



# Collective Get T★ether

## 2024 Executive Summary.

The Collective Get Together (CGT) brings together young people and participation groups for those aged up to 25 years with a Special Educational Need and/or Disability (SEND), to give opportunity for meaningful participation and providing a platform to input into national agenda items.

This year's Collective Get Together which took place on Friday 9<sup>th</sup> August, was again held in two locations; London<sup>1</sup> and Nottingham<sup>2</sup> as well as online via Teams.

CGT24 brought together 39<sup>3</sup> young people from across the country, as well as 23 parents, carers and practitioners.

Below is an outline of event:

**Introductions.** Attendees go to know the space, say 'Hi!' to people they have met through online power hour sessions and meet our consortium partners.

**Power Hour 1** – National Standards. Young people identified what is good and what needs improvement in education settings to create minimum standards for inclusion in mainstream schools.

**Room session 1** – Kids Governance – being heard at the top! Thinking about why its important young people are heard by leaders and how to start a process that will engage young people meaningfully.

**Power Hour 2** – The Communication and Engagement Team (DfE SEND & AP). What Government should communicate with young people about, top tips for doing this well and who young people trust to represent them and their views.

**Room session 2** – Your priorities and experiences. Clearly identifying what is important to young people and collecting experiences to support them to speak up on these topics.

**Evaluation.** What went well and what could be improved next time.

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<sup>1</sup> Greystar, 40 Finsbury Sq. London

<sup>2</sup> DfE office, Unity Square, Nottingham.

<sup>3</sup> 48 signed up but increased % drop out due to public unrest across the country and YP feeling 'unsafe to travel'



## 2024 Opportunities for Development.

The Collective Get Together (CGT) gave opportunity for meaningful participation and a platform to input into national agenda items. The following opportunities arise from the Collective members input and offers Kids, the Department for Education and The Government suggestions for positive change.

Opportunities presented from CGT24 event:

### **Power hour 1** – National Standards for mainstream schools.

- DfE. Co-produce a checklist with key stakeholders (education, parents and young people) to support school accessibility and supporting guidance on designing school environments in consultation with young people.
- DfE. Co-produce a ‘crib sheet’ (1 page quick guide) to a young person’s EHCP for teachers. Include any important support mechanisms, reasonable adjustments, communication support etc that are school/classroom relevant.
- DfE. Create a database of successful reasonable adjustments that schools have implemented.
- DfE. Review and develop training for all staff within schools.

### **Room session 1** – Kids Governance – being heard at the top!

- Kids. Develop a well-informed syndicate of young people to support Kids senior leadership team and trustee board to be part of discussions and making decisions about the charities work.
- Kids. Young people chair/co-chairs who can link in directly to the board of trustees and represent the voices of CYP with SEND.
- Kids. Identify at least 1 current Kids trustee to be a champion for CYP voices, who will attend the ‘group’ and support the co-chairs (where possible) to represent CYP at meetings or be an advocate for them (when they cannot represent themselves).

## **Power hour 2 – The Communication and Engagement Team (DfE SEND and AP)**

- DfE / Government. Make use of the Collective communications to disseminate key messages to young people with SEND, as well as gathering useful and useable intelligence from this diverse cohort.
- Kids. Increase regularity of Collective sessions and develop the communications matrix.

## **Room session 2 – Your priorities and experiences**

- Kids. Review opportunity for policy work in areas that young people have said is important to them.
- Kids. Support young people to take a lead on the 'speak up' agenda using the information gathered as a starting point to develop future campaigns.



It was good to have DfE here listening. We will wait and see the impact!

The Collective were friendly and listened beautifully.

It felt very relaxed but purposeful rather than too formal. This helped me be more open.

Important topics and valuable work. Proud of what we achieved.





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

This session<sup>1</sup> aimed to establish what young people with SEND feel would help to make mainstream schools more inclusive and support better educational outcomes for more students who have a special educational need or disability.

Attendees thought about different areas of the school and school life, and ways it could be made more inclusive. For each area considered, young people were asked what they felt were the most important things to make a school inclusive for those with SEND. Appendix 1 shows all information captured from London, Nottingham and online and those highlighted were the ones indicated as most important for young people.

It was noted by all session facilitators that young people felt;

EHCP's were not being read

Reasonable adjustments were not being made

'People' made no effort to understand or work together with young people to make positive change or support them better.

Young people showed a desire for comprehensive set of standards. These standards should cover not only making the space accessible but also for staffing (both teaching and support).

The young people were keen to continue co-production of these national standards, and resources to help make meaningful improvements in mainstream inclusion.

### Opportunities for development and implementation of more inclusive practice:

- Designing school environments in consultation with young people and using a 'check list' for school accessibility
- Reviewing and developing training for all staff
- Co-produce a 'crib sheet' (1 pager) to a young person's EHCP for teachers – including any important support mechanisms, reasonable adjustments, communication support etc that are classroom relevant
- Create a database of successful reasonable adjustments that schools have made

These begin to offer a clear picture of what young people would like in order to make schools more accessible, with practical examples laid out in the appendix.

