Collective Get Together
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

Written up transcripts of the session discussions can be found in appendix 2.

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.
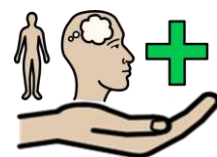
Appendix 1. Listening Leaders (worksheet) Write up.

🏠 School

- What's one thing you'd change to make school or college better?"

- More SEN support in mainstream provision.
- SEND Hub provisions
- Schools to use the Local Offer
- Not to forget those on an EOTAS package
- Better social groups for those studying through online provision
- More wheelchair access in physical school spaces
- Better mental health awareness and support in school
- Early help hubs and 1-1 support
- Lower waiting lists for EHCP's
- Teach teachers and students about SEND.
- Understand the many different disabilities and that it is different for everyone
- Fairer in school
- Disability support
- Teachers to be less angry, they need more training
- Access arrangements more reliable
- Better support for young people, with trained staff who understand their needs.
- Making better reasonable adjustments to help young people learn better
- Better pastoral support in schools including special provisions
- Trying to help young people and not just 'kicking them out' for being dyslexic or autistic
- There needs to be a cash injection
- Change from 'cant do' schools (who say they cant make accommodations) to 'can do' schools, with better outcomes for all students.
- Cultural change is needed
- Everyone should have a mentor, who understands, supports and really gets the best out of you, helping you to be as successful as you can be. Not tutor or random teacher, but someone who will understand you and consider any diagnosis you have.
- Smaller class sizes
- Follow through on the help you should have.

❤️ Health

- Available health services and accessing them

- More accessible across all services
- Make services easier to use and more accessible using innovation based on voices
- Remove health inequity / inequality

- Remake the services that are discriminatory by design. e.g. phone only service, limited time availability, only available in certain places (with poor transport links)
- Stop services saying 'you too this or not enough that' so you cant access
- Reduce waiting lists – long waits extend the pain
- Getting an appointment with the GP and getting support to access it as I'm autistic
- Finding a dentist is too hard
- Priority support for those young people who have disabilities to make sure they are getting the support they need
- More accessible information about health services
- Poor services but some good ones in some areas
- Find out what is available in your area
- Believe my health issues even if you cant see them
- See me as a whole – do not separate out disabilities and medical needs
- Better early support services are crucial to reduce the need for higher level support in the future
- ME/CFS support feel non-existent despite the increasing number of people requiring it.
- My needs were too severe for a mild/moderate service so left with no support which lead to more mental health issues and hospital admissions.
- Kinder people in A&E
- Better accessible information in letters from hospital
- easier access to MY GP, who knows me and I know them.

🏠 Community and Independence

- Becoming a happy and successful adult
- What's something adults don't always understand about young people with SEND?

- Adults lack understanding of SEND
- How to communicate with young people
- We are competent! We deserve to have a seat where decisions that affect our lives are made.
- They don't understand our way of thinking.
- Everyone is different! Just because you met someone with the same condition, doesn't mean you know them or the same things will help.
- We can do things! basically anything with the right support and mentorship
- We can be extremely successful
- Lived experience IS experience and we ARE professionals in these areas. WORK WITH US!

- People don't understand coping mechanisms. Sometimes they perceive it as being rude.
- They need to remember our brains are wired differently.
- Normal parenting methods have to be adjusted for young people with SEND
- Preparing for adulthood takes time, navigating the world differently; working out what you want to do, finding a job, even living on your own and also travelling/getting transport by yourself can be hard things. We try hard to fit in, to act normal but need more support.
- Adults might not understand people with SEND very well. I think a lot of this is in employment!
- Teachers don't understand me. They need to be better at communicating with me (and my parents)
- We need to be given more confidence to try, even if we could fail. Let me try
- We are different and have different needs.
- Adults that don't really understand SEND assume you cant do things because you have disability.
- There is no 'one-size fits all' for disabled people and everyone has unique access needs.
- Our views about our own lives should be paramount…. No decision about us, without us.

💡 Sharing Ideas

What would you like the listening leaders to know?

- If you were in charge for a day, what would you do? (school or government)

- Less policy – More action! We don't need perfect, we just need better.
- I would change the SEND system forever!
- Make things more equal
- Stop LGBT restrictions, bathrooms, surgeries, or just the choice to come out, support people with disabilities whole life for life.
- I would make sure I could see friends more often, and help others to do the same.
- I would make sure there were the right support services.
- Fixing the cost of living crisis and encourage more equality for young people with SEND
- Bring strong young voices together – we have ideas and opinions
- Bring large culture change in schools, hospitals and government. Doing what's best for children (happy staff work better). We all want the best outcomes – Lets enable them!
- Make sure everyone is heard, no matter if they are a teacher, parent or student.
- I would change a number of laws relating to SEND and change a number of policies that are more of a barrier.

- I would make colleges, schools and settings more accessible And inclusive, with trained staff to support young people's needs. Supporting every young person in preparing for adult hood making sure their needs are met.
- Making employment more accessible for young people and providing more opportunities to help young people add to their CV, get more work experience and other experiences.
- I would listen to what young people are telling me giving them a seat at the table to tell their thoughts and make positive change on issues they are passionate about.
- One of the biggest challenges facing children and young people with send is accessing an education that truly meets their needs and supports their personal goals. There is growing pressure to conform to traditional classroom settings, sit exams and cope within a rigid system that is not built for them this is having a serious effect on young people's physical and mental health.
- The system must recognise that education happens in many settings - mainstream schools, special schools, home education etc - and support should be consistent across all of them. Young people deserve to have their needs met, personalised plans that help them thrive, and staff who are trained to understand diverse needs. Families shouldn't have to fight for help there must be accountability for when a child is failed by the system.
- Children and young people deserve a system that recognises their individuality supports their well-being and empowers them to thrive not one that leaves us behind.
- Children must have a say in all decisions that affect our lives we want to be consulted on policies on legislation anything that affects us.

