

COLLECTIVE GET TOGETHER

2023 write up

London, Nottingham and online

The Collective Get Together 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 a platform for meaningful participation. This includes sharing and celebrating both individual and local participation and providing opportunities to input into national agenda items.

This year's Collective Get Together was held in two locations; London¹ and Nottingham² as well as online. This enabled more young people from across the country to attend by reducing travel times and keeping the online option. Another change this year, based on feedback was hosting during the summer holidays, not October, offering more regional inclusion.

Collective Get Together 2023 brought together young people from across the country, although representatives from the North-West and South-West were unable to engage on the day. There was attendance from a young person with SEND from Wales³, who was able to share their learning and experiences of participation.

Feedback from the event has been very positive and the following session briefings will identify page numbers for the write up and input gathered from young people for each.

We would like to thank DfE on behalf of KIDS and The Collective for their continued support, both through funding and the meaningful opportunities to engage in systemic change.

¹ Colt Technology Services, Great Eastern Street, London

² DfE office, Unity Square, Nottingham.

³ Although she had recently been studying in Oxford

Power hour 1 – Impact and Celebration! (pages 3-4)

This session included those joining virtually, celebrating the work that young people have been involved in locally as well as through The Collective on national agenda items, highlighting the co-produced outputs. We also had an update directly from the Department for Education and this session saw the 1st annual Collective Achievement Awards, with an individual and group being recognised for their valued contributions.

Room session 1 – Preparing for Successful Adulthood (pages 5-10)

Session focused on independence as part of transitions and preparation for adulthood. This included young people sharing their top tips in key areas of successful adulthood (which were co-produced with young people before the event) and recipes which will be collated into an accessible resource.

Power hour 2 – Change Programme (pages 11-16)

Young people were introduced to the Change Programme, we shared information on the path to development, it's implementation and how to work together moving forwards.

Room session 2 – Mediation Guidance Review (pages 17-21)

This session looked at guidance produced for families around mediation. Young people shared their thoughts and opinions around the design and content, as well as options to develop guidance.

Evaluation (pages 22-23)

Young people were asked at the end of the event for feedback, as well as being offered opportunity to follow up afterwards; this has been overwhelmingly positive. Practitioner feedback was sought after the event, and all agreed that they would bring young people to future Collective Get Together events.

Power hour 1

During the 1st Power Hour, the 2 groups in London and Nottingham were also joined by online members. The following 4 points are the key themes covered.

1. Young people local/regional participation

- SEND Review
- Staff recruitment
- Trustee interviews
- OFSTED
- Local area participation strategy
- Mental health
- SEND youth forums
- Local area audits e.g. museums, libraries
- Careers policy
- NHS
- Safe places and sensory environments
- Youth parliament
- Local offer

Full information on what young people and specific local areas have been doing is available on request.

2. Collective impact update

We reminded young people of all the amazing work they have been part of and picked out a few key pieces of work to highly their achievements. The resources and outputs can be seen on the KIDS HUB.

- Overcoming barriers factsheets (for practitioners and young facilitators)– A variety of barriers were identified at a practitioners' conference, which were grouped into key themes. Further work with young people and practitioners identified ways in which the barriers could be overcome. The final designs were co-produced by young people and practitioners.
- Participation group audit tool – Collective staff supported young people to draw out key areas from an audit tool designed for local areas, amend these for accessibility and then add other areas that they felt were important for participation groups. This was further amended using feedback from CGT 22, to create an audit tool designed for young people to use to evaluate their participation group.
- Careers policy unit – Young people discussed careers education, information, advice and guidance including creating more accessible definitions and their experiences.

- Working together – Young people highlighted the importance of 2-way information flow between young people, parents/carers, practitioners and decision makers to ensure that any changes in policy
- Tailored lists – Young people inputted into key areas that they felt were of importance and should be included in tailored lists. Generally, young people felt that tailored lists could be helpful, but only if they contain the right settings and information.
- Transitions – Young people have highlighted this on multiple occasions as an important area and have shared many ideas for ways that transitions could be better supported.
- Co-production – The Collective worked alongside practitioners to create the FUNdamentals of co-production. These were shared as a factsheet.