<sup>1</sup> previously scheduled for June but postponed due to the General Election



# Collective Get T★gether

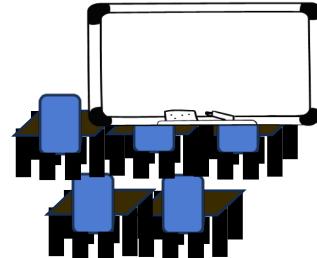
## P★wer Hour National Standards for Inclusion

### Appendix 1. National Standards for mainstream schools

**Those in bold are ones that young people identified as most important.**

#### Classroom

- Controlled class (e.g. noise levels)
- Sensory safe environment
  - Temperature
    - Sound
    - Smell
    - Lighting
    - Cramped tables
- **Don't give fake choices**
- Freedom to stand up / move around
- Better training for teachers
- A quiet place to go to outside the classroom.
- Class pass for time out
- Good learning support
- No ticking clocks (use digital)
- Quiet room / sensory room
- Reasonable adjustments
- Make classroom fun
- **Small class size**
- Lights that don't flicker
- Open windows
- Enable quiet fidget toys
- YP allowed to fidget / stim
- Seating arrangements / space and safe people
- Smaller classes and groups
- No manual light switches
- Access arrangements
  - Technology
  - Laptops
  - Computers
  - Headphones
- Clear spaces around white boards
- Space to move around classrooms can feel like they are sat very close together
- Visual timetables
- Communication friendly – Better training for teachers
- Sensory breaks
- Space in the room
- Nice teacher who are properly trained
- Key person that matches you
- Saying when things change or before a big change
- Helping and learning with travel
- Being able to leave the classroom and not told you can't.





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Reasonable adjustments – desks
- Space/ personal space – support when need. Enough personal space for personal items
- Different seating options e.g. cushion, beanbag, wobble or ball
- Individual desks
- Layout of desks
- Group work rather than on my own
- No distractions both room and noise
- Allow me to meet people
- Share common and important people
- Timetable for the week – prepare for the next day
- Headphones to be able to listen to music while working. Noise cancelling headphones
- Stop bullies
- Standing desks
- Teachers not picking on me to answer questions
- Overlays for anyone who needs them
- Different pens
- Different styles of learning
- Broken down tasks
- Support sessions
- Reasonable adjustments
- Access arrangements for exams
- Money management
- Independent travel/ travel training
- Wheelchair access to all areas of classroom
- not being up stairs with no lift access
- sensory seeking seating options in classrooms.
- Environment being not too overwhelming for sensory, so
- lights not to bright
- not too much noise,
- no clutter
- Colourful displays,
- visuals,
- sensory items,
- deaf awareness - captions
- Ask where students feel comfortable to sit/ Get rid of seating plans, able to choose seat
- Reading pen
- communication cards or AAC or other ways to communicate,
- calculator,
- having laptops etc available for those who might need to borrow them for school, but also allowing students to bring in their own devices
- being able to wear ear defenders/ headphones/ear plugs in the classroom - Ear defenders are not always suitable.



# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- different colour paper options for everyday learning- not just for tests!!
- Allow phones/ipads/tablets if a student needs to use it for things like communication or glucose monitoring etc because sometimes we need to use it and it not fair to not let us because of a rule that applies to non-disabled people
- being able to leave the classroom for breaks when needed
- Teachers wearing lanyards with radio mics can be really distracting - Horrible staticky noises!
- smaller classes for those that cannot learn with many distractions around them
- I think there should have been a place for people who struggle to mange their feelings to go as it quite often distracts others from learning and it was really frustrating.
- Having work available on an online platform so that we can work elsewhere if needed. Also having all the resources online so we can keep up to date if we've missed things
- to add to this. hybrid learning being a possibility for every student if they need it, it's useful for chronically ill folk as well!!
- access to different ways of learning- such as videos explaining topics, print outs of slideshows for students who learn at a slower rate, summary notes of topics etc, all being available before during and after lessons
- The teachers should have made adjustments for me so I could participate in PE Lessons more like doing the same activities in groups at a slower pace .
- allowing students to opt into projects such as speeches etc
- Not forcing students to pair or group up if they don't want to.
- grades not being based on testing

### Break and lunch times

- Ability to access tech – headphones / phones / laptop to recover.
- Friends to sit with
- Dim lighting
- Being able to find a quiet room (Bring a 1 friend)
- Calming, low social pressure space
- Bullying can take place at these times – better supervision and training of staff – have teachers supervise.
- Leaving to break early
- Help with trays and carrying food
- Cater for allergies
- A reasonable time limit to work with (20min break, 1hr lunch).
- Helpful friends and staff
- Extra time for travelling to classes
- Assigned personnel
- Safe spaces with predictable environment
- Sensory safe environment
- Not everyone can queue (at same time)
- Breaks on longer lessons – rest breaks
- Don't be hypercritical standards for all pupils





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Quiet lunch – less people – quiet space
- Supervisors are educated on supporting SEN
- Simple safe
- Basic foods
- Flexible times
- Different rooms
- Quiet rooms
- Headphones
- Variety of choices for food.
- To have more time than 15mins (so more time)
- To know what food there is each day.
- Being able to queue in the line or front
- On the playground being able to have a teacher to go to
- Teachers knowing what happening at all time.
- Quiet space
- Room to move around
- No 'keeping in' or detentions at break / lunch
- Not made to rush (to eat)
- Separate space away from main areas
- Queues/ lining up
- Activities
- Assistance making friends
- Staff that you're comfortable with
- Something to help with busy/ tight corridors
- Staggered lunches
- Good food
- No long lines
- No busy corridors
- Kind dinner ladies
- Stop other YP pushing in
- Able to walk around
- Able to bring in packed lunch of safe foods
- Someone else go to the canteen for me
- Social activities
- Enough space and room for everyone to manouver
- More variety in playgrounds
- Bit longer lunch time
- Access to clock
- Edible food
- Balanced meals
- More lunch variety
- Drink options
- SEN group
- Therapy dog