Appendix 2. Listening Leaders session transcripts

Session 1.

Q. If you could make one change, with school or college and make things better, what would it be

1. I'm going to merge 2 into 1 because I can't do one. First of all, I think the obvious cliche answer is we need a cash injection into SEND provision.

The LA's can't own debt because of SEND. The schools can't cope. The SEND funding is still capped at what 10,000 for child with SEN? With inflation and all the rest of it, it's just not cutting it anymore for children and I fully believe once that kind of cash injections in when schools are more better funded, teachers have more funding. Once the LA's had the funding to give to the schools and all the rest of it. You can then start looking at a cultural change, which I think is the biggest thing for me which is turning what I call 'can't do' schools, which are schools that are like 'ohh we can't do this. We don't have the funding, we don't have the time, we don't have the energy, we don't have the resources', into those 'can do' schools that are more, 'Ohh, we might not certainly get things right, but we can give it a go. We can speak to young people. We can try and put a plan in place'.

And like I said, not necessarily get it right, but at least try and support those children and find a way to build it from inside. I don't necessarily think we need new policies because the ones we've got are just rolling. We've just finished pilot schemes for EHCP's. We've just we've only just finished the last SEND papers and all the rest of it. And we've not really given it a time to work and the level of like I said, funding in the school means that we it hasn't had the chance to work probably if you get what I mean.

2. I was gonna say, well, a similar answer, but I thought I'm gonna go achievable. I said actually what I would like to see is everyone having a good mentor who understands you, supports you, gets the best out of you and makes you as successful as you can be because I'm now a medical student. It's all lovey dovey and things, but I had a horrible time at school and things, but actually one of the things that made the main difference, actually I had a mentor who wasn't a teacher. After I got my diagnosis, I had the specialist mentor who was an expert in me, got to know me. Wasn't surrounded by any of the grades and didn't care about any statistics, their statistic was you're gonna be as happy healthy as you can be. And we're gonna get you through it. And actually, I feel like if I had had that before, I had had a massive mental health and before I had all diagnosis and before everything happened. Actually, it could be so much better. And we all talk about children not knowing what they want to do next and not being supported. And I don't feel like teachers are always the person to go to for that because teachers go into teaching for teaching and they are, some of them are specialists. But you can't expect them to know absolutely everything and be a medical professional.

To actually, if you have somebody in a school that is a safe person to go to that isn't worried about those things, that's gonna build confidence and people will come to school and people will be happy. People will actually be able to thrive, which is kind of, I think that's what ever really, really wants is in it that actually everyone's gonna be as happy, healthy, successful as possible. So yeah, that's what I would say to do.

3. Following off that little bit is smaller class sizes because teachers already have loads of students, but they don't in classes. You can't help everyone because the classes are only an hour, but they have 30.

4. Cool for me it's a little bit different, I say and a bit more specific. I say increasing support and awareness within STEM subjects. I mean I do maths, physics and computer science which are quite heavy subjects and you don't see any support or consideration into it. I describe it as a treadmill, even though you're tired, you have to keep running and the speed increases as you go along. I mean, there's so much work and content that it feels like you're almost drowning in it, and teachers as well are really, really bad at encouraging you, instead of just cheering you on and giving you support. They'll be like, well – If you don't wanna do it, then you can retake the year or you can fail or you can get a U, or go to a bad uni. All of that it's really not helpful and it just adds so much unnecessary pressure and I feel, and it also makes people quite unbearable to be with. I mean, a lot of people don't understand that flexing and being quite rude about the fact that you might be a little bit better at the subject. Can be really damaging to someone, especially with SEN needs, because it feels like they're so far behind you, and feel they will never be able to reach the success that you have. So I would say increasing support and awareness, but through training, through really relooking at how they teach the content and how they teach the exam, how the exam boards teach the teachers and give instructions to administrators to provide support in these subjects.

5. I think professionals shouldn't make a decision about you, especially if it's like about you to do with you. They should always consult the young person.

6. Accessibility in the school. As there wasn't enough electric doors in my secondary school and I changed it. I got a couple put it.

FINAL SHARE OPPORTUNITY

1. Yeah, I was gonna switch on the being part of planning and decision making. It's been a lot of the news recently about EHCP's and the potential of them being scrapped. And I read the conversation about EHCPS today and we feel that a lot of people with an EHCP actually don't need it.

You just need bespoke support and I think when you talk about planning that potential, not abolishment but sort of alteration, I think you need to get local authorities involved, you need to get SEND youth voice groups involved, the young person's assembly as well.

And ideally as well, a lot of our school councils as well that that a lot of us SEND student councils. I think especially when you look around consultation into that because that's a big decision and that's gonna affect a lot of our families and young people.

2. I'm going to jump off on the back of that with the being a part of planning decision making. I think on a more generic scale, children want to seat at the table! We are not just children with SEN, we are people with real life experience, we're people who understand what's at stake and the impact of what we say and the decisions that I made about it, and that is too many instances when we are not getting a seat at any table, let alone the tables, we need to have a seat.

That for instance, the children well-being bill DfE themselves, have said in the last week or so, I heard in my own ears, that they have not yet consulted with a single child, on the children well being bill or anyone has, which I just think is absurd. You can't have a bill about children, about education, about social care, about academies and all the rest of it, without speaking to a child, there's other instances of this with the SEND white paper. I am fortunate to have been involved on some of the discussions related to like the new diversity task and finish Group.

Via the one for ADHD, cant remember its name. I've been involved on the assisted dying bill and stuff like that. And I'm extremely fortunate to. But even from that perspective, we are still struggling to get our voices heard where it matters most and the diverse representation of people is not there.

