



Collective Get T★gether

2025



COUNCIL
FOR DISABLED
CHILDREN



National Network of Parent Carer Forums

contact

For families
with disabled children



Department
for Education

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Introduction.

The Collective Get Together was held Friday 1st August 2025, online (via Teams) and in-person in Nottingham.

Attended by 52 young people, representing all regions from England as well as key senior leaders from Kids, PIA consortium colleagues, Department for Education representatives and the Minister for Schools Standards, Catherine McKinnell MP.

Members of Kids Advisory Panel supported the Kids Voice Team to co-produce the content of the event and co-delivered elements of the introduction. They took part in all the sessions and wanted to ensure they empowered other young people to take part.

The event agenda included;

Session 1: Introducing the White Paper.

This session was designed to introduce young people to the concept and purpose of government white papers, with a particular focus on the forthcoming *Schools and SEND* white paper. It aimed to initiate meaningful discussions around policy developments, exploring how young people prefer to receive such information and how they wish to engage in ongoing dialogue. The long-term benefit of this approach is more informed and empowered young people, capable of contributing to the development of inclusive policies that support all learners, particularly those with additional needs.

Session 2: Listening Leaders.

This session created a vital platform for young people to be heard directly by those in positions of power. By bringing together Kids senior leaders, DfE officers, and the Minister for School Standards, it reinforced The Collective's commitment to ensuring youth voices shape policy. It marked a meaningful step toward inclusive decision-making, where young people influence the future of education and SEND support.

Session 3: Inclusive Classrooms

Focus has previously been around difficulties and problems faced by young people within education and the SEND systems. As the experts in their lives, young people are often able to reflect and share creative ideas for solutions. This session was solution focused and offering ideas for improvement and development.

Session 4: Snakes and Ladders of the SEND system

This session gave young people a meaningful opportunity to share their experiences—both positive and challenging—within the SEND system. It enabled thoughtful reflection and discussion on how future experiences, inclusion, and support can be improved for all.



Collective Get T★ether

Power Hour - The Schools and SEND White Paper

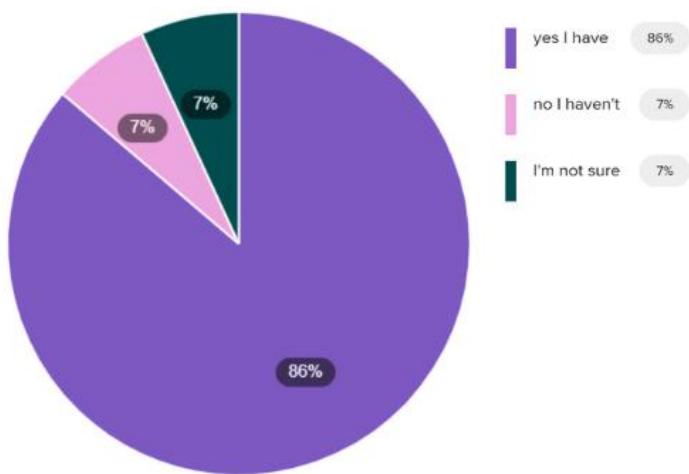
Session was held on Friday 1st August as part of the Collective Get Together

Attended by approximately 52 young people, representing all 9 regions from across England.

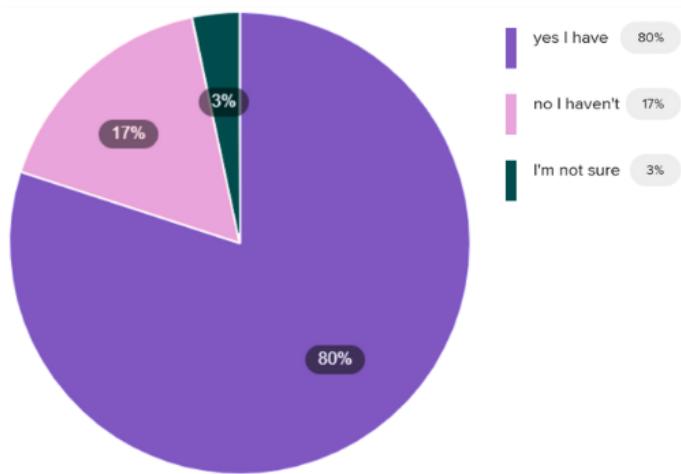
The Schools and SEND White Paper was a key topic throughout this years' Collective Get Together, having been the focus of multiple 'rumours' and causing concern for young people. The aim of this session was to inform and update the young people, as well as gathering information.

A vast majority of young people agreed that there is a problem with the SEND system and school support.

