



# Autonomy, Rights and Children with Special Needs: A New Paradigm?

## Working Paper 9 English Case Studies Findings

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# Research Aims

- How is policy being put into practice following key legislative and policy reforms? (Children and Families Act 2014 & SEN Code of Practice 0-25 years, 2015)
- **Considered whether a new era of children and young people's participation rights is materialising in practice within the processes of decision-making and redress across the field of SEN in England.**
- Explored factors affecting children and young people's opportunities to exercise their rights of participation and redress.
- Case study research focused on eliciting children and young people's accounts of their involvement in decisions on matters such as school choice, educational provision, funding including individual budgets (where appropriate), the resolution of disagreements including mediation and tribunals, curriculum and planning.
- Considered the role of the LA, parents/carers and professionals in supporting children and young people to access their rights.

# Case study context

- Case studies were drawn from three local authority areas that participated in an earlier LA survey.
- 25 LAs expressed an interest in being involved in this phase of the research. Final fieldwork sites were chosen after careful analysis of the administrative and survey data of all prospective fieldwork sites.
- Bigtown, Northshire and Greenshire chosen as representative areas in terms of high, medium and low levels of socio-economic deprivation and of urban and rural populations.
- Senior SEND managers, LA SEND staff and a range of education and social work professionals were interviewed to gather information about how LAs were responding to the reforms.

	<b>Bigtown</b>	<b>Northshire</b>	<b>Greenshire</b>
<b>Total Population</b>	545,500	1,201,900	317,500
<b>Type of LA</b>	Urban	Urban/Rural/Coastal	Urban/Rural
<b>IMD 2015 Quintile</b>	1 <sup>st</sup>	3 <sup>rd</sup>	4 <sup>th</sup>

# Recruiting participants

- Small sample size (n=18), intention to highlight as wide a range of factors as possible which can enhance/impede CYP's realisation of rights and explore experiences of participating in decisions about education and support in greater depth.
- Recruitment of families via promotion of the project on parent/carer forum websites and education and 3<sup>rd</sup> sector professionals facilitating contact with CYP and parents/carers who might be interested in the project.
- Risk that education professionals may have been more likely to suggest participants with whom they had a good relationship with or had positive experiences of engaging in EHCP processes.
- Mitigated to some degree by the inclusion of families who were introduced by 3<sup>rd</sup> sector organisations or who had self-selected through parent/carer forums.
- Aimed to include participants reflecting differing levels of deprivation, as well as a range of ethnicities and ages and a representative gender balance.



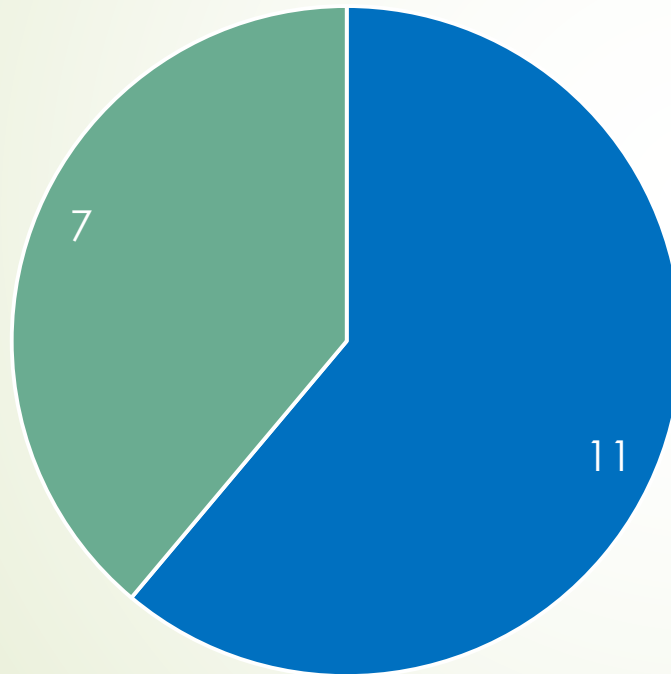
# Characteristics of participants

- 18 CYP took part in the case studies, aged between 7 and 22 years.
- Many participants had more than 1 type of SEN. Included SEMH, ASD, ADHD, SLD, SpLD, SLCN and sensory needs.
- There was a high proportion of White British participants (83%) despite efforts to include a more diverse sample.
- The sample included a high proportion of CYP with EHCPs (78%).
- A third of participants qualified for FSM, 3 were care experienced children or young people.
- Settings included a range of mainstream, RP, special and independent schools and colleges with a variety of governance structures.