I've been part of groups where they've only spoken to children with a specific condition or children that they've put through like a application process and then gone. 'We know you're like articulate and all the rest of it, so you're going to be the voice of all these people', but there is so many children who haven't had any say whatsoever and anything and don't get me wrong, you're not going to speak to every child. I completely understand that. But there is, there has to be something that sits there and someone needs to sit down and go. We are making a decision about a child's future, and what we're doing may affect a child we haven't yet spoken to a child. How can we know how this is going to impact them? Because we're living it now. Your experiences and your beliefs might be 20 years out of date. How many of you have gone and sat in the classroom as a student, in the last, no offence 20 years or so.

3. I'm gonna pick the if I was in charge because why not be in charge for a little bit?

I did have a few things, but I think the one that meant the most to me was talking about actually, I mean it does fall into the other ones about people saying, We're not idiots. We're not incompetent, we're not stupid, and we actually have ideas. And it was just last week I was working a residential, so I'm now 21. So I was working with 15, 16, 17, 18 year olds from widening participating backgrounds in Norfolk, very deprived areas and they were just given a project and they say go, present to us, whatever you want, they had two days to do it and they came up with such incredible like projects between them about poverty, about SEND systems, about engaging the community, community centres and things. And I was expecting worst of the worst. I was expecting to die from embarrassment

about these presentations and the 16/17/18 year olds blew me away with something like actually this took you 3 days if you paid these people minimum wage for three days, you're talking actually about less than £1000 investment for some absolutely incredible ideas. And I think it's about valuing these people as actually lived experience, is experience and yes, they're not always going to be the best use of money makers and decisions in that sort of sense. Actually, none of us won't understand all of the wider concept, all the policy, but I don't think we need more and more policy and meetings about meetings and waiting for I know that it's like 'Oh well, it's going to be in August and September then October, November it's like well, hang on a minute. Why don't we just do something? Now, why don't we just sit down and go? Actually, this is what we want. How can we get there? Let's put in a plan. We're all working for the same thing. Everybody wants the same thing. So I think it's about actually communicating that. And if I was in charge, it's getting that culture. Actually, we're all on the same page.

The more time we spend fighting each other about things, the more time is wasted. The more time we spend emailing each other, the more time wasted. Why don't we just get down to the point book out a day, smash it out? Done. You know what I mean? Like do it. Is it not that simple? That that's what I'm saying. Like I'm free for all of August boom.

Yeah, let's get together. Yeah.

You talk about young people being out of education and out of employment whack them with a year work experience, doing exactly this, getting there. Why don't you create an apprenticeship where their role is getting other youth voices heard? They're a young person. Has the experience that has connections. They've just turned 18, they're down with the kids or whatever you want to say. Why not use them as experts for a year, and to give them that valuable work experience, give them that engagement, those understandings. You can train somebody up over a year to understand those things, and you've got plenty of people like us around here today. I'm off university for the whole summer, and I'm a sad person. I like reading things. I've literally said as soon as the White Paper comes out, I'm gonna be going through it with a fine marker. So why don't you used us before instead of us coming out in October and actually it looks like actually part of pants and then it might as well have done that bit now right.

4. If I were in charge for a day, what would I do? Accessibility in all areas of public transport and disabled toilets?

In Southampton there was a disabled toilet facility but there were stairs up to the toilet with no ramp

4.5 We have an accessible ground floor at university that you go in and it's down 3 Steps of stairs.

5. Yeah, I think something that adults don't always know about young people is that we're all different. And just cause you've had someone who's had one condition doesn't mean someone who has the same condition is the same.

6. I'm gonna go also for what adults don't understand. It's not linear.

It's not that when if your kid has, let's say, autism, it's what Mr Doctor said on Facebook. Ohh your kids just likes trends and he's going to be a little bit socially awkward. No, it's a spectrum. It will change. And that goes for every single disability and special needs. It's about working with your child and making sure that they get the best support possible. I mean, I've seen a lot of parents just get overly get so annoyed with their kid when they're not understanding or feeling a bit over stimulated, especially at parties, it's all goes on to the having fun and making friends bit, but it's like just because your kids has some sort of disability doesn't mean you have to get so aggressive and angry with them and shout them. It seems to be this idea that if you're harsh on a kid, you hammer down on them, forget gentle parenting, be strict, be authoritative then all sorted. Your kid will respect you. And this is, no, your kids just gonna fear you. They're gonna be so scared to the point where they don't want to speak to you and share what they're actually going through and share anything with their diagnosis.

Especially if it's something that's not seen as very serious, and unfortunately that's something very common, especially in school. Let's say you have ADHD and or autism, but it doesn't affect how you perform in school or doesn't really matter how you behave in school. Then the teachers quite frankly don't care. They'll be like, yeah, that's fine. I mean, I've been denied extra time many times because they said my autism isn't eligible for some odd reason I don't even know.

I want to go on to the social point because at school I've had trouble making friends and it's not very helpful when you have teachers saying ohh, just go to someone and be like – hi, do you wanna be friends? Yeah, sure. That's not how it works. It can be quite awkward and quite troubling to go up to someone and say, Just have a conversation and it feels like a lot of people are quite judgy, especially if you seem weird. And trust me, people will talk about you behind your back if they think you're weird, or you've had a bad interaction, they'll be like, is this kid kind of special.

7. I think a lot of young people like adults can undermine their ability and stuff, especially with SEND. It's not just about that undermining, but also underestimating, yeah.

FINAL THOUGHTS

1. Can I just ask, are you guys gonna be around at lunch so we can have discussions and stuff with you?

2. Yeah, I mean, just touch on White paper again. I mean, you guys won't see, well maybe you probably do see the impact. But I mean people like myself work extremely deprived community, and if this White Paper, if it's not done properly, bit like the PIP a couple of weeks ago and then it will, you'll see the detrimental impact.

3. Yeah, just something that I love that you guys did. It didn't feel like you were pushing us for time because I've seen a lot of leaders. Always. It feels like we're working on their time rather than them working on our time. I think that's important because it's important that young people feel like they've got the power. Not, it's they're having the privilege to talk to someone who has power, and it's nice that you guys aren't sort of rushing us the time, even though we did have a limited amount. Its nice it's not feeling rushed. It's not feeling quite crammed and it's not thinking more about time and thinking more about how to have discussions.