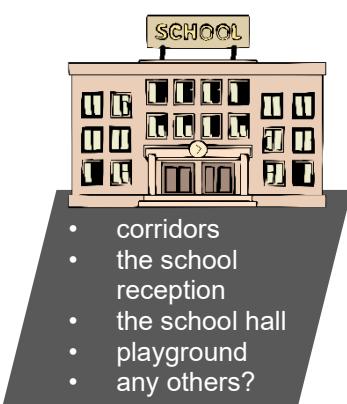
# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Too loud
- Queue passes – come into lunch earlier while quieter, less stressful
- Easy read menu
- Ear defenders
- Free school meals
- Provided with food when on trips
- Quieter alarm
- Indoor space
- Extra breaks
- more accessible canteens for all disabilities
- More time to get lunch
- fast track queue
- School dinner portions .
- Nut free room / allergen room
- Support for students with eating disorders or anxiety around lunchtime so they not alone and have someone to support them
- for those with ARFID, or sensory difficulties around food to have multiple options available for them!!
- Wide variety of options for lunch, hot and cold.
- being able to eat in your classroom
- fridge facilities available for those that take medication that needs to be kept cold. And freezer. Probably a small kitchen for those who would need it
- being able to play sports at lunch time
- more benches and tables outside

### Other spaces

- **Rage room (to get anger out)**
- **A flower or vegetables or fruit garden**
- **Ensure safety on school buses (bullying can take place as not supervised)**
- **Sensory opportunities – somewhere to go to regulate themselves.**
- **IT rooms**
- **Quiet areas**
- **Quiet room / sensory room / dark room**
- **All areas accessible**
- **Be allowed to go to the toilet when you need to be.**
- **Toilets**
  - Consult disabled people on how build
  - Scary People
  - Wheelchair accessible – which actually is accessible
  - Not locked
  - Sensory friendly
  - Big toilets – Often the wheelchair accessible toilets don't have enough room.





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- With hoists
- Paper towels – so not using hand driers (loud sensory options)
- **Alternative routes**
  - Less busy
  - Green / gardens
  - Ramps
  - Automatic doors
  - Lifts
- Activities to burn excess energy / strong emotions
- Large corridors and rooms / seating / more corridors – less cramped
- Widen corridors / 1 way system
- Access to library and quiet spaces that are sensory friendly.
- Able to wear ear defenders.
- Signposting – also have touch sense on route (markings)
- Small corridors and lots of people – not a good idea.
- Space to run around and move.
- Game room / quiet place
- A room to be alone and work in
- A person to talk to who don't have stupid ideas and are actually helpful.
- Fresh air and natural lighting.
- Comfy room to have a minute in and just relax.
- Always have access to toilets (don't lock them during class time) and ensure access to sanitary bins.
- Green spaces
- Library
- Time out card
- Safe places to escape to
- Calm spaces/ wellbeing hubs
- Temperature
- Ramps
- Lift access
- quiet stairs
- accessible libraries (with easy read)
- Activity room
- Windows with adjustable blinds for sensory needs
- Use colour
- Enough space
- Turnstiles hurt your bum when you walk in
- Comfy chairs
- Fun stuff to do on the field
- Study areas for study not messing around
- Allow students to leave 5 mins early to next period
- Areas to sit outside
- After school clubs



# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Warning before fire alarm drills
- Wide corridors
- Online access to big assemblies from a different room

### Libraries

- libraries should have a quiet area
- Being able to eat and drink in the library - or at least a designated area in there

### Playgrounds

- Having accessible play things
- smooth floor in playground for wheelchair and mobility user access
- playground equipment, toys etc being wiped down properly to reduce others getting ill easily
- wheelchair swings and roundabouts in playground
- not making students go outside at break if the playground is to loud
- shade available outside!!!
- Sensory garden
- Swings
- tactile surfaces available outside, as well as signs next to apparatus for those who are blind and use braille
- being able to play sports at lunch time
- more benches and tables outside

### Corridors

- one way/ effective streamlined system in corridors so it isn't so crowded
- Allow students with SEND to leave lessons early to avoid crowded corridors
- stairs are an issue - should have a quiet staircase/route
- Good size corridors with curves.
- good echo management

### Reception

- Lowered receptions thing
- having a different way to go into reception if needed
- some school have ipads to sign in but they're often too high for wheelchair users to reach so have lower ones

### Other building

- Universal design!
- Make sure lifts/automatic doors/ ramps aren't broken
- Lift passes for those that need it - whether it's a visible disability or not
- Having a lift in place for people with mobility issues as I had to leave lessons 10 minutes early for my next lesson as a lot of the time lessons were upstairs in different parts of the school .
- Automatic doors/ doors that aren't heavy and push both ways- pull doors are really difficult to use as a wheelchair user- especially when the handles are high up
- Halls not being major spaces for echoes and florescent lighting
- rather than a school bell to dismiss individuals, have breaks at a set time so that students are aware of when they can leave- loud ringing can be distressing
- Accessible fire alarms (with light and pagers)



# Collective Get Together

## P★wer Hour National Standards for Inclusion

- Make sure wheelchair users and staff know what to do in fire alarm
- having functioning air conditioning as well as fans etc being available for students who have heat intolerances- especially during the summer
- Assistance dog toilet area
- Tactile signage, Signage with colours and shapes
- Changing places toilet. Don't use accessible toilet as a storage cupboard
- Hoists in studio space or therapy rooms
- Every school should have a sensory room
- Sensory tent for people to go to to calm down or for some quiet time fidget toys to help people who struggle to sit still for long periods of time.
- Plenty of disabled parking that is actually accessible
- Lighting adjustable and thought about
- Accessible sports equipment and sports equipment for disabled specific sports
- having a space that is always staffed so you know where to find someone if needed
- closed-off medical rooms rather than one open space
- We welcome people at any time
- do events or assemblies for disability pride month and other days/weeks relating to disability because it shows they care about disabled community