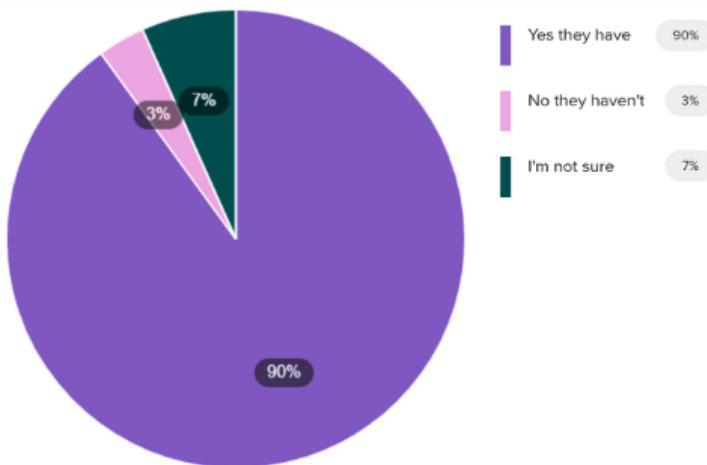
Those who have experienced long waits and delays for assessments, access to services or support to be put in place



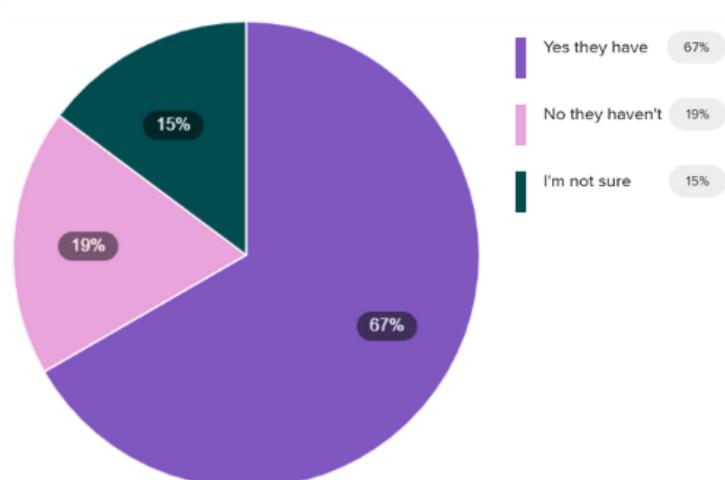
Stress due to things not happening at the right time, not getting the help when needed.



Parent carer and family Stress due to thing not happening at the right time, not getting the help when needed.



Education placements struggled to support young people properly due to funding



Young people shared that these problems make them, and their family feel the things identified in this word cloud.



The White Paper aims to look at the problems within the system (many of which contribute to making young people and families feel the above) and bring about ways to make change for the better.

Ideas previously shared by young people include:

- early help
- getting the right people in the right jobs
- using money more wisely more support in (mainstream) schools
- better training for teachers and assistants
- making it fair
- listening to young people and families

When asked if they had any more ideas for things that needed to change to make things better, the suggestions were able to be grouped into the following clear categories:

- SEND hubs and alternative provisions
- Person centred education
- Knowing and listening to young people
- Communication with young people and families
- Support needs identified and support put in place
- Wider disability understanding (staff and students)
- Exams
- Accessibility – physical, sensory (uniforms)

Full answers can
be found in
session summary
document

Moving forwards

Young people have made it clear: they want information to be shared promptly, in multiple formats, and in various locations. This ensures they can access what they need, when they need it, in the way that works best for them.

Some examples include:

- Concise themed sections
- Information Videos
- Easy Read documents

Full answers can be found in session summary document

To keep young people engaged, information must be shared widely and made easily accessible. There must be multiple, flexible opportunities for involvement, so individuals can choose how they engage in ways that suit them best

Young people suggested mechanisms they would like to engage in:

- Online and in person
- Themed activities
- Creative and arts-based sessions

Full answers can be found in session summary document

Young people shared clear views around the behaviours and values that they expected from those engaging with them, and that youth voice should be included and respected!

Don't beat round the bush and be honest

Take accountability and take action





Collective Get T★ether

Listening Leaders sessions

Sessions were held on Friday 1st August as part of The Collective Get Together and was attended by approximately 45 young people, representing all 9 regions from across England.