That's something I really wish leaders did a lot more. Forget. I know. I understand that timings are really difficult and it needs and you might have a strict schedule, but it's also nice to show that you're not thinking much about it, and you're really focused and locked into the conversation.

4. However, what you've just said is kind of I don't think it's what annoys me but, it is yes, we have these days where we all come and we all sit and we all have a discussion and we sit in front of you. We get 10 minutes with the Minister who didn't make any notes in here. So to be honest, I'm not sure how much she's gonna remember by the time she gets to the point where she's writing stuff down.

You've just said that you look come and speak to us and you love coming to sit and have these discussion about it, but you've but you've not come and consulted us on any of your on any new policies. You haven't. You've admitted it yourself, not you, but but education. No, no, no. But the Department of Education themselves, have said to me personally they haven't consulted the children on several different policies, bills and whatever you like. I don't. I just don't see a logic in that, just that.

And I'm going to. I'm just I'm he's mentioned about his group that you are part of. So I'm going to drop one, speak to the children's commissioner, send panel because we do have opinions.

I'm gonna throw out KAP (Kids Advisory Panel) as well.

5. It's a shame it's only once a year that you came here.

Session 2.

Q. If there was one thing you could change at school or college to make things better, what would that thing be.

1. Doing a lot more training

2. Support for staying in schools and colleges and stuff.

3. A lot more training.

4. Get rid of league tables.

5. Every staff member has the same rule in classrooms, yeah.

6. Same rules across for everybody.

7. I disagree on that point regarding removing league tables because they assist parents deciding what school their child should go to.

8. I'd argue the idea that parents have a choice is a myth. You know that requires economic capital, that requires social capital that requires the ability to move into the catchment area of a good school, and if you're poor, or your from a marginalised background you don't have that opportunity to choose and also that means that funding is diverted towards schools that are doing better. So it's do or die. And that's not fair, schools aren't businesses. They shouldn't be competing with one another. You're all in the same boat, which is teach these children.

So it is about just all schools being better, getting the right funding to help them to be better.

9. I think getting the right equipment, stuff like reading pens and stuff.

10. Not even just funding for provision. So obviously that's important, but protected time and things for teachers to do this training. I had so many teachers who, I had a support plan or whatever it was in schools back then but they just didn't read it because they didn't have time or it wasn't important or it wasn't compulsory. So they didn't read it, and then it led to stupid or embarrassing or uncomfortable events because they just couldn't do the best.

11. Something is, more than anything is just because I'm having a really good SENCO teacher. Because remember, in one of the schools that I went to those really good SENCO teacher, they helped me through English. I was struggling with it and in the end I managed to get a really good marks and then went on to sixth form. There wasn't as much put in place there, other than just extra time with the exams and I kind of, I failed one of my A levels and barely passed two.

12. I study online education funding from my EHCP, but I wish there were better social groups because we so often lose the social aspect of it. I'm unable to attend in person college because my health issues and I felt really isolated at times because there wasn't that social side of things. That's what I would change.

13. But also kind of left in the dark when everyone talks about mainstream schools and special schools. But not everyone fits into those categories, and it's like I'm online. Other people are home schooled, and I feel like we just kind of get neglected a little bit.

14. On that topic of different schools, I went to private school for primary school and because they're independent, they didn't have to have send coordinators. And you know there wasn't send training. They were given free reign to do what they want. And that's just wrong. They're not monitored or anything. They should have Ofsted, they should be monitored. You know, because they are kids who are entrusted to them . And when you have young vulnerable children entrusted into your care like that. You are paying for something that you know you should be getting a good product.

15. And also private schools you have to pay, so surely you should have at least the same level of quality as public schools.

16. Careers advice and like careers support, having those right and like high aspirations for people, because I feel like to many are not given that opportunity.

17. Yeah, just because you have a label of learning difficulty they feel that you can't process that.

Q. So are these issues around that transition stage of leaving secondary school to go on then.

1. Yeah, I feel like that it is related to that. Even like, because they say you should start having careers support at like 14.

I think some of it is in relation to not having enough knowledge. Like I know a friend of mine has an assistance dog and she was asking for support in terms of which universities would best accommodate that, like with having an outdoor space and the reason why it was like, well, I have no information on this but this hasn't happened before and sometimes it's specific situations like that, but sometimes it's like for me, I was told I shouldn't go to university. I should do a supported internship, but no one actually asked me what I wanted and I have now been to university, but it's like those big boxes ticked off into those and because its an important one.

Having those careers people that understand the support that's available, but also have high aspirations for young people.

2. That kind of data would be so useful in terms of what universities or schools they offer. Like when I was applying to different universities. I had no clue what any of them could offer me in terms of disability support or, even if I asked on an open day, there was still like no way of comparing one against another, not like we can with waiting lists of things with councils and having that insider knowledge, almost like a SEND league table for universities or schools would be so interesting, so helpful as a disabled student applying because then I can know like OK, they offer all of the support and knowing realistically, will I be able to access any of it during my time?

Not league table in terms of like grades and stuff, I mean it just in terms of like how long are these like waiting us, how supported do people feel, more in terms of like non academic data, do you know what I mean in terms of like both like in terms of like people's, like first hand experiences, I think like there's definitely like that kind of TripAdvisor like glass door idea, you know. Yeah. Like employees give their take on like what it is like to work there. And I think that kind of data would be really useful as well as seeing like, the quantitative stuff on How long would I be waiting to get a disability advisor? Or is there a disabled part of the student union so is there one lift so like?

But I know DfE don't cover universities right now, not sure why but these things even in terms of schools. That kind of thing would be useful and interesting.

Q. What are people's thoughts on being part of planning and decision making because you've got decision makers in the room.

1. I think one of the things is hearing what the outcomes of the decision is, I think so many times we're asked to give our feedback on things but then we don't necessarily hear. Even if the outcome is negative, like we cant do what you wanted, like knowing that and knowing why it's really important.