### The people

- **Less bullying**
  - Rumours
  - Assaults
  - Accepting of fidgets
  - Take headphones and fidgets away
- **All staff have a basic understanding of SEND / mental health and of needs mental / physical / social / emotional/ spiritual**
- **Teachers that help you and don't shout at you if don't get the answer right.**
- **Have received meaningful training**
- **Speak to parents like adults!**
- **Training on disability**
- **Regular 1:1 with teachers**
- **Teach students about disability awareness.**
- **Explains things clearly**
- **Empathy**
- Don't take advantage of needs / behaviour
- Staff do active check ins with pupils
- Access arrangements for writing / reading / skills
- Accessible sports equipment and changing rooms
- Less of them – staff on duty
- Less noise
- Educated better
- Treating you like a normal person
- Access to support staff inside and outside of lessons





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Counsellors
- Learning support
- Mentors
- Nurses / therapists
- Educational psychologist
- Staff on duty
  - Have common sense
  - Decency
  - Friendly
  - Supportive
  - Understanding
  - Approachable
- Trained teachers and not giving their opinion about their lives.
- Teachers who don't have favourites (so they teach everyone the same)
- Medical people don't just say you are fine and actually help you.
- Teachers that don't lock you in rooms and follow your timetables.
- Bigger corridors letting different people use them at different times.
- Knowledgeable or find out if they don't know
- Empowering children to prepare for their adulthood, including becoming independent.
- Someone who listens and believes parents
- Someone who is a good advocate.
- Have a head teacher who instigates a strong inclusion culture embedded throughout the schools
- Good SENCOs to do the basics
  - Read and follow EHCP
  - Support plans
- All about me
- (Well) Trained teachers
- Clear instructions
- Help me to understand
- Listening
- Calm teachers
- kind
- Patient – allow students to go at their own pace
- Give us time
- Teachers not talk too much
- LSA
- Key familiar person/ worker – builds understanding and relationships
- Friends
- Safe people who understand needs
- TA should give space to be independent
- Know their roles
- Headteacher that understands us – students getting their input on (to) headteacher
- No shouting
- No demanding look at me / eye contact



# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Not demanding respect
- Feel like they want to not just have to
- Believing need
- Encouraging
- Engaging not excluding people
- Treats everyone equally
- Counselling
- Meet students needs
- Mellow
- Sensory awareness
- Remember that we are people, don't talk down to us
- Adjust communication styles to the young person
- Kind dinner ladies
- supported staff that have the right training
- Teachers having an awareness of SEN and listen/respect us. Realise that we are all different and need different things
- Teachers not being mean and making fun of disabled or SEN students and understanding each persons individual needs
- Clear communication
- instructions that don't mean that a student has to infer what they might mean by it- a lot of autistic individuals struggle with inference
- Staff having an awareness of what eating disorders look like - Being aware of students that may not be eating
- Training for all staff
- having an awareness of all disabilities or being willing to learn
- Teachers accepting that sometimes they are wrong or have misunderstood
- be understanding of everyone's unique needs
- Understanding
- Patient
- not dismissing someone's experience
- having some disabled staff- it can help to feel represented by staff
- Learning basic bsl
- Attitude of collaboration
- Pressuming competence
- understanding inter-sectionality and respecting all parts of your identity (Religion, ethnicity, LGBTQ+, culture) as well as disability
- kind
- being flexible
- Not seeing the non-disabled or neurotypical way as better e.g. speech over aac or bsl, communication is the goal not speech. Mobility is the goal not walking.
- staffing being representative of everyone
- teachers spending time with us if we need it.
- Look at our individual learning plans and follow it, otherwise it's pointless!



# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- teaching assistants available for those who need it
- consistent 1 to 1s for those that need them

### Communications and home

- Regular emails / meetings with the SENCO
- Making sure actions are completed
- EHCPs that are followed
- Our views should be checked and respected.
- Communication it's not the same for everyone and there are different styles / ways and preferences.
- Travel training
- Community
- Communication between schools when transitioning
- Students know ahead of time any news
- Tell the YP what they are telling parents/carers
- PECs and visual aids
- Working to resolve any issues
- Flash cards
  - Yes
  - No
  - Maybe
  - Emotions
  - Red
  - Amber
  - Green
- Pupil profile – what works for the child (as long as teachers read it!)
- Your teacher has to ask if they can say something or write something
- They don't have communicate with home.
- Home don't have to tell schools stuff
- Communication through books / Apps
- Ability to work from home
- Pre set rules / conditions / boundaries / info on school layout.
- Actually email parents / students keeping them updated.
- Early timetable access
- Young person has a physical book to pass info – person, parents, staff
- Non – verbal understanding and education – don't force
- Visual information
- School communicates with parents
- Communication / disability passports that are yours – stops you repeating yourself and your needs, intelligence and your story
- Homework merges home / school. Divide of learning and safety.
- If something bad happens and a staff member knows – tell the parents / carers about it.
- Communications
  - Events calendar
  - Emails





# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Social media
- Youth groups
- Clear the format and timetable
- How well are students getting on with homework
- Should it be mandatory?
- Some do not complete or make a start.
- Students need positive mature teachers.
- Disability shop
- Clear communication methods
- Special training e.g. BSL
- Understanding the communication needs
- More regular reviews
- Time to digest information
- Accessible/ easy read EHCP and supporting info
- Sharing good practices with parents on how they can help the child be independent at home
- Phoning mum if struggling
- Helping my parents to help me
- Learning students body language
- Consistency
- Writing key messages down
- Only call for good reason
- Students to be heard
- Sharing messages with parents so when I'm anxious or if I forget, they know what is happening
- Online learning (Teams and Zoom)
- Easy explanations for parents
- Disabled is not a bad word or bad thing it's natural stop avoiding it! You will either become disabled or die young
- don't call us 'special'
- setting up a club/group - neurodivergent/disability/SEN
- Treat us with respect and experts on our own lives (even when we can't communicate it)
- inclusive language being taught- as well as the evolution of language and peoples preferences on it. for example id rather be called disabled then additional or special needs.
- No home work as weekends are for people to have fun and enjoy themselves and not think about school work.
- Disability history, deaf history and disability rights movement taught
- Bilingual bsl and English schools!
- We were talking about a similar topic in our forum this week and although the young people are not able to join me this morning they did raise: making sure teachers act on what they say they will do
- Allow to use AAC devices
- Website accessible info



# Collective Get T★gether

## P★wer Hour National Standards for Inclusion

- Don't assume parents are always right - listen to us as well, we may have different perspectives
- Regular meetings to check how we're getting on
- I'm going to go to work now thanks everyone nice to meet you all.
- have interpreters both for students and parents/carers who need them
- informing students on what you are going to talk to their parents about, especially if it is about us
- ask student what they need not just assume everyone the same

### Other

- having flexibility around clothing/uniform



# Collective Get Together

## Kids Governance

Kids are looking to develop young people's involvement in governance (the direction and running of the organisation). Questions were asked to help identify and shape the development process.