3. Update and response from Department for Education

DfE representatives attended the Nottingham venue but spoke to the whole event cohort.

Thanking young peoples for all their input, and reflecting that the information gathered helps them to shape their work and move forwards. It was highlighted that co-production (working together) is really important, so they have started to roll out training to different teams about 'what it is and its importance'.

DfE also said that they know how important it is to give feedback to young people, letting them know how any information is being used. They are developing processes to do this more effectively and meaningfully.

4. 1st Collective Achievement Awards were presented.

These celebrate young people's involvement and participation in The Collective's work, including Making Participation Work development work.

The group participation superstars award was given to Shout Out for Change. As a group they've attended and sent extra feedback on every power hour and do lots more outside of the sessions. Members from Shout Out for Change also supported with the development and delivery of training to multiple local authorities.

The individual participation superstar award was given to Carly. Carly has been involved in participation for several years and noticed a drop off in services at 25. She has set up her own group, supporting individuals 20 years and over to help transition into adulthood and services. She also volunteers with her local participation group, encouraging and supporting young people to share their experiences, thoughts, and opinions.

Room Session 1. Preparing for successful adulthood

Young people from across The Collective have made it clear through consultations and group work that they want to be happy, healthy and successful adults.

This session was co-developed with young people; some who asked for help because they don't feel prepared, some who shared their lived experiences but all who want to help others achieve their potential.

During development of this session were heard from young people that:

- Being independent is not easy
- Sometimes support isn't available because you are over 18
- Support isn't teaching us to do things for ourselves
- That top tips for day to day stuff would be really helpful

The first part of this session was around independent 'cooking'. Young people wanted to create an 'easy' to make recipe book for young people who start their independent living journey. The group co-produced a recipe sheet which young people filled out at the event, and others have submitted afterwards.

This will be an ongoing co-production project for The Collective members.

The second element of the session was around top tips for independence. The development group identified 8 key areas for being a successful adult.

- Cooking and food
- Travel
- Personal appearance
- Shopping
- Jobs and working
- Relationships
- Money
- Chores and house skills

Young people were asked to give any tips they had for each area, this is shown on the following pages.

This is going to be an on-going co-production project which we hope to link in with NNPCF and the forums as well as practitioners who support those with SEND to be independent to create a useful resource.

Chores and skills in the house



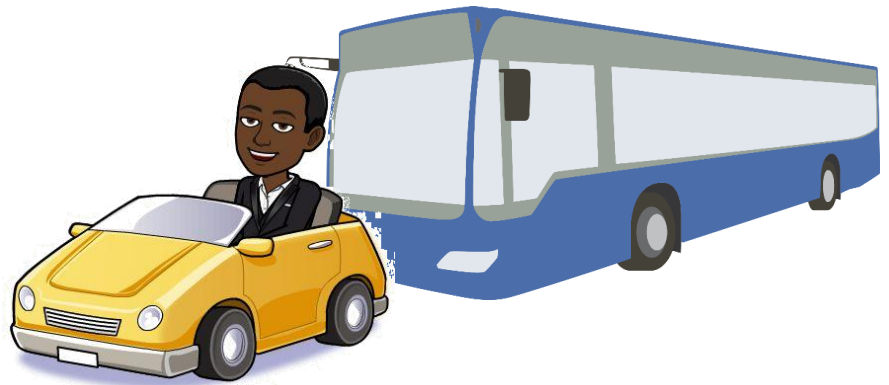
- List of what you are doing or need to do
- Split it into smaller tasks
- Aim time to finish
- Get the hardest ones out the way first
- Take little breaks
- Listen to music – it can help keep you motivated
- Plan ahead
- Have a weekly planner with set days to do set chores to help keep on top
- Have an alarm to remind to take medication
- Apps like Timo – made for time management for people with ADHD and autism
- Wristwatch
- Rewards for tasks that need motivation
- Split them up so you don't end up doing everything
- Practice things like ironing and folding