2. I think there should be Co production with disabled people from the very start, and of course that's hard with if something's already established. But new things setting up, it's not great to set it all up and then ask disabled people, we should be involved in actually building it up in the first place.

3. When I was in Oxford, it was like one of the things that we always spoke about was about how like so often accessibility as an afterthought.

As instead it should be this very foundational building block, because that that makes it easier, like in the long term, if that's built in right from the beginning, like rather than adding on at the end, but also then it feels like more meaningful like this is done in Co production like from the beginning. Like your having participation, it's meaningful if decisions, if things can't be done, then tell us why, have that transparency and also then it feels more meaningful. And I think by that participation feeling meaningful rather than tokenistic and having that transparency with government you incentivise young people to engage with our democracy more because we feel like we're being respected by decision makers and that, all voices, do have some kind of power to them. Instead of you think like, oh, why should I engage? Why should I bother when they will just do something else anyway.

Q. What are the sorts of things from your participation group that you are working on or engaging in at the moment?

1. Our priorities right now are SEND acceptance in the Community and accessibility, sharing 'Include me too' trainings, they designed it and we deliver to anyone and everyone yeah, fantastic.

Different organisations in the county, as well as social services they are doing social services in a few weeks, both adults and children's.

And just whoever wants to have accessibility or to give good training to?

The government, but we have, we've had local voluntary action. We've had Citizens Advice really had a local private company, whoever!

Q. It is just as important that you're there Co delivering and be a part of that sharing?

Yeah! Its all from us

Q. Do you enjoy it?

Yes, I mean it means you can help young people understand some adults as well. And then it just makes it easier and it makes it fun.

Q. What does the Include me too training include?

What kind of autism is which, we can help people give strategies, I think on them on how to have a could help that person or if or if they could just ask the person if they're OK, alright, stuff like that.

FINAL SHARE OPPORTUNITY

1. So I'm not part of a forum, but I have done work with an organisation for ambitious about autism and through that we did, a course called understanding you, discovering you, in which it young autistic people could join and I could facilitate, then we talk about what autism is, what is masking, stuff about problem solving and stuff. And I also said some of my own personal experiences of some autism.

2. So, I'm a sociology student myself, and I deal with research and things in my spare time, and I'd ask look to Finland, look at what they're doing. They have the best education system in the world they have the highest life satisfaction for young people. They don't have homework. They don't have exams, standardised testing, they've got rid of it. And their children are happy. They would leave school with smiles on their faces. I see kids trudging from school, looking like, but in the military not happy. See what other countries are doing well and learn from them.

I think the finish pedagogy and education systems will solve all our problems.

(what's pedagogy?   It is Child practises and how children develop and learn)

3. And I'll just talk about accessible health services and accessing them because I feel like you don't have a good, well a lot of disabled people can't access a good education if they don't have the health system to support them wholly around it. I had severe chronic fatigue and I was told by my local fatigue service that they only deal with mild to moderate cases and because I was severe they wouldn't see me and there was no replacement service, that meant I couldn't access education. It meant I had to fall into like really, really depressed and I had hospital admissions, and I all I wanted was an education and like I, I want to be a maths teacher and it just felt so impossible because I didn't have the right support in health. So it needs to be intersectional.

4. If I was in charge for a day, I would help people understand learning disabilities more and how they can support people.

5. Becoming a happy and successful adult. For me personally, I am trialling out getting a provisional driving licence. And then talking after that I want to be able to get my own bank account, get start looking for a job. And then go from there. I do, yes. I also have someone helping me look for a flat.

6. The one regarding the change at school or college to make it better and this it's not a personal thing, but it's an initiative, a bit of research that's being conducted by an organisation that I lead and basically we're looking at researching the impact and also the legal premises regarding isolating pupils in schools punishment.

And the sort of changes that could be incorporated moving forward and I think it's something that's quite important to consider. There's a research team that focus on it within the organisation, so I can definitely ask them to share something.

7. I think that there's loads of different things that I could talk about for this, like different angle, maybe also interesting the decision makers, but I'll go with having fun and making friends that just say that like one thing that I've learnt especially like in my university years is like the importance of like disabled friends and disabled networks and having positive disabled role models around you who you know there are always jokes that like you can call it like both like lucky or unlucky that like all of my siblings have the same disability that I do. But it means that growing up like I was never abnormal within my house and I think having disabled friends or disabled support network around you is so important. At least it is to me in terms of being able to voice frustration, being able to talk about little things that people might not understand, but also like the grief that comes with disability in terms of the frustration of being different or perhaps, you know, in my case like one day like not being able to get up and what that feels like, that people might not understand. And I feel like it's really important to have, for me disabled friends and that disabled support network to remind you that like, you're not alone and also like that it really doesn't matter and that you're allowed to feel all of these things. And that's absolutely fine and absolutely valid. And you can still be a super successful happy adult and nothing should put anything in the way.

8. I think a resource bank for teachers to use. with like easy read or like adjusted materials because I feel like all teachers at the moment are making their own resources or if they have time and sometimes they don't and there's like a way that like massively can cut down on that teacher workload in terms of having resources that are adjusted and adapted in different areas of work, which is shared somewhere centrally. And of course they won't be right for every child and the teacher will need to adapt for more children, but having something that's central would make massive difference.

9. I want to go for something adults don't understand about young people. Its that, it's a spectrum and this is a different disabilities and they don't understand that everyone is a bit different that how wide ranging the spectrum is. And we've got different struggles and stuff.

HIGHLIGHTS FOR FINAL SHARE

- I'll probably say more education to be taught. So that training for students and teachers and stuff around all SEND.
- EXPECT MORE! Wanting more and believe in more and so maybe something around not just your own aspirations, but other people's aspirations for you.

Session 3.