### Why is it important that your voices are heard at the top levels? (Strategic participation and engagement in governance)

inclusion matters for my/others future different focuses it's about us not by moral will meet needs allows freedom we are strong hotline equality show your listening actually make a change there not affected we know what works it's about us different challenges feel valued discovery to get it done inclusive practice support freedom together it values experience we know what we need get right support young ambassador sense of empowerment builds trust to show you matter

your old were not belongings important we are worth so much understood we experience result learning

higher in hierarchy positive change everyone is included we know world today helps my family to help make changes not their struggle listened

get what we need everyone more efficient understanding our pov

you're old we're not to make a change

disabilities matter exploration accessibility address the problems generation gap miscommunication

have choice. cared for reflect diverse need it's about me wellrounded decisions keep us safe

to be represented

remember we r people organisations

not living your life are voices heard

make a change more power

inclusion have choice. cared for reflect diverse need it's about me wellrounded decisions keep us safe

make change

we are the future

i have good ideas it's their life

opinion

doing right by law

understand people belonging

make change

we know best to feel seen

feel included gives purpose

opinion

we understand better

it's cost effective

everyone - different

kids + no yp = irony

### How would you want to be involved?

Data was gathered through a game of 'would you rather' where target questions were combined with filler questions. There were mixed responses and young people reflected that preferences change and that;

'This opportunity should not be held back by this or that, when using both could get Kids better outcomes'.

Target questions were:

- Visit the trustees or trustees visiting you
- Young people present their own ideas or have your ideas presented by someone you trust
- Meet the trustees in person or join the trustees in an online meeting
- A trustee champion or a young person trustee

Young people welcomed **trustees visiting** and having **a trustee championing** young people views, however identified that this should be alongside gathering views from a range of young people and **representatives presenting this in a section of the trustee meeting**.

Kindly supported by





# Collective Get Together

## Kids Governance

### Who can apply?

- Children and young people with SEND (maybe ages 13-25)
- Kids service users – young people
- Past beneficiaries / experts by experience
- Anyone (who wants to and can be involved)

Young people noted that DBS and background checks would be needed.

### Where to find YP

- Schools/ colleges/ University
- Hospital
- Social media
- Internet
- Youth groups
- Events
- Kids services
- Youth forums

### How to apply

- Websites e.g. Charity Jobs, LinkedIn
- Through sharing lived experience
- By completing relevant work experience
- Different methods – online, paper, video (record yourself answering the questions)
- Interviews
- Face to face
- Social media links

### Opportunities for development

#### Kids:

- Develop a well-informed syndicate of young people to support Kids senior leadership team and trustee board to be part of discussions and making decisions about the charities work.
- Young people chair/co-chairs who can link in directly to the board of trustees and represent the voices of CYP with SEND.
- Identify a current Kids trustee to be a champion for CYP voices, who will attend the group and support the co-chairs (where possible) to represent CYP at meetings, or be an advocate for them (when they cannot represent themselves).

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# Collective Get Together

## Power Hour The DfE Comms Team (SEND and AP)

Power Hour 2 introduced The Department for Education (DfE) Communications and Engagement Team for SEND and AP (Comms Team). This team works to promote and explain what the government is doing to improve the SEND system.

Elia Clarke (Communication and Engagement Lead) and Debbie Froggatt (Senior Communications Manager) showed commitment to hearing youth voices directly by attending the Nottingham venue, and will have access to all additional information from other locations.

The recent change in government gives a fresh start to the relationship with the country, including young people. They have an open mind about youth participation, and this was an opportunity to develop new ways of working and communicating.

## New government, new start



Bridget Phillipson  
Secretary of State  
for Education



Catherine McKinnell MP  
Minister for School  
Standards

The Rt Hon Jacqui Smith  
Minister for Skills



Stephen Morgan MP  
Minister for Early  
Education



Janet Daby MP  
Minister for Children  
and Families



Anneliese Dodds MP  
Minister for Women  
and Equalities

The Participation Collective is part of the Making Participation Work project funded by Department for Education

While the 1<sup>st</sup> 100 days of ministerial action is pre-planned, DfE and ministers are keen to hear how stakeholders would like to work together moving forwards.

### Q1. What should 'the government' (including the DfE) be communicating with you about?

Young people had a lot to say which could be drawn out into over-arching themes:

- Schools (and school experience)
- Outcomes
- Future life and independence
- Accessibility
- Equality (and equity)



Young people and parent-carer/practitioners reflected that communication should be around 'everything that impacts young people with SEND and their families'.

The full list can be found as appendix 1.

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# Collective Get Together

## P★wer Hour The DfE Comms Team (SEND and AP)

### Q2. Important things to remember when communicating with young people (with SEND)

Information should be:

- In simple, clear language (free from jargon)
- Supported with images
- Available in various formats including easy read, BSL, audio and video
- Given in the way that people want, and in a timely manner
- Repeated if needed, to help young people digest information



Young people said that they want people to be honest, admit when things go wrong and people to be accountable. People should also be patient with young people and accept them and their needs.

