber

CO-PRODUCED FOR DIALOGUE WITH NHS, DfE AND PARTNER ORGANISATIONS

Healthcare event • 2026

THE CENTRAL MESSAGE

“Nothing about us without us.”

This report brings together direct experiences, views and recommendations shared through regional SEND youth engagement.

About this report

This report brings together the experiences, views and recommendations of SEND young people who participated in three regional engagement sources: the Campaigns Committee, the Health and Wellbeing Committee, and the regional SEND Collective summer social. The conversations explored healthcare experiences, mental health support, physical health conditions, complex needs, transitions into adulthood and healthcare inequalities.

A QUALITATIVE LIVED-EXPERIENCE REPORT

The material captures what young people told the network. It is intended to inform discussion, service improvement and co-production; it is not presented as a prevalence survey or as a statistically representative sample.

Who contributed

- Neurodivergent young people, including autistic young people and young people with ADHD.
- Young people with mental health needs.
- Young people with physical health conditions including epilepsy, hydrocephalus and chronic health conditions.
- Young people with multiple and complex needs.
- Young people involved in SEND participation groups, regional campaigns and youth voice activities.

How to use the report

- Use the themes as prompts for service design, workforce development and improvement conversations.
- Listen to the direct language of young people alongside the practical examples of what helped.
- Treat co-production as an ongoing relationship rather than a one-off consultation.
- Use the questions in the final section to identify where partners can take the next conversation.

Executive summary

Across the engagement, young people described healthcare that can be fragmented, difficult to navigate and insufficiently adapted to SEND needs. They also described positive experiences where professionals listened, understood, communicated across services and built trusted relationships.

10 themes Understanding, listening, whole-person care, joined-up services, mental health, waiting times, sensory environments, transition, transport and visibility of SEND.	What good looks like Active listening, longer appointments, shared decision making, continuity, integrated care, appropriate reviews and individualised support.
Small adjustments Sensory packs, healthcare passports, quiet spaces, flexible communication, longer appointments and consistent contacts.	Core principle “Nothing about us without us.” Young people want meaningful involvement in service design, workforce training, policy development and improvement.

The message for system leaders

YOUNG PEOPLE ARE ASKING FOR Healthcare that is accessible, coordinated, sensory-friendly, trauma-informed, neuroaffirming, person-centred and consistent.

The strongest examples of positive healthcare were not described as expensive interventions. They centred on professionals listening, understanding, communicating, working together and building trusted relationships.

What young people told us — at a glance

THEME	WHAT WE HEARD
01 Understanding	SEND, neurodiversity and trauma are not always understood.
02 Being listened to	Young people do not want to repeat themselves or rely on others to speak for them.
03 Whole-person care	Conditions and treatments need to be considered together.
04 Joined-up services	Young people should not have to coordinate fragmented care.
05 Mental health	Support needs to work for SEND young people, not exclude them as “too complex”.
06 Waiting times	Long waits can mean delayed diagnosis, treatment and hope.
07 Sensory access	Healthcare environments can create overload before care even begins.
08 Transition	Moving into adult services can mean losing clarity about who to contact.
09 Transport	Rurality, accessibility and long journeys can affect access to care.
10 Nothing about us without us	Young people want a meaningful role in decisions about services.

CROSS-CUTTING POINT

The themes are connected. Listening, communication and continuity sit underneath many of the experiences described across physical health, mental health, complex needs and transitions.

01 Understanding SEND, neurodiversity and trauma

Young people consistently reported feeling misunderstood by healthcare professionals. They highlighted the need for better understanding of neurodiversity, sensory needs and trauma-informed approaches.

YOUNG PEOPLE SAID

“As soon as they see you've got autism or you're wearing your sunflower lanyard or something, they just go straight to patronising baby voice and like you don't know anything.”

What this meant for young people

- Feeling patronised.
- Reduced trust in professionals.
- Increased anxiety.
- Reluctance to seek support.
- Feeling invalidated and dismissed.

What young people described as helpful

- Professionals who understand SEND and neurodiversity.
- Communication that respects young people's knowledge and autonomy.
- Trauma-informed and sensory-aware approaches.

02 Young people do not feel listened to

Many young people described having to repeatedly explain their needs and feeling that professionals were not listening. Some described relying on parents or carers to explain what they were trying to communicate.

YOUNG PEOPLE SAID

“I have to explain everything over and over again.”

What this meant for young people

- Frustration.
- Emotional exhaustion.
- Reduced confidence.
- Increased dependency on parents and carers.

What young people described as helpful

- Active listening.
- More time in appointments.
- Direct communication with the young person.
- Follow-up support and shared decision making.