Shopping

- Make a list of what you need
- Have a budget plan, how much do you wish to spend.
- Try not to get things that you do not need
- If you want to try something new, don't bulk buy in case you do not like it.
- If you know you won't be able to get your full groceries in one shop, then think of a shop where you can get everything instead of going to multiple shops and spending lots of money.
- When buying different items there may be a lot of types for example: branded, unbranded, supermarket savings, choose which ones you prefer instead of going for the branded because its 'popular'
- Use a trolley to help
- Plan it in sections
- Sunglasses and noise cancelling headphones for sensory issues in supermarkets
- Don't go to the supermarket while hungry
- Make a meal plan
- Go from room to room making a list of what you need
- Know where things are so you don't overspend

Travel



- You can use contactless cards on the bus and train – you do not need to purchase a ticket before hand.
- Get on the right transport and make sure you have the right tickets
- Prepare your route before hand – you can use google maps to do this.
- Pick your train tickets up the day before travel – that way you will not worry the night before if you can't get your tickets for some reason and takes longer than expected.
- If you have problems with tickets, find someone who works there and they will help you.
- Plan your journey and don't take advice from others while on your journey. Keep to your plan with accessibility.
- I arrive 20 mins early in case the transport is early because they often are.
- Apps can help with timetables
- Ear defenders/ sound cancelling headphones can help
- Apply for blue badge
- Apply for bus pass
- Apply for disabled rail card
- Book wheelchair spaces in advance
- Love 2 meet U app (building friendships and travelling together)

Money

- Make sure you find out what benefits you are entitled to and your family – speak to citizens advice or SENDIASS if under 25. You may be eligible for universal credits.
- Always know what your interest rate is.
- Don't get into dept
- PIP (You may be entitled to) Get support with forms etc..
- Always make sure you pay depts off on time.
- Always check your bank account on a regular basis.
- Find a job you enjoy
- Keep track of what you spend
- Open a bank account
- pay by card always check the amount
- Get tips from your local bank
- If you're young you can sign up to go Henry or hyper jar
- Budget and track your money
- Try to save
- Learn about different coins and note
- Check the exchange rates on currency for when you go abroad
- Don't share your personal details with anybody
- Don't give money to strangers
- Be responsible for your money. Use a wallet, zip it up in a pocket so it's safe and secure.
- If your card gets lost ring up the bank to get the card frozen and get the card stopped or blocked.



Jobs and working



- Arrive on time and be prepared.
- Reasonable adjustments for employee's to provide
- Ensure employees know what your individual needs are
- Try something new get out of your comfort zone [independent travelling]
- Join the club
- Volunteering can help you get a job
- Practise interviews
- Shadow people at work
- Learn about different jobs
- Try your hardest and push yourself to your limits but make sure you don't push yourself too far
- focus on your dreams
- Network
- Social media account dedicated to certain topics
- Read books on topics
- Make sure you enjoy what you're doing
- Plan for the future-also enjoy the moment and journey

Personal hygiene and appearance

- Shower every day (if you can) or flannel down intimate areas/ use dry shampoo etc..
- Keep stocked up with products (check these regularly)
- Don't feel under pressure to remove body hair if you don't want to.
- Flavoured toothpaste can help if mint is overstimulating/ too unpleasant
- Brush teeth twice a day for two minutes
- After a bath or shower put on deodorant
- Some people might like to wear perfume or aftershave
- Some people might shave
- To keep smart have routine haircuts, maybe every other month
- Wash every evening and morning
- Use shower gel and used shampoo to wash your hair
- You should clean your skin
- Check products if you have allergies
- Wear clean clothes and dress in a way where you like what you wear
- You might want to iron your clothes after they've been washed
- It can help to carry breath mints or gum
- Cut and clean under your nails especially if you are handling food
- Keep your eyebrows tidy, you might want to pluck them
- Don't bite or pick your nails, instead distract yourself
- Remember to pick up any prescriptions if you need them



Cooking and food



- Asda and Morrisons best for people with allergies
- Use by date = unsafe to eat
- Best before date = Lower quality past written date
- If using knives/ chopping meat, veg etc... you can get lots of pre sliced, carrots, chicken, peppers etc...
- Always check what the temperature is on the knob – check the label and what temperature the food needs to be to set the temperature
- Write shopping lists to help you make healthy lifestyle choices
- Meal plan
- Arrange transport if needed
- Go to the same supermarket every time by doing this you will become familiar with what is in the shop
- Budget and make sure you can use money safely, including checking your bank balance to make sure you have enough for your food
- Use a freezer
- Be aware of allergies
- Eat regularly and drink plenty of water-put it in a planner if you need to so you don't forget
- Keep a list of the things you need to buy next time you go shopping
- Try to eat healthily

Relationships



- Always keep in contact
- Keep to yourself.
- Keep conversations short.
- Healthy relationships game
- Be open and free
- gender equality
- Networking
- Honesty
- Go to local groups
- Use the Internet to keep in touch if you can't see people in person
- Keep communication flowing
- Know your boundaries and enforce them
- Check in with those that you care about
- Learn how friends communicate- be respectful and attentive to their needs
- Consent!