The sessions were held as small group conversations to allow all young people the opportunity to share with the 'listening leaders'. The leaders present included:
Anna Collishaw-Nikodemus – Head of Policy, Voice and Influencing, *Kids*
Claire Coussins – Director of Fundraising and Engagement, *Kids*
Amy Yoxall – Participation team, SENDAP outcomes and experiences division, DfE
Hannah Jacks – DfE

young people's 1 change to make school or college better included:

- Appropriate resource – Funding, time, access to equipment
- Pastoral support and mentoring
- Smaller class sizes
- Training for staff and young people
- Resources for teachers to access
- Support – for those studying at different levels including A-levels, subjects (STEM)
- Accessibility
- Participation, planning and decision making – being honest and transparent
- Understanding disability and young people (and viewing them as capable individuals)
- Abolishment of league tables
- Consistency in rules
- Social opportunities
- Types of provision – including homeschool and online schooling options
- Careers
- Disability sport
- Private/ Independent Schools
- SEND departments integration into wider schools

It (accessibility) should be this very foundational building block, because that makes it easier in the long term, if it's built in right from the beginning.

Further sharing opportunity – young people shared anything else that was important to them, with many choosing to use the sheet (found as appendix 1) to develop their pre-thinking. Topics that young people chose to share more on included:

- Education – somewhere to go before school to decompress and transition, more toilets, difficulty navigating schools due to size and neurodivergence

- Happy and successful adulthood
- Community and independence – people not understanding mental health disabilities and neurodivergence as being wired differently, parenting methods for neurodiverse children and young people, accepting coping mechanisms
- Public transport – buses to alternative parts of localities, renationalisation
- Health – understanding/ believing of hidden disabilities, treatment as a whole person rather than separating disabilities/ medical needs which can lead to refusal of and discharge from services, getting doctors appointments (especially ones to fit around working life), referrals to hospitals/ specialists and long wait times, lack of disability awareness
- Transition to adulthood – knowing what job, travel training, independent living, budgeting, practical experience
- Employment – not accepting/ don't make reasonable adjustments, unwilling to complete necessary risk assessments, out of area

Young people also spoke about university, including the need for more information so they are able to compare different universities and courses and if they can access the university and course. Ideas for this included a SEND league table, or a TripAdvisor type of site.

I was told I shouldn't go to university, I should do a supported internship. But no-one actually asked me what I wanted!

Planning and decision making was a topic that was important to young people, sharing points of importance such as:

- Feedback!
- Co-production from the outset
- Meaningful when there is transparency
- Encourages young people to engage with our democracy
- Respected by decision makers and that all voices have power to them

Transcripts of the discussions can be found in session summary document.

Highlights shared within the final summary sessions:

- Visuals + knowledge -> direction
- Children MUST have a say in all decisions that affect our lives as soon as possible
- It's not a 1-off. Continuously engage us at all stages.
- We are always here, always want to talk, always have ideas
- Better training on SEND for all
- Expect more – aspirations for CYP, have happy successful lives, live independently

The information young people gave should be shared with any relevant departments, as well as being used by Kids to inform policy positions. Where possible, ideas should be tested and implemented, with feedback being shared with young people via The Collective.



Collective Get T★gether

Inclusive Classrooms

The Collective Get Together was held Friday 1st August 2025, with this session being delivered in person to 29 young people, representing all regions of England, that attended in Nottingham.

Within this session young people took part in creative activities looking at solutions for the current reported issues in the SEND system.

Young people looked at classroom pictures that were created with AI. The prompts were points from sessions at Collective Get Together 2024 and Youth Voice Matters Conference 2024, looking at the areas that young people find inaccessible and cause difficulties.

Themes young people identified as resolving the issues included:

- Changes to the environment and its contents
- Staff training and practices
- Access to and use of both assistive technology and general equipment (e.g. interactive whiteboard)
- Techniques to support learning for all

Full information shared by young people can be found in session summary appendices, along with additional activity gathering positive and negative lived experiences

We are creating a fabric patchwork quilt together to signify working together to build "a better SEND System". Young people shared their wants and ideas on patches. A write up of the patches can be found in session summary document.



Moving forwards, we should learn from the ideas and experiences shared by young people, working together to replicate good and where needed, to ensure change is put into practice and embedded into the culture of education provisions.



Collective Get T★gether

Snakes and ladders of the SEND system

The Collective Get Together was held Friday 1st August 2025, with this session being delivered in-person in Nottingham to 29 young people representing all regions in England.

The snakes and ladders game played was co-produced as part of a workstream involving both young people and parent carer forums.

Ladders were examples of things that work and help support young people, and snakes were examples of challenges young people had accessing support.