03 Physical health and complex needs are not managed holistically

Young people reported that healthcare systems can focus on individual conditions rather than the whole person. They described difficulties when multiple conditions, treatments or medications interact.

YOUNG PEOPLE SAID

“Nobody looks at the whole picture.”

What this meant for young people

- Repeated appointments.
- Conflicting advice.
- Delayed care.
- Medication challenges.
- Significant burden on young people and families.

What young people described as helpful

- Whole-person assessment.
- Communication between teams.
- Appropriate medication review.
- Collaborative planning across conditions.

04 Services do not work together

Many young people felt that healthcare services are fragmented and that information does not always move with them across teams, trusts or providers.

YOUNG PEOPLE SAID

“You end up being the person trying to communicate that information.”

What this meant for young people

- Delays in treatment.
- Repetition of information.
- Increased stress.
- Young people becoming responsible for coordinating their own care.

What young people described as helpful

- Shared information.
- Integrated care.
- Communication between services.
- Collaborative planning.

05 Mental health support often does not meet SEND needs

Young people repeatedly discussed mental health services that did not meet their needs and described support designed around neurotypical assumptions.

YOUNG PEOPLE SAID

“The support didn't work for me because it wasn't designed for people like me.”

What this meant for young people

- Escalation to crisis.
- Loss of confidence in services.
- Withdrawal from support.
- Increased isolation and distress.

What young people described as helpful

- Individualised care.
- Consistent support and trusted relationships.
- Time to talk.
- Mental health approaches adapted to SEND needs.

06 Long waiting lists and delayed support

Waiting times were one of the most common concerns raised. Young people described long waits for assessment and referrals and the effect of waiting on hope, diagnosis and treatment.

YOUNG PEOPLE SAID

“Referrals, I think they just take so long.”

What this meant for young people

- Worsening health conditions.
- Delayed diagnosis.
- Delayed treatment.
- Reduced trust in healthcare systems.

What young people described as helpful

- Clear information about waits and next steps.
- Joined-up pathways that reduce duplication.
- Timely access to assessment and support.

07 Healthcare environments are not sensory friendly

Young people frequently discussed sensory challenges within healthcare settings. Overload could begin before an appointment and make communication harder.

YOUNG PEOPLE SAID

“By the time I get into my appointment, I’m already overwhelmed.”

What this meant for young people

- Anxiety before appointments.
- Distress during appointments.
- Difficulty communicating.
- Avoidance of healthcare settings.

What young people described as helpful

- Quiet spaces.
- Sensory packs.
- Flexible communication options.
- Environmental adjustments that reduce overload.

08 Independence and transition to adult services

Young people highlighted concerns about moving from children's to adult services and losing clarity about who to contact or how to access support independently.

YOUNG PEOPLE SAID

"I knew who to contact before, then suddenly I didn't."

What this meant for young people

- Uncertainty about where to go for help.
- Loss of continuity.
- Challenges understanding adult healthcare systems.

What young people described as helpful

- Preparation for adulthood.
- Information young people can access independently.
- Maintaining support during transitions.
- Consistent contacts.

09 Transport creates healthcare barriers

Young people highlighted transport as a key barrier, including rural transport limitations, inaccessible public transport, long journeys and poor disability awareness among transport providers.

YOUNG PEOPLE SAID

"Transport affects whether young people can access healthcare, education, employment and social opportunities."

What this meant for young people

- Missed or difficult access to healthcare.
- Long and demanding journeys.
- Reduced opportunities across health, education and employment.

What young people described as helpful

- Accessible transport.
- Better disability awareness among transport providers.

- Planning that recognises rurality and travel burden.

10 SEND can feel like an afterthought

Young people expressed concern that SEND is not always visible within healthcare priorities or strategic planning. They emphasised that they are the people using these services.

YOUNG PEOPLE SAID

“We’re the people using these services.”

What this meant for young people

- A sense that SEND needs are considered too late.
- Limited visibility of neurodiversity and trauma-informed approaches in planning.

What young people described as helpful

- Meaningful youth voice in planning.
- SEND built into service improvement from the beginning.
- Co-production in policy, workforce development and healthcare improvement.

What good healthcare looks like

Alongside challenges, young people described positive experiences that show what good care can feel like in practice.

Professionals who listen Active listening, longer appointments, shared decision making and follow-up support.	Consistency and relationships Trusted relationships, consistent professionals and continuity of care.
Joined-up working Shared information, integrated care, communication between services and collaborative planning.	Effective treatment Appropriate reviews, finding the right medication, long-term monitoring and ongoing support.
Positive CAMHS experiences Consistent support, trusted relationships, time to talk and individualised care.	Right to Choose experiences Young people described joined-up pathways where assessment, diagnosis, psychoeducation, medication review, prescribing and ongoing support could sit within one service.