Q. One change at school or college to make it better

1. I was talking about, you know, me, my about me, it's not been updated for a while. Life is changing and it needs changing to

2. The one thing you should change even in college, I feel like there's some teachers that don't get educated on certain disabilities and that. So I feel like some form of training for each teacher or substitutes. They understand what it's like for different mental health and physical disabilities so they know how to cater to it in the class. Rather than saying they're misbehaving when they're probably not they're just not saying it to the student in a way that they'll understand.

3. College would be not being kicked out of being dyslexic due to the fact that I was slow at English. They kicked me out. They didn't come to me. They didn't give me any help. And when I did finally get that help because I kept pushing it. They just said. Don't come back, but they didn't tell me. They told my mom instead. So therefore I basically got kicked out. They didn't say, oh, you're having issues. In certain classes, can you like opt out? Since it was a choice? They just said we're not having you anymore. So they basically kicked me out for being special.

4. Maybe more funding. So there's less people in classes.

5. Having a more personalised approach to students rather than expecting each individual to conform to an out of date structure. And prioritising the goals that the student has and where they want to be in life rather than statistics and grades.

6. Well, I was going to say disability sport, but it seems like a given. So the other one I'd probably say is being honest with what's going to be in the course. I've had so many courses which have promised me things which haven't actually delivered. Yeah, like full transparent honesty. So you know, honestly like, what you're going to expect, what's going to happen and stuff like that.

7. For me, like it's about better pastoral support. I think also I'm better knowing about provisions, so we know what's best for what we need.

8. I think better supporting colleges cause I found GCSE maths really hard and I've and I've got an exam so there should be different options if like English, and maths for special needs, instead of GCSE.

9. It also helps if you are a visual learner to have something different instead of numbers and words.

10. The number of kids in the classroom and better teaching of young people about special needs so that everyone gets it.

FINAL SHARE OPPORTUNITY

1. Yeah. So big thing for me was being happy and so happy and successful adults is most important. (*adult shared on YP behalf :* I was very impressed with just doing bus audits and he was basically independent.) I liked travelling on the bus.

2. OK, Community and independence. I wrote down two things because it says what's something adults don't always understand about young people. Listen, these are from experience I've had. I remember 2 off the top of my head that, uh, one thing I've noticed with some adults is that they don't fully understand that people with mental health disabilities that are brains are sometimes wired differently, and I find they don't keep that in mind, and I find that even when an adult thinks they understand that they don't fully understand it as the well they say they do cause my mum is very supportive. There's points where she, she says she understands up from those points where she's contradicting herself and she's definitely not understanding the situation. Another one is, this one's more of an external thing from just other things I've seen, but I've noticed that some parents think that normal parenting methods will help their SEND child. That's not going to work. It's sometimes the methods need to be adjusted to help that young person grow, again, they're wired differently. They're gonna need to be raised slightly differently, and just some parents just aren't equipped to deal with it sadly. Again, the saying goes every kid deserves parents, but not all parents deserve children. That's a quote my mum has told me growing up. She says every kid does deserve parents but some parents just aren't the best, OK?

3. Mine is from an experience that I've had, and it's not the first experience that I've gone through like this, my boyfriend's parents, we went out for a family meal for the first time ever. Now my coping mechanisms, people don't always understand them, which is kind of annoying. My hat controls big emotions, so my big emotions would be if someone yells at me in a restaurant, my autistic response would be to break down if I didn't have a hat, so I would go on full autistic meltdown, with the hat, I will just tear up and then be like questioning it. Did I do something wrong? Vice versa, the headphones block out all the noise. Now my boyfriend's parents didn't ask questions. They just assumed that I was being ignorant, rude or vice versa, OK.

Now. It made me realise that other people go through this as well. I did get petty revenge. I wrote a song and slapped it on Facebook saying I'm autistic. Basically accept me as I am or screw you. It made it very clear because I also tagged him in the Facebook post so. Brilliant. So I did get petty revenge. Always the best kind of revenge. But if I went through that, it made me realise that other people go through it as well.

But different people have different coping mechanisms, so it just be nice for other people to understand that. And if they've got issues with it, ask questions. Don't just assume.

4. Mine would be if I was in charge for a day. I would, and this is generally aimed at Portsmouth, but I would change the way the buses operate. So say I if we could renationalise the buses, I'd have say I'd make maybe the 23, less frequent maybe every 15 minutes. And then use whatever buses are leftover from that to go to different parts of the city. It's like if you want to go to talking changes, which is the mental health team because you can't actually get there now on the bus because it's in Saint James's Hospital.

4.5 Not just that there used to be a bus to Selby as well. There's no longer a bus to Selby in Leicester. You have to literally go to Barrow upon soar and then get a bus to Selby or get a bus somewhere around about Mansoor and then walk. It's ridiculous.

5. I think this is another education one if that's OK. I feel like in a lot of schools and other educational establishments, the setup of SEND departments seems to be built in a way to isolate young people with SEND. So going from the places I've been to, they always seem to be tucked away somewhere that most students in the school probably don't even know exist. And although for some young people, I'm sure it's useful, by having it so tucked away and It makes it both inaccessible for students who could be benefiting from it, and. Like for me, I mean in my case I was put in isolation altogether for an entire year where I didn't speak to teachers or anything, so my school didn't know what to do with me, but by putting everyone with SEND, especially people who might already have difficulties with socialising and building social skills. It's not giving them a chance to develop those skills or for other neurotypical and children without SEND to engage with people would send to normalise it. Just see us as people.

6. My secondary school definitely didn't have any specialist training. They more antagonised the kids with disabilities than supported them. It was not a good look, but my one, I'm think I'm gonna go for health.

And I got kind of two points, one believe my health issues even if you can't see them. The whole hidden disability thing. Yeah, well, I had a Doctor, who told me syndromes were a state of mind, but I dare him to say that someone with Down syndrome, you know, like it just doesn't. It doesn't make any sense like syndromes are a thing and then - Don't separate disabilities and medical needs. You need to kind of treat the whole person.