Power hour 2

During the 2nd Power Hour, we were joined online as well as having the 2 groups in London and Nottingham!

This session was about the DfE Change programme. KIDS worked with the team to simplify information and share with young people how it has been developed, how they are implementing it and asked how young people feel they and others can be involved in the ongoing process.

We started by recapping the work done by the Collective to feed in to the SEND and AP Green paper and then the Improvement plan – with young people having reflected that they felt their views were part of this meaningfully.

SEND & AP Improvement Plan

Our ideas for changes



A new single SEND and alternative provision system



Better support for children and young people with SEND



A better understanding of how the system works

What's going to happen next



We will work with areas across the country to make some of these things happen now.



We are going to use something called a **change programme** to test difficult ideas to make sure they work well.



We will continue to work with children, young people and their families to develop these ideas.

SEND & AP Green Paper



We looked at what isn't working well with SEND services and support and alternative provision.



The paper had ideas about how to make support and services better for children, young people and their families.



We looked at those provided by the government, local authorities, nurseries, schools, alternative provisions, and colleges.



We spoke to children, young people, families, and those who support them, about these ideas.



In 2022 we wrote a paper about what we found. We called this the **SEND and Alternative Provision Green Paper**. It is available on the [gov.uk](https://www.gov.uk) website!



The review gave us ideas for changes that should make SEND and alternative provision services work better.

The word cloud shows what young people said.



Next we looked at why the change programme was happening and a little about what it is designed to do.

- improve outcomes and experiences
- deliver a system that there is enough money for,
- avoid negative outcomes



**Participation
Collective**

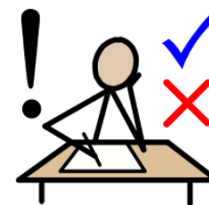
SEND & AP Change Programme: Design

The Change Programme will create up to **9 Change Programme Partnerships**. CPPs will:

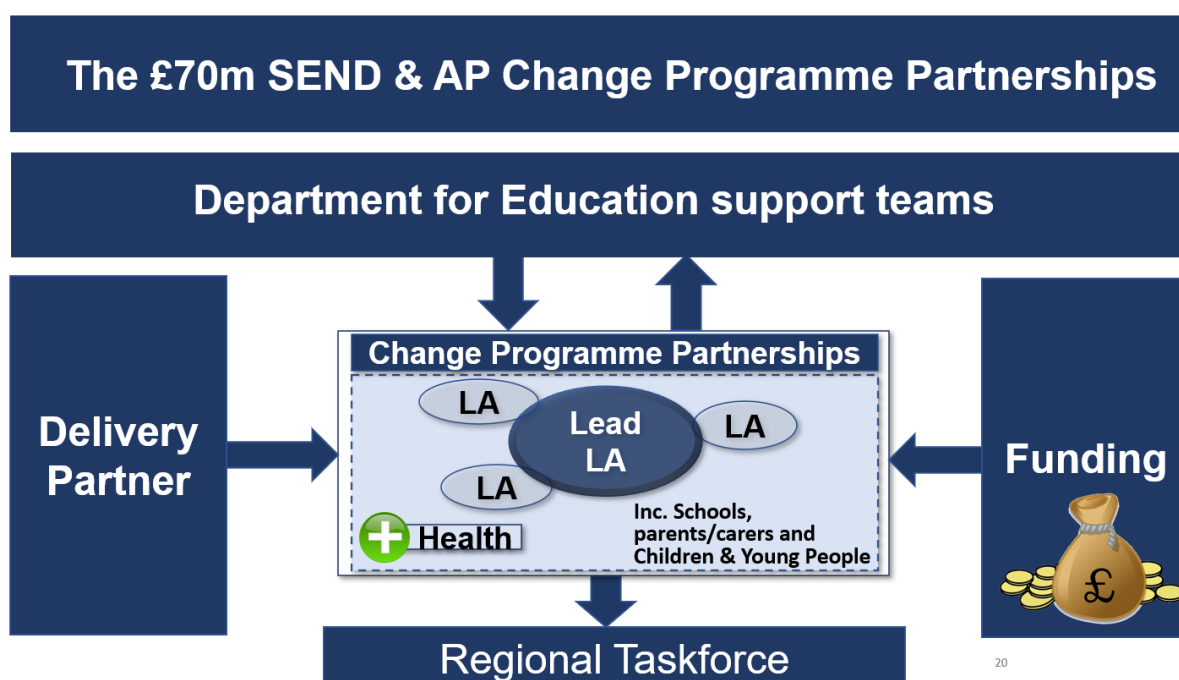
- **Test, deliver and identify key changes needed.**
- **Support and build on ability** to spread the testing of reforms, through a taskforce who will target at local areas that need help to improve their practice.