Participation shouldn't be tokenistic, and young people should be included from the start. Talking to parents/carers is an 'as well as' rather than an instead of – they're not a proxy.

Full responses can be found in appendix 2.

The Collective previously developed a top tips for giving feedback postcard, which represents many of the themes contained within this list. This can be found in appendix 3.

### Q3. Who is trusted to be the voice of CYP with SEND when they can't be present?

- Organisations such as Kids who hear from young people and share what we have said directly.
- For some young people, individuals who they see frequently (teachers, health practitioners, youth workers etc.).
- Other young people with SEND
- Older people with SEND – experts by experience
- People whose job it is (SEND participation workers/ SEND experience apprentices)
- For some they may trust parent/carers to represent their voice



It's important to note that some young people were strongly against parents/carers and practitioners such as teachers and doctors representing their voice

It is evident from this list that it is varied from person to person on who they are comfortable with sharing information on their behalf, so where possible individuals should be consulted.

### Opportunities for development.

- Kids. Increase regularity of Collective sessions and develop the communications matrix.
- DfE / Government. Make use of the Collective communications to disseminate key messages to young people with SEND, as well as gathering useful and useable intelligence from this diverse cohort.

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# Collective Get T★gether

## P★wer Hour The DfE Comms Team (SEND and AP)

### Appendix 1

#### Q1. What should 'the government' (including DfE teams) be communicating with you about?

##### Young people

- Communicate with YP about their personal opinions. Young people don't want to hear government opinions – not relevant as won't affect them
- Expectation timeline – give deadlines for what they plan to do (should be a standard)
- how they will do co-production
- What are they doing to solve the problems
- Telling us about the policies they're making and communicate about these in an easy way for us to understand. Talk to us about any changes/policies that impact us including updates and new policies
- ask us what we want them to do
- How they will improve our lives and the lives of future disabled people
- our experiences and use that to impact change
- how the decisions they want to make impact us- the negative but also positive impacts of these decisions
- Opportunities to get involved and have our say: Consultations, select committees, participation groups.
- They should regularly check in with us, because things change and new things come up. Having regularly scheduled meetings with disabled people, we are under-represented in parliament, and when it comes to getting meetings with MPs, this can be hard. we should have meetings as a standard.
- Making sure kids feel safe and happy in school and are getting the education they deserve in a way that works for them ----- we're really hopeful that the national standards help to do that!!!
- The support they get in schools including the types of SEND support they will put in place.
- What are they doing to make school better. Asking young people how things should be done because we are in school now not years ago
- How they plan to make improvements to SEN services and mainstream (and when)
- What is important in schools.
- Extra teachers they will get
- Teacher training on SEND
- Whatever they are doing. Their priorities (the governments)
- How and what they will be spending money on to improve SEND
- Funding, what it is being spent on and is it essential spendings? The public (including young people) should be involved in what it is spent on
- How the safety net will affect yp – taking away provision, help, school places isn't the answer for those affected – they don't go away
- Local Offers
- Town Hall events
- Whether they care and the discussion will make a difference, not just photo for the 'gram'





# Collective Get Together

## P★wer Hour The DfE Comms Team (SEND and AP)

- Nothing about us without us!
- Young people's rights and where to find them
- What is the Children's Commissioner doing for young people?
- Why are so many EHCP's being refused to be assessed (other than the excuse of funding)
- Things they want our opinion on – summarised with no complicated words
- Their ideas and being open to hear what we think and how to improve them
- Keep us in the loop with decisions they're making
- Feedback on events so we know we've been listened to
- You said, we did updates
- How we can contact them
- Services and help available and how I can get help/support
- Hear how the government are going to provide apprenticeship opportunities for young people with SEND. Workplaces offering more supported internships
- Know how the government are helping young people to find jobs
- Transition and focus on EHCP. What happens when you leave school and what happens in adult life
- General independence
- Staying safe when going out and travelling
- The increase in prices (cost of living)
- Taxes
- Public areas to be accessible
- Racism and hate crimes
- Anything to do with young people

### Parents, carers and practitioners

- Everything... with honesty / transparency and in a timely way
- Keep it simple and don't over complicate the wording
- Write in a way everyone can understand it; easy read videos and different languages
- What you have done to improve things. What you are doing to improve things. What still needs to be done to improve things.
- Make consultations meaningful – not tick box and don't over complicate them!

### Appendix 2

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# Collective Get T★gether

## P★wer Hour The DfE Comms Team (SEND and AP)

### Q2. Important things for the government to remember when they communicate with young people (with SEND)

#### Young People

- Don't do tokenistic participation
- Accessibility is a foundation not a follow up
- Being real - Often when you meet ministers they will just repeat party lines, so no doing that. Being able to have a human conversation without just repeating party lines
- Being honest about the failures. Admit it when you get something wrong, we value that and it shows you are human
- take accountability what went wrong
- it may take some of us a bit more time to process things
- Repeat the question so I can digest
- We are often upset and frustrated, there is a lot of emotion behind what we are saying
- Allow us to take breaks if needed.
- Remember that YP, let alone YP with SEND, is a very broad demographic with different needs. This covers many levels of development and needs just when looking at age alone and it needs to be accessible to all
- We are all different so need information in different ways including BSL
- Talk to parent carers but not use as a proxy - It's so important that it's an as well as not an instead of
- We are also more than just our disability, but at the same time our disability is often part of our identity
- Don't make false promises - If you say you are going to do something do it. If you can't tell us that. We need to trust you.
- Don't listen to us just to fill an agenda, do it because you want to and want to help us
- We aren't worth less than you because we're disabled, our voices matter
- To stop wasting energy on feeling pity for us and instead use that energy to make positive change.
- We already have to live the reality of being disabled every single day, we don't need you going oh I'm so sorry about that and not actually doing anything.
- Paper copies, as well as different paper options, braille for blind individuals and colour paper versions for those with migraines or dyslexia etc. high contrast really helps as well.
- Don't always expect us to make eye contact
- We may get our words mixed up, we may take time to process information.
- Stop telling me I don't look disabled, and don't keep asking what our SEND is!
- You are not 'well qualified' because you know a disabled person
- Stop calling us inspirational for having/living a real life
- Stop segregating disabled services and imposing age limits
- Don't talk down to us or patronise us
- Do not make assumptions about our disability
- We are the experts of our lives not you
- Respond to emails (contact) in a timely manner to avoid trust issues and break down in working relationships
- Be accommodating with how to best communicate with young people: 1:1, online, emails, text, videos, face to face etc