Because I've been discharged from chronic illness teams cause I wasn't getting better or I wasn't able to separate out autism and my chronic illness, and it's just been a nightmare getting health support.

7. I yeah. I think for me community and independence, I think the thing is that I'm trying to like navigate the world in different ways. But the problem is it's just finding out, you know, about what job we want, around independent living and

doing travel training, about getting that right support is actually quite hard. And I think school needs to be really helping those people go through those transitions because it feels like we're just leaving those young people aside and thinking, OK, because you're like 20/21/22, you can do all these things. Actually, I'm still a young people with SEND and we need that extra support. We need that guidance.

Yes, how money item of a budgeting as well on a budget money and work that out because it's difficult. It is really hard for sure.

7.5 Sorry, can I add on to that? I think anything like that would also benefit non-SEND young people as well, I guess something to benefit everyone.

8. If you go for a job, not all jobs are accepting.

8.1 Well, or they are not in the local area. I've had several friends who've been told they need to go up to different places in the country to get jobs, and when it should be more, maybe if they do have to do jobs they don't want to do anyway, which is stupid because they should go based on like what they're interested in.

But like maybe go for stuff that is in their area or if there isn't stuff, then that's when you refer outwards.

8.2 Yeah, I've had to work for myself because nowhere will fill out a risk assessment. It's not me that's the risk, it's the stuff that's wrong with me

9. And I'd like to go for health. I think the NHS these days is a bit poor, like getting doctor's appointments. It's they don't fit around like working life and even getting their referrals to hospital can be a trouble. If there's, I know, some areas might refer to, like, private hospital where there's a bit more bit more flexibility, but not a lot of areas will have local towns have private hospitals and there might be a long waiting list for urgent or non urgent referrals.

9.1. It's annoying because sometimes they'll even like you'll get an appointment, but they'll fob it off. Like Ohh, it's not important.

9.2 I don't know. I think they could definitely use some more disability training. I was trying to find out what medications I could take for my chronic illness and they were giving me a list of side effects and how I could die from taking medications and stuff with my autism and my anxiety. Yeah, and it was just quite horrifying to hear. And some of the medications I've got family members on and there's. Ohh, yeah, they could die of dementia. And it's just like, yeah, that helps.

9.3 I've been doctors multiple times about my legs because summer since my bike accident when I was younger, they've gotten worse, something from my brain to my legs doesn't communicate properly and they're like ohh, there's nothing wrong with it. There is clearly something wrong. I can't walk for hours on end sometimes.

9.4 I have something to add to it. I do agree that they do need to have a bit more knowledge. I specifically think the GP's need to be better, not I mean, I feel like the GP's referring to the doctors are pretty bad. There was one GP I went to where I've been having like issues all over my body and we're trying to work out what's up,

and I mentioned to him one of the things I was having was having lung pain and it turned around to me, I can't believe he got a doctor's degree, he says. It's probably normal for your body to have lung pain. I don't know how he got a degree when he turned around and said it's normal for my body to have lung pain.

10. So that you can come down in the morning and just kicking them out because that's. not ok. Would you like this? Yeah. So you see, we've got to having someone that you trust and go to and maybe SENCO or someone but you need a safe space you cant just be kicked out and done.

11. I also find it kind of stupid because certain places have like 3 cubicles of toilets. If you're late to class, you get a mark that you're late. You're only late to class because you're waiting for a queue to the toilet. Give us more cubicles if you don't want us late. But it's also stupid as well because I get confused in big places, so I tend to stick with my group of friends. They know where they're going. I don't. My brain doesn't remember it because I'm ADHD. I don't remember directions unless I've been in that room multiple times. Now I got moaned out for being late to class multiple times as well., but that's cause I didn't know where I was going and everyone kind of just went without me. So I explained that to multiple different people, but no one listens. That is the only annoying thing in schools and colleges and any type of educational place.

Q. So what would help that situation, do you think?

1. They had a map. Because then you if you have ADHD, open the map, don't lose it and follow it.

2. Yeah, it's probably a really stupid idea. You know how in hospitals they have those, like arrows on the floor and on the walls? What if each arrow said, like, what section of the school is, so like the math section, English and stuff

3. A buddy system would be great as well due to the fact that at least if one of you struggles with directions, you'll eventually get there, because I also struggle with like keeping time and stuff like that, it's to the point where I'm like, I've got 20 alarms on my phones for like 20 different reasons, and each one is like a different class, but in Brooksby as well. You didn't get a full lesson 5 minute or a 5 second class and then you move on to the next class and whatever like whatever information goes in your brain in in that 5 minutes they talk really quick. So it got to the point where I was like phone on the table record the entire thing.

HIGHLIGHTS FOR SUMMARY SESSION.

1. Training and knowledge, but also like school systems or directions and stuff.

What is one thing that you'd change to make school or college better for SEND young people?

I'll probably say more support in terms of on the pathway for people rather than just once you've got a diagnosis, because I was like considered late diagnosed so by the time I got through the education system. It would have been useful for me to have it when I was younger rather than when I was like 16-17.

Just a follow up question, what type of support or what sort of thing would have helped you earlier on do you think?

I think them just knowing me better as a person.
Knowing about people masking and stuff and what I might struggle with and help me communicate because that would have been really good practise for me because I never really got to practise communicating or advocating for myself because I'd never done it, so then it was a quite difficult transition into adulthood because I Not only had to do the transition into adulthood, but also start from the beginning in terms of send.

There should be more ramps in schools, colleges and universities for people that require wheelchairs.
I would have liked my disabilities to be acknowledged and adequately supported when I was younger in primary school

I think probably schools knowing that everyone is different and not one size doesn't just fit all and that the school's focus should be on providing the pupil with an education and that it doesn't matter if the way they're learning is seen is as the norm or if they're not attending school in person. As I think schools can sometimes be a bit strict and not very flexible. And I had a lot of problems accessing an alternative to in person education because my school was so focused on me getting into a person school even though it wasn't working.