The Delivery Partner has good knowledge and understanding of SEND, Alternative Provision and System change. They will:

- Support programme delivery
- Share best practice and innovation through national/regional events, webinars, communications etc.

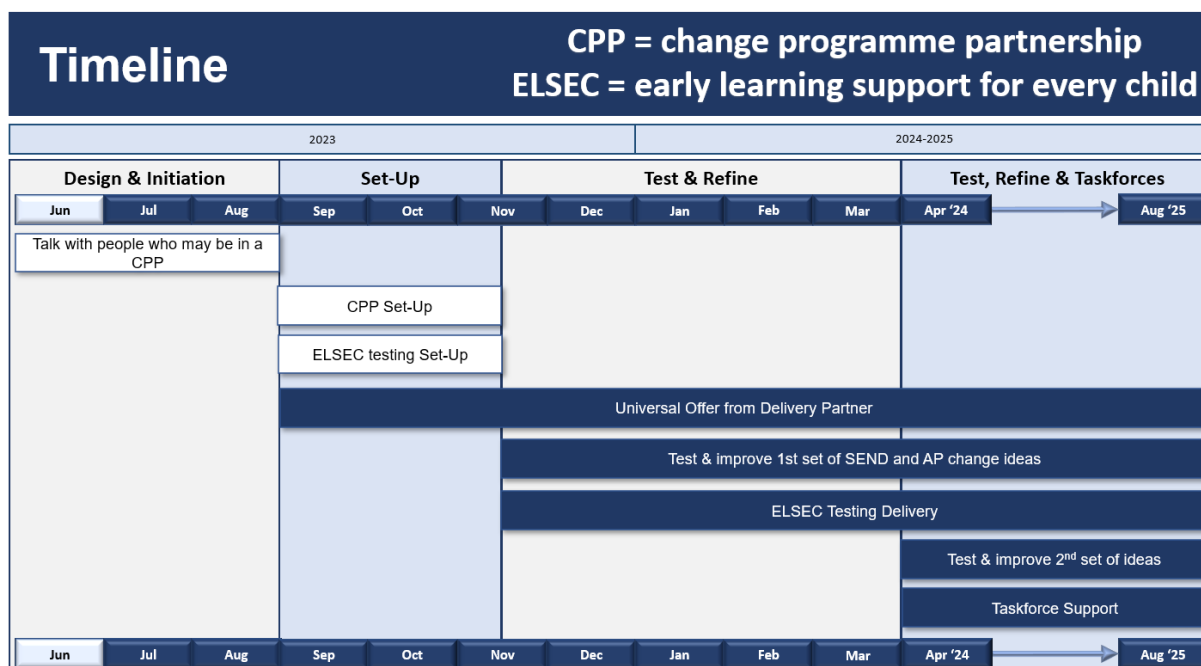


We shared some details around what the change programme will look like including some information about who and what is involved...