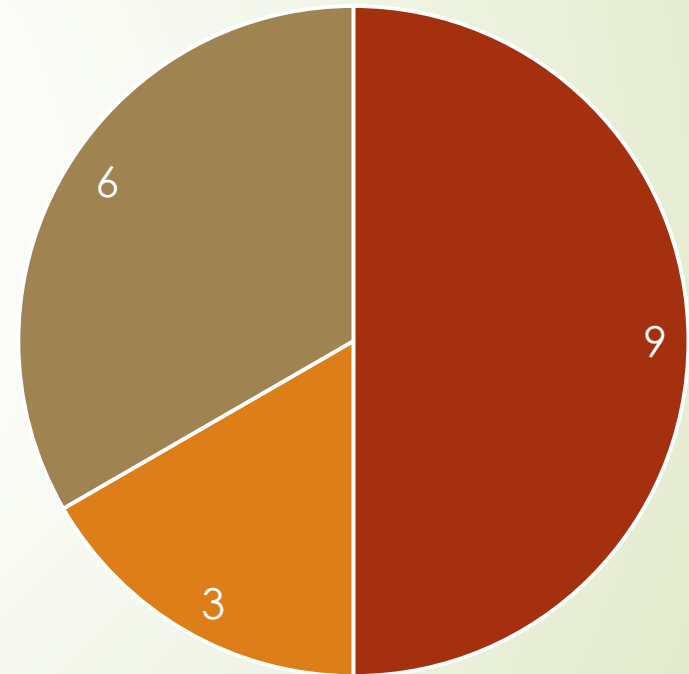
# Characteristics of Case Study Participants