They support me by making it so I don't have to wear parts of the uniform because they are difficult to put on.

Health services - how they support SEND young people and families?

If you've got anything that you want to share around just health in general and the services that you access.

Mental health as well as physical.

Do you feel like school support you with your mental health?
Some schools do, but some don't. On paper, they say yes, but reality is no.
the school would be like, oh, we have mental health services and stuff but usually feels like more of a brush off and kind of being told the same thing over again and feeling like they don't actually. They're just trying to get you to sit down and do the exam and get out their door, especially towards the end of school. They were trying to get rid of me in one piece. I felt a bit kicked out the door and not really supported.

I found it difficult to access appropriate mental health support because again, I found it's not very flexible at tailoring things to your needs. And they should be looking at you as a whole person

Let's talk about being happy and successful, prepared for adult life, your independence and gaining skills
I don't think school prepares you very well for the future and gaining independence.

I went to a mainstream school and college, and it's probably seen as getting high grades, but I didn't actually learn anything that was useful to me in terms of how to live day-to-day life. Other people might be able to pick those things up naturally and with general knowledge, whereas I felt like there definitely should be some more
because it's only through SEND places, I've learnt that type of thing.

Sometimes people rate the education of mainstream school higher than SEND education, whereas I think a lot of the information I value much higher, I've learned in SEND spaces and I'm a much, more developed person since then when I was getting high grades.

Do you feel that some of those things that you learn in the SEND specific education settings could be kind of copycatted in mainstream schools?
I think definitely, even if it was just a small segment, like when you've got your PSHE sessions. I think the priorities need to be balanced out a little bit more.

I don't think school prepares you very well for the future and gaining independence.

My school does business as a subject.

I think it would also be better in the education system if the environment felt more like you being celebrated and that they knew you personally.

I never did work experience because I didn't feel able to. Since I've been in SEND groups, I've been able to do supported work experience.

I've had a lot more achievements in the SEND space, even though it might have been suggested that I'd do better in mainstream. And it hasn't taken a whole lot of work. It's just taken someone to actually consider me as an individual and empower me and make me think I can do things rather than just a school saying this is how you get a job. You shouldn't fidget in an interview. You should make eye contact.
Actually thinking about how people can be successful in their own way is more useful.

I do feel reasonably prepared for adulthood, but I that's come from me being proactive and searching for information, help and support networks myself. However, I'm aware that this might not be possible for some people to do themselves. I think it would be good if schools offered support with this and perhaps offered some sort of mentoring 1:1 or in a small group.

If you guys were in charge for the day, what would you do? What would you change?

Change the exam system, there's far too much pressure on young people, especially if you have additional needs or mental health difficulties. All the pressures on an hour and a half exam.

"I think school's focus shouldn't be on exams and results, they should be about the person you leave school as, not the grades you come out with."

They I would like to change it so that we stay in classrooms and don't get moved into halls where expected to stay silent. It doesn't work that way – how many hours we spend in the classroom, (a hundred or something hours in a classroom for one academic subject per year) then we're expected to do 2 exams in 2 hour time slots in a different place. That's not enough time to readjust your brain.

Being in silence does work, but the time pressure and having to essentially have your mind run and grab things. You normally have someone guiding you through it, but then you're left isolated for your exam.

Oh, I think I'd probably change the exam system too, as there's far too much pressure on young people, especially if you have additional needs or mental health difficulties, and then all the pressures on an hour and a half exam. I think the school's focus shouldn't be on exams and.
So they should be about the person you leave school as, not the grades you come out with, yeah.

So you guys, do you guys think it's more important to build the skills if you up as a person as a person and those experiences up to make you feel prepared rather than the grades and the qualifications that you leave with?

Understanding

A lot of time in school, it'd be adults deciding what I can and can't do, mainly saying that I can do things and that I'm very capable, when they actually won't recognise what the cost of that was to me like, I might be like able to do it. But actually like if I'm in severe burnout.
Which actually led me to be really physically ill and couldn't walk. But they say no. I was coping fine and that I should be pushed as hard as I can to get good grades and was if people say your attention seeking.

teachers and General staff members in my school understand my needs and provide support for me, which is fab. I struggle with writing for long periods of time, so they gave me a laptop to type with.

Lots of adults around me do not understand personal issues that people with special needs face and looks at the surface of conditions rather than make an attempt to understand the deeper nuances of my conditions

When I was younger, before I had a diagnosis, people didn't really understand, as I feel that they didn't see me as a whole person, they just thought I was a 9 year old who didn't want to be in school, but really there was a lot going on in my brain and a lot that I was feeling, which they didn't see. Now my experiences are much better and people are generally really understanding and supportive, which is good, but I think that also highlights that maybe I wasn't heard because I was a child and couldn't communicate fully what I was experiencing and they failed to recognise it and try to understand me.

A lot of people wouldn't understand somebody's conditions when the person's at a young age. Important thing is listening in the 1st place, instead of listening once things have gone wrong because that's what I had like, I reached out maybe when I was in like year 8 or 9 really struggling. To start they were like there is no

problem and I was like it's a problem for me and they only listened years later and to it became a problem for them and they were worried about like, you know, statistics or people being poorly because things had gone wrong with other people in my school and they didn't want someone else. Something bad happened to someone else, so that's the only time they stepped in, and they were just kind of panic.

Lots of adults around me do not understand personal issues that people with special needs face and looks at the surface conditions rather than make an attempt to understand the deeper nuances of my condition.

When I was younger before I had a diagnosis, people didn't really understand as I feel that they didn't see me as a whole person. They just thought I was a nine-year-old who didn't want to be in school, but really there was a lot going on inside my brain and a lot that I was feeling, which they didn't see.

Now my experiences are much better, and people are generally really understanding and supportive, which is good. But I think that also highlights that maybe I wasn't heard because I was a child and couldn't communicate fully what I was experiencing and they had failed to recognise it.
And try to understand me, yeah.