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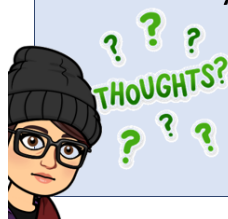
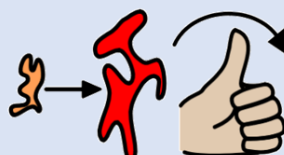
We also shared information on the timeline for the Change Programme. This is presented from now until August 2025!



The session ended with some questions regarding how everyone can work together moving forwards and young people's ideas for improvement and change.

Questions

- How can we make sure CYP have a voice in the setting up and testing of the changes in each LA?
- What do local areas need to put in place to make sure CYP get the right support in school as soon as they need it?
- What do you think needs changing to make the system work better?



Please see young people responses on following pages.

How can we make sure CYP have a voice in the setting up and testing of the changes in each LA?

- Online
- In-person
- Surveys shared
- Via schools/colleges (either promotion or go and visit them)
- Fund YP involvement and participation groups (like parents forums)
- Social media
- News
- Promote locally
- Discuss with those who the changes will impact
- Ensuring information and opportunities are accessible
- Opportunities for those who aren't involved in groups (hard to reach young people)

What do local areas need to put in place to make sure CYP get the right support in school as soon as they need it?

- Training of school staff, teachers and SENCOs – including:
 - Updating to current understanding and terminology related to SEND
 - Understanding different needs and variety within conditions
 - Mental health training done and renewed regularly
- Disability awareness and acceptance lessons with students
- Quiet area/sensory room/ safe spaces (mental health rooms with access to professionals)
- Pupil passports and reasonable adjustments
- EHCPs/ plans in place and reviewed regularly (termly)
- Homework not compulsory – praise not punishment
- Mental health days if needed
- Easy access to information – relaxation/ dealing with exam stress
- Easy access to assessment
- Pride people on individual achievements rather than exam results/ league tables
- Access to resources e.g. coloured paper
- Support continued into higher education
- Increase use of BSL
- Communicate with families and young people, ask them what they need
- Behaviour is communication
- Young people know they are entitled to support even if they're undiagnosed, and have a "safety net" for young people who don't know how to ask for help or have the awareness that they need help
- One stop shop for SEND parents where they can go and talk to others who have been part of the process

What do you think needs changing to make the system work better?

- There must be disability education for children and young people aged 4-18 years and for teachers. This should include hidden disabilities, be more extensive and be written (and taught) by disabled people.
- Understanding not all conditions are the same and people can present in different ways and that disability can vary by day for some people
- Disability education will hopefully lead to a change in attitudes, not only in the education system but across society
- Universal diagnosis provision for SpLD accessible to all
- Local offer
- Individual needs and strength focussed
- Plans grow with you and last throughout education
- Listen to people with SEND
- Meaningfully working with us. People at the top being here and talking with us.

Room Session 2. Mediation Guidance Review

The DfE mediation team requested that young people review an early draft of the guidance document that had been produced to explain mediation and the process to families.

The document initially shared was 'family' guidance, however an updated version had been titled as 'a guide for parents and carers'. Young people felt it is important that they can access guidance around this process as well.

The Collective were shown the full document briefly, not looking at content detail, but to see look and overall impression.

Then large prints of 2 pages were given and young people read the information, giving feedback on the sheets. The pages chosen for input were 'what is mediation' and 'glossary'.

General comments/ideas received included:

- The 'look' works but seems a lot to it
- Too long. Break it down into stages / sections.
- Language is too complex for young people.
- Easy read or video guidance for young people.
- The document is for parents/carers, it should be reviewed by them/forums.

Specific detail relating to the content and pages reviewed follows.

Important info needs highlighting

No devolved guidance
Section on how to access
this document.

Unsure what mediation
would be used for. Some
YP thought it could be
used in a disagreement
with family

Need an easy read version

Big words

Too long, too much info in
whole thing but not enough
to understand this.



Mediation



What is mediation?

Mediation is an informal way of settling a dispute between you (parent/carer or young person aged 16 or above) and the Local Authority (LA) and sometimes the Integrated Care Board (ICB).

The mediation is run by an independent mediator, who is there to help clarify the issues and reach a resolution. Mediation is free for you to use.

I still do not
know what
mediation
means?