Below are topics identified in response to snake cards (challenges accessing support):

Reasonable adjustments

- Feeling unheard
- Not given what I need

Accessibility

- Took a long time for support to be put in place
- The right services not available
- Too Autistic or not enough

Funding

- Always hard
- There isn't enough money in schools to pay for the support

Transport

- Buses are unavailable

Lack of trained staff

- Didn't know how to cope with my disability
- Without an EHCP little support was given
- They don't know how to support or just don't have time

The following were identified during the ladder card discussions (things that work and help to support young people):

Co-produced

- Youth groups – art drawings
- Mental health first aid
- Training

Reasonable adjustments

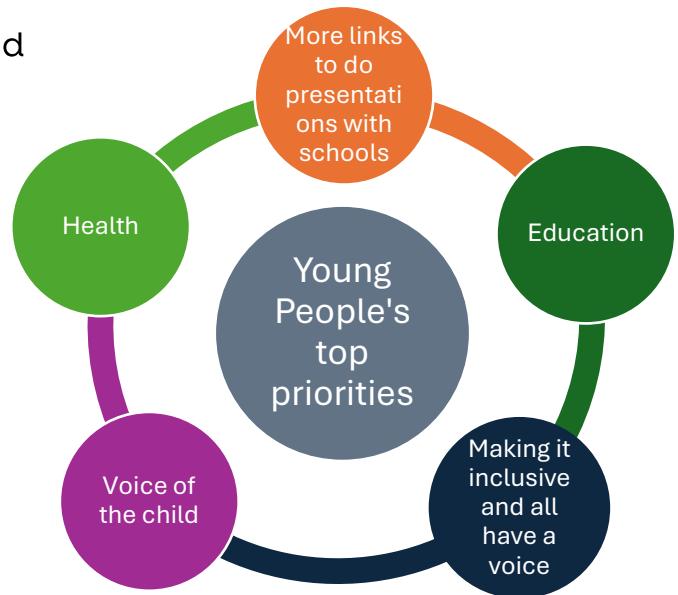
- Having a reader for exams
- I was given extra time for exams

Transitions

- Early access to school really helped me
- EHCP put in place so I could get extra support

Feel listen to

- A friend within the forum, listens and understands me
- Best work which has been completed
- Working with SEND leaders, so we now feel listened to
- Every young person should have the option to be in a forum or be heard



Trained staff make a difference

- School staff all need to be trained

Person centred plan

- SENCO advocated for me

Also in the deck were mystery cards; if they landed on a mystery card they read out a question to answer. These created discussions around their forums, co-production journeys and impact and can be seen below:

How often does your forum meet?

- Every other month – London

The impact the forum has made

- MacDonalds parking changes
- CAMHS support
- Workshop's which they have been a part of speaking with professionals
- A terminology guide for ASC people.
- Sit on interviews
- Sit on loads of panels

Best thing about the forum

- Food
- Learning to be independent
- Have a voice
- Make impact
- Change
- Friends
- It was co-produced from the beginning

How does your forum communicate

- WhatsApp chat
- Attend meetings regularly
- Emails
- Social media
- Lots of visuals

Areas of interest

- I love Lego
- Supporting mental health charities
- Watching movies

When and where do your forum meet

- Online and face to face

Other discussions had

- Having accountability for LA's
- No more Jargon
- More accessibility
- Leaflets through doors
- Need more easy read guides
- Local offer needs to be better suited for us – work with us
- Forum info is the local offer but is it easy to find – is the question
- Young people need to be part of their EHCP – so many young people are not

- Portals hard to access
- Have glossary to explain words – too many acronyms and long words.
- Case workers not attending stuff
- Digital poverty.
- Long waiting lists
- Was seen quickly once I was in a mental health crisis, but that was far too late – should not have got to that point

Following on from this, information should be shared with the relevant people in order to enable change, or at a minimum to make them aware of lived experiences of young people who use and are impacted by the current systems. Efforts should be put in place to share and replicate good practice.

The Collective encourages departments to reach out (via contract leads) to gain further insight, with potential to support co-production.



Conclusion.

Young people were encouraged in their groups to identify their key priority points to share with everyone at the end of the day.

Sharing experiences

Accessibility for all

Less acronyms, less jargon. Let us talk – listen. Involve us in own care.

Breaking down jargon consistently

Listening leaders

Visuals + knowledge → direction

Children MUST have a say in all decisions that affect our lives as soon as possible

It's not a 1-off. Continuously engage us at all stages.

We are always here, always want to talk, always have ideas

Better training on SEND for all

Expect more – aspirations for CYP, have happy successful lives, live independently

Better futures

Being heard

Everyone supported to be the best they can be, doing what they want to do, succeeding

The importance of accessibility in the classroom

Moving forwards, the content of this report, or sections of, should be shared with the appropriate teams and departments, and be utilised to inform policy positions and development of practices. The Collective hope to share feedback with other young people around any changes or developments made because of their input.

We would like to thank:

- Kids staff, Parent carers and Practitioners who supported the day
- Department for Education for providing the venue and attending
- Catherine McKinnell (MP) and team for attending and listening to young people

Our biggest thank you to the young people, who came together and shared with such insight, passion and reflection.