A USEFUL CONTRAST

Young people described joined-up pathways as reducing duplication and improving continuity, compared with traditional pathways that can involve multiple referrals, long waits between stages and separate providers managing different parts of care.

Small adjustments can make a big difference

- Sensory packs.
- Healthcare passports.
- Quiet spaces.
- Longer appointments.
- Flexible communication options.
- Consistent contacts.

The impact on young people

YOUNG PEOPLE REPORTED

Anxiety • isolation • reduced confidence • loss of trust in professionals • deteriorating physical health • deteriorating mental health • delayed support • increased reliance on family members.

The report includes particularly strong statements about disengagement from healthcare following repeated negative experiences:

YOUNG PERSON'S EXPERIENCE

“That's why I don't go to the doctors.”

YOUNG PERSON'S EXPERIENCE

“I literally refuse to go to doctors now because I don't see the point.”

These statements are presented as direct lived experience. They underline the importance young people place on being listened to, understood and supported in ways that work for them.

A shift from ‘fixing the young person’ to improving the system

- Ask what helps the young person communicate and participate before assuming what they need.
- Avoid making the young person repeat information that could be shared safely across services.
- Design environments and appointments around access needs, not as an afterthought.
- Build continuity so relationships and knowledge can carry across appointments and transitions.
- Involve young people in the design and evaluation of the services they use.

Questions for NHS, DfE and partners

These questions translate the themes into practical prompts for the healthcare event. They are designed to support discussion rather than prescribe a single solution.

LISTEN	How will young people know that their views have been heard — and what changes will they be able to see as a result?
WORKFORCE	How are staff supported to understand SEND, neurodiversity, sensory needs and trauma-informed practice?
JOIN UP	How can information and responsibility move between services without the young person becoming the coordinator?
TIME	Where do appointment length and communication flexibility need to change so young people can participate fully?
ACCESS	What practical adjustments — including quiet spaces, sensory packs and healthcare passports — are available consistently?
MENTAL HEALTH	How are mental health pathways adapted so SEND needs are understood rather than treated as a reason someone is “too complex”?
TRANSITION	How will young people know who to contact and what will carry over when they move into adult services?
WAITING	What communication and support are available while young people are waiting for assessment or treatment?

TRANSPORT	How are rurality, accessibility and travel burden considered in pathway design?
CO-PRODUCTION	Where are young people involved in service design, workforce training, policy development and improvement — and how is that involvement sustained?

Nothing about us without us

THE STRONGEST MESSAGE ACROSS THE ENGAGEMENT

“Young people want to be actively involved in service design, workforce training, policy development and healthcare improvement.”

Co-production means more than asking for feedback after a service has been designed. The young people represented in this report are asking to be part of the thinking, decisions and improvement work that shape the services they use.

A practical co-production cycle

1 INVITE Involve young people early, before priorities and solutions are fixed.	2 LISTEN Create accessible ways for young people to explain what works and what does not.
3 DECIDE TOGETHER Show how young people's evidence informs choices and trade-offs.	4 ACT Make changes and identify who is responsible for taking them forward.
5 REPORT BACK Tell young people what changed, what did not, and why.	6 KEEP THE RELATIONSHIP Build ongoing youth voice into improvement rather than returning only for consultation.

A SIMPLE TEST

If young people are the people using the service, they should be able to recognise their experience in the way the service is designed, delivered and improved.

Closing message

SEND young people are not asking for special treatment. They are asking for healthcare that is:

- Accessible.
- Coordinated.
- Sensory-friendly.
- Trauma-informed.
- Neuroaffirming.
- Person-centred.
- Consistent.

THE CHALLENGE FROM YOUNG PEOPLE

“If healthcare services are already inaccessible, fragmented and poorly adapted to the needs of SEND young people, how will wider SEND reforms succeed unless these healthcare barriers are addressed first?”

AND THE FINAL MESSAGE REMAINS

“Nothing about us without us.”

Source and engagement note

This report is based on direct experiences shared through: Campaigns Committee engagement; Health and Wellbeing Committee engagement; and the regional SEND Collective summer social, alongside wider health and wellbeing engagement activities. Quotations are reproduced from the supplied source report. The source material does not provide a participant count or claim statistical representativeness.

Prepared for dialogue with NHS, DfE and partner organisations • Yorkshire & Humber • 2026