Disagreement

Explain what this is. An
independent person,
called a mediator

An agreement
or decision

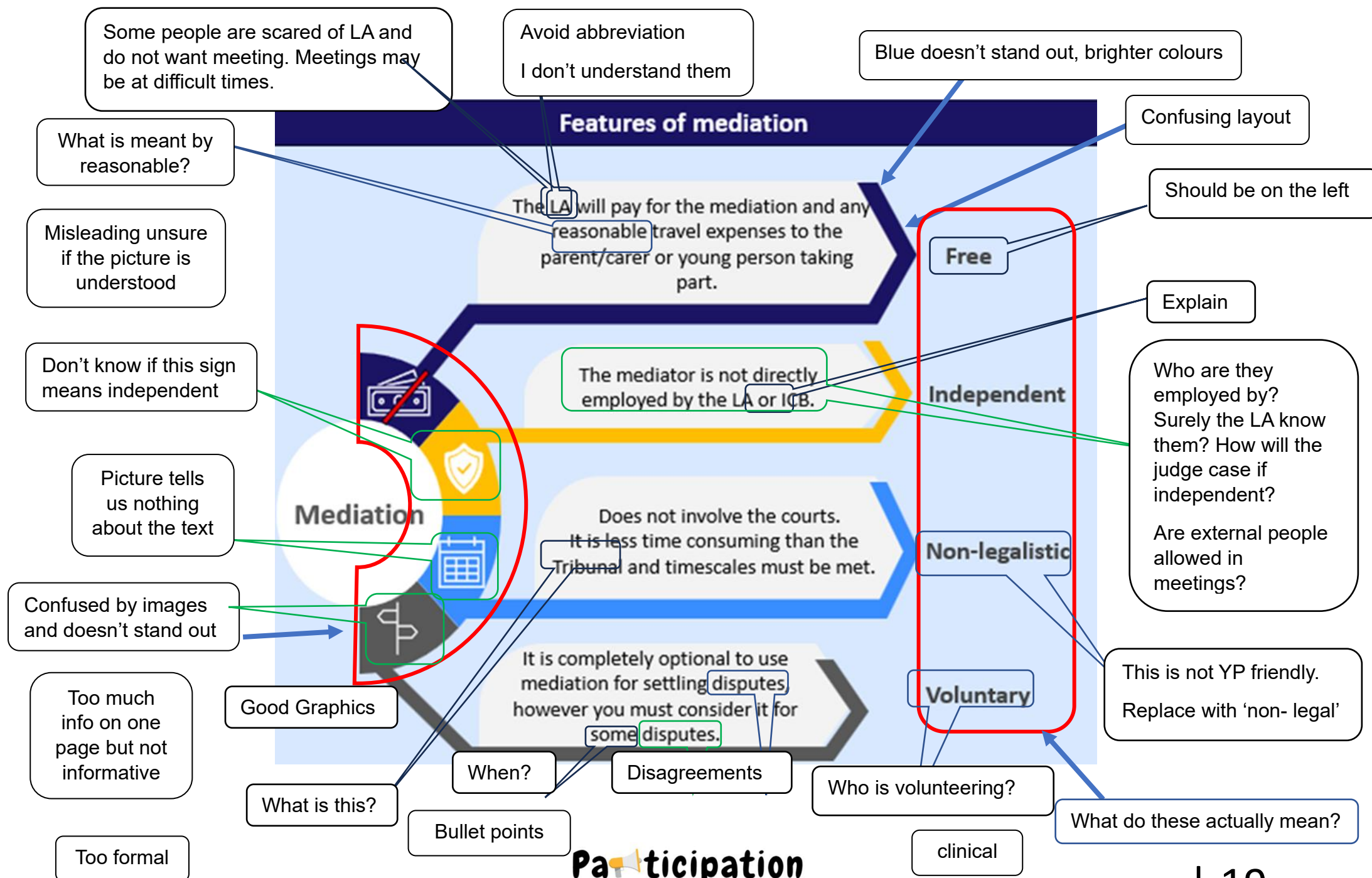
Who?
More explaining
Use examples
What is this?
Is this new?
What do they do?

Can't see the info

Use open dyslexic font

Fed up of reading
and not
understanding

Examples of disputes between
LA and young people



There are words that young people didn't understand within the definitions but they feel 'it is good to have glossary' and 'information to help people understand the words used'

Who?