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# Collective Get T★gether

## P★wer Hour The DfE Comms Team (SEND and AP)

- We don't use the same social media (only old people use facebook)
- Use social media to keep in touch
- Be mindful of hidden disabilities
- Summarise
- All info plain English, alongside an audio version, bsl and easy read. Don't use jargon
- Easy Read – simple words and images. When publishing an easy read document, don't just think 'yes this is fine', ask people who uses easy read if they understand it and it is accessible format before publishing it to wider group of people
- Images are so important. I don't want a big chunk of text
- We are the ones experiencing the results of change – listen to what we say
- We are not stupid or silly. We are intelligent and deserve to be treated as such
- We are capable in our own ways
- Have patience when communicating or trying to gain trust with young people
- Don't cut us off mid-sentence.
- We have different needs but might have the same disability or diagnosis
- Kids should be involved
- Ask everyone for impact, no matter how loud or quiet

### Parents, carers and practitioners

- Remember we are individuals not numbers
- Make sure you communicate in a way everyone is able to understand: easy read, sign, different languages, videos etc
- Keep the language simple
- Don't waffle
- Give proper answers and don't dodge questions
- Tell the truth

### Appendix 3.

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# Collective Get Together

**P★wer Hour** The DfE Comms Team (SEND and AP)

## Top tips for giving feedback to young people

Tell us what's happening and the difference we made

Show us the changes - before and after

Show us in person if possible

Keep it simple and clear

Be kind and friendly

Be Honest



**Remember - always provide feedback, even if it's to say you can't make changes and why, or that nothing has happened yet!**

PLEASE  
PLACE  
STAMP  
HERE

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## Making Participation Work



project funded by



Department  
for Education

**Tell us about the participation work in your area!**  
Email: [takepart@kids.org.uk](mailto:takepart@kids.org.uk)

## Appendix 4

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# Collective Get T★gether

## P★wer Hour The DfE Comms Team (SEND and AP)

Q3. Who is trusted to be the voice of CYP with SEND when they can't be present?

### Young people

- Organisations (like Kids) who work directly with young people
- Youth voice team
- Parents and carers but not as parents and carers – representing our voice
- Young people should have opportunity to join virtually or feed in their voice in advance
- Specific people: Dame Christine Lenehan OBE, Aisia, Jimmy, Sarah Clarke, Jo NNPCF
- Young people with SEND for young people with SEND – other members of youth forum
- Older people with SEND
- SEND experience apprentices (so yp can be in meetings for their job)
- People whose job it is to represent young people's voice (like Sam, Warwickshire County Council voice, influence and change team)
- Support worker who knows me well
- SENCo
- Me, myself and I
- I don't necessarily think that anyone can share our views/ wishes better than us whether through in-person, meetings etc. We need to be consulted.
- Disabled individuals. No matter your economic class, inaccessibility is something that everyone faces. Some have it easier than others, but it is inevitable that a disabled person will face it at one point in their life.
- It is great when disabled people share our views and represent us, but it's also important to remember they've not lived every disabled young person's experiences, so there will be times they get it wrong or don't understand. It is important to hear from a wide range of people and different disabilities to get the most representation.
- Not someone who is a parent of a disabled child, not a doctor who specialises in disabilities- because although these people have their own insights into disability, they do not have our lived experience.
- Someone we choose