Are?

Grammar?

?????

Not clear

Term	Definition
Education, Health and Care Plan (EHC plan)	An EHC plan details the education, health and social care support that is to be provided to a child or young person who has SEN or a disability. It is drawn up by the local authority after an EHC needs assessment of the child or young person has determined that an EHC plan is necessary, and after consultation with relevant partner agencies.
Integrated Care Boards (ICBs)	Health boards which bring together the local health system and is responsible for commissioning healthcare services. They replace clinical commissioning groups (CCGs) and hold statutory responsibilities including SEND and safeguarding duties.
Mediation	An independent statutory service commissioned by local authorities which is designed to help settle disagreements between parent/carers or young people and a decision-making body such as the local authority or integrated care board. Disagreements are over EHC needs assessments and/or EHC plans which parent/carers and young people can use mediation before deciding whether to appeal to the Tribunal.
Mediator / Mediation adviser	An independent person who is not employed by any local authority, ICB or NHS England who supports the mediation between the parent/carer or young person and the LA or ICB.

?????

Why?

?????

Talks??

This is better than 'disputes'

Special Educational Needs Co-ordinator (SENCo)	A SENCO is a qualified teacher in a school or maintained nursery school who has responsibility for co-ordinating SEN provision. In a small school, the headteacher or deputy may take on this role. In larger schools there may be a team of SENCOs. Other early years settings in group provision arrangements are expected to identify an individual to perform the role of SENCO.
Special Educational Needs and Disabilities Information, Advice and Support Service (SENDIASS)	Special Educational Needs and Disabilities Information, Advice and Support (SENDIAS) services provide free impartial and impartial information, advice and support on education, health and social care matters relating to SEND. The service are run at an arm's length from the local authority to ensure that children, young people and their parent/carers have confidence in them.
Tribunal (also known as First-tier Tribunal – Special Educational Needs and Disability)	An independent body which under law determines appeals by parent/young people against the local authority decisions on EHC needs assessments and plans.

What does this include?

What does impartial mean? Should it be here twice?

Metaphor? Does this mean independent or not part of the local authority?

Should this say is?

Evaluation

The evaluation process is essential in the development of not only the Collective Get Together event in the future but the on going movement that is The Collective.

Giving attendees opportunity to share what worked, what didn't and their ideas for improving all areas of the Collective Get Together allows us to make changes where we can and show young people that this is a meaningful and progressive process.

Young people can also feedback after the event along with practitioners. It helps us to see what we can do to make sure The Collective members and their supporters, keep coming and sharing their views and experiences for us to all learn from.

Below are key areas reviewed and any comments from young people.

Power Hour 1

Nottingham 75% thought the session was very good and all others said it was ok-good.

London 100% said it was very good

Great experience to be acknowledged.

Good to meet people

Good to see what changes are being made out of our local area.

In room session 1. (Independence)

Across both locations this session was reviewed as very good by 98% of attendees. 2% said it was good.

Very eye-opening certain situations people are in. Support needs to be worked on.

Can't wait to see the guidance. I think its really going to help a lot of young people.

It's nice to be able to give my own tips and help people. Spreading knowledge while learning something new too!

Power hour 2. (change programme)

Of attendees in London and Nottingham 80% thought this session was very good 15% thought good and 5% ok-not good.

Feels good that we can make an impact

Step in the right direction that we are being told its happening – not that its happened.

Good plan – try and test first

In Room session 2. (Mediation)

72% of attendees across both locations said this session was very good. 20% said ok – good with the remainder saying the session was not good or not answering.

This was hard to understand - sorry

Like looking at things on the big print outs you can see it better and work with friends

Things I don't understand as I have not been in the situation

No comment

Practitioner Feedback.

100% of respondents said they would be very likely to bring young people next time.

The day was well structured with breaks

Having food to graze on throughout the day was great for the young people.

The young people felt their contribution was meaningful and they were inputting in to a bigger picture and said they felt honoured to be there.

A bit of networking time built in would be good

All in all an amazing day!

Online engagement just needs a little more attention.

You improved things from before and it was already good. The event is inspirational and empowers these young people to really want to achieve things

Having a more local venue in the midlands worked well.