### Parents, carers and practitioners

- Parents and carers
- Trusted teachers
- Trusted professionals
- SENDIASS

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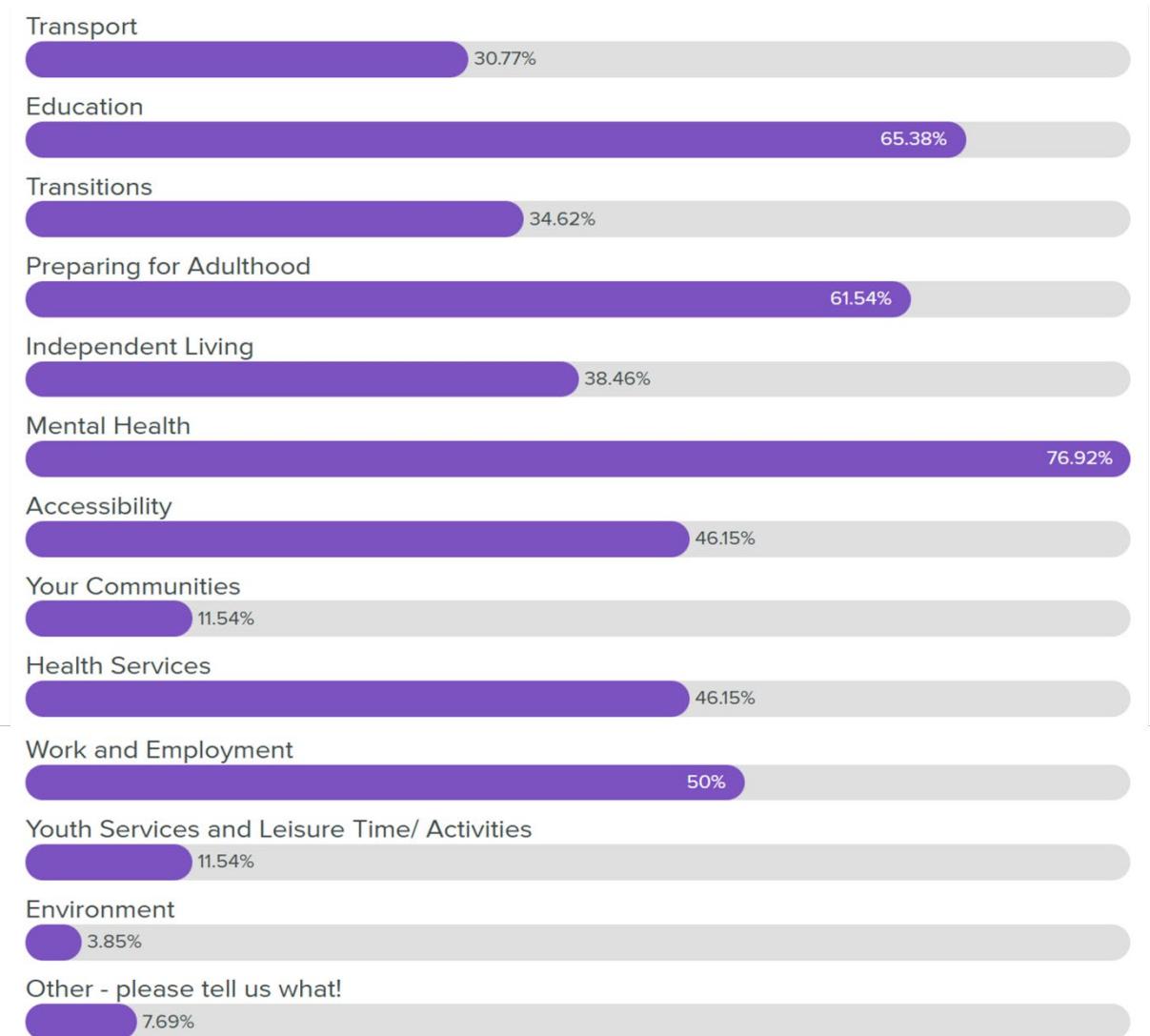


# Collective Get T★gether

## Young People's Priorities

A steering group made up of young people provided some broad level topics that young people may be interested in.

Young people chose their top 5 most important topics – the things they really want a say on, to make changes and make things better.



### Opportunities for development

- Kids to review opportunity for policy work in areas that young people have said is important to them.
- Kids support young people to take a lead on the 'speak up' agenda using the information gathered as a starting point to develop future campaigns.

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# Collective Get T★gether

## Young People's Priorities

As outlined in the image above, results for an overall top 5 were:

- 1) Mental Health
- 2) Education
- 3) Preparing for Adulthood
- 4) Work and Employment
- 5) Joint – Health Services and Accessibility

What things are important to you under these topics?

### 1) Mental Health

- People with SEND are at a much higher risk of mental health issues and there is limited support in this area. And where support is in place it is nearly impossible to get access. Especially SEND specific and neurodivergent support.
- Mental Health need to understand hidden disabilities and how it affects their future
- Be able to support me with the right support
- Have neuro-diversity training
- Not set up to support autistic people
- CAMHS being more understanding of neurodivergence and mindful what is shared with parents
- Validation
- Education
- Reduce stigma
- Adjusting environments
- Access to treatment
- Support for change
- More trained school staff around mental health
- Reducing waiting times
- Flexible with money spent in the health services

### 2) Education

- Child and parental choice
- Don't limit education – age range and accessibility
- Ensure transport is available
- Put in place the support people need - more flexible in approach to meeting needs
- Reasonable adjustments shouldn't be one size fits all
- Accessibility
- Suitability
- Peers and staff educated on SEND
- Transitions
- Adjustments
- Not just ending EHCP – a plan for the future

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# Collective Get T★gether

## Young People's Priorities

- Schools are very subject based with little to no life skills such as budgeting, cooking and cleaning
- The school system isn't always suited for young people and they fall through the cracks – like those with autism or some who might be more able but need help

### 3) Preparing for Adulthood

- Support for budgeting
- Life skills
- Appropriate support for different needs
- Independent living (real life)
- Additional lessons
- Adult services vs children's services
- Don't get real life skills in schools
- Need support in leaving school and what to do next
- Work experience needs to be real experience and independent living experience should be real. We don't learn when its not real and we are set up to fail

### 4) Work and Employment

- Accommodations and adjustments. Tailored support
- Flexibility
- No discrimination
- Safe working environment
- Work experience
- Volunteering experiences
- Job centre support is not appropriate / doesn't work. Should be individualised and tailored support
- More awareness of good programmes like supported internships and apprenticeships
- Support to find a job and apply for a job

### 5) Joint – Health Services and Accessibility

- Shorter waiting lists
- Follow ups and check ins
- Reasonable adjustments and safer environments
- Don't charge for hospital parking or in disabled bays
- Don't segregate disability services
- Better training for medics – talking to young people themselves

Additional activity found that other 'hot topics' of importance to young people included:





# Collective Get T★gether

## Young People's Priorities

- Equality, Diversity and Inclusion
- Planning
- Funding and how to challenge
- NHS waiting lists
- 'The Budget'
- MP for SEND
- More help for charities (in general and to deliver services that are needed)
- More free higher education – people can't afford university but want the opportunity to go
- Cost of living crisis (cost of food, changing plans due to lack of money)
- Police officers



Young people also shared experiences that they'd had around topics. These can be used to ensure young people's views and experiences are at the heart of any speak up campaigns.



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