Gender of Case Study Participants



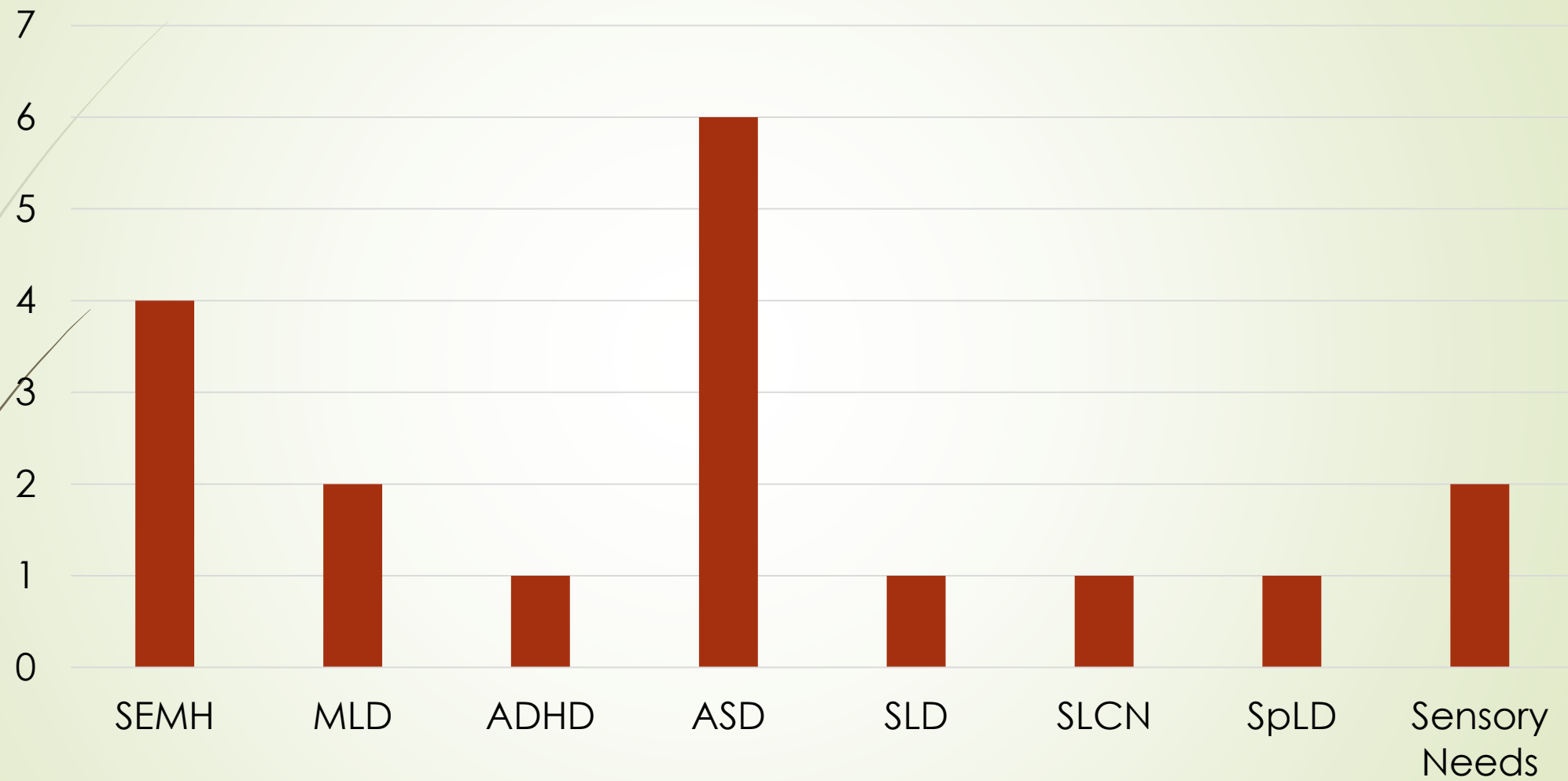
■ Male ■ Female

Age of Case Study Participants



■ Primary ■ Secondary ■ 16-25


# Primary SEN of CYP Participating in Case Studies



Total Number of CYP = 18



# Data collection

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- Data was drawn from semi-structured interviews, classroom observations and activities with CYP and significant adults involved in their SEND support and decision making (i.e. parent/carers, education and social care professionals).
  - Research activities (stories, decision-making charts & other visual aids) and interview questions piloted with Children with SEND in local school, head teacher and SENCO.
  - Activities were helpful to facilitate understandings of different decision making contexts and encourage younger children or those with more profound difficulties to talk about areas in which they had more/less say in decision making in school/college. Often participants went on to answer interview questions as well.



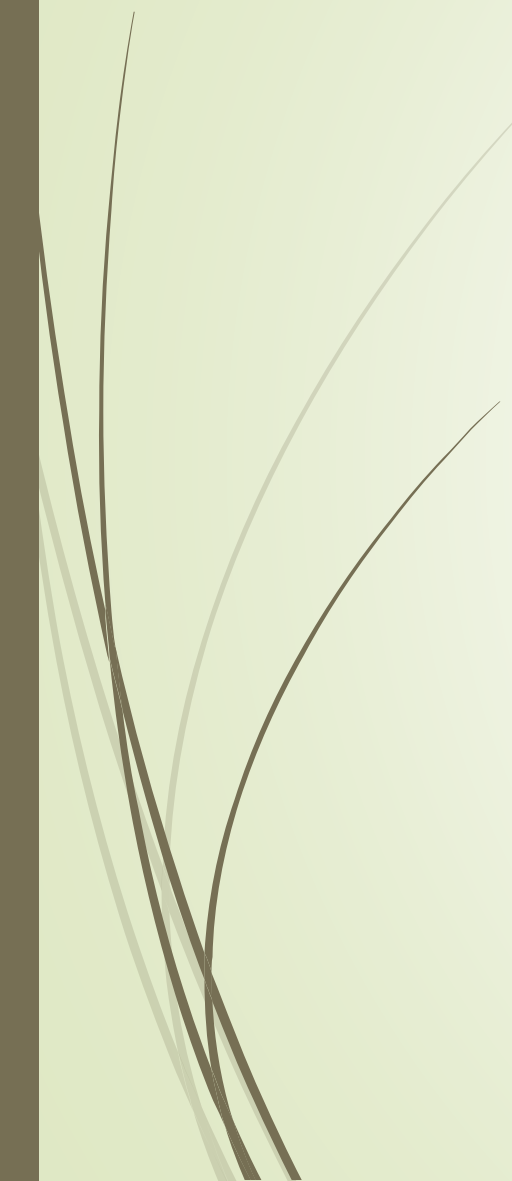
# Research Activities

LA officer interviews	8
CYP interviews	18
Parent interviews	19
Head teacher/Teacher interviews	18
Classroom assistants and support workers	10
Others (SENCOs, Educational Psychologists, leaving Care worker, Student Voice Co-ordinator, Sixth form lead)	8
Observations	1-2 days per child
Analysis of documents	e.g. EHC Plans, Individual Pupil Plan & Personal Education Plans (Re Looked After Children), Appeal evidence documents provided by parent.



# Findings...

Thematic analysis identified significant factors which influenced CYP's autonomy in SEND decision making in terms of:

- Individual factors affecting children and young people's ability to participate
  - Family relationships and dynamics
  - Cultural awareness, resources and knowledge of rights
  - External sources of support
  - Enabling environments
  - Children and young people's prior experiences of participation processes.
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# Individual factors affecting CYP's ability to participate in decisions about education and support

- **Factors identified as potentially impacting upon a child or young person's ability to participate in decisions about their education and care:**
- Their level of confidence in their own decision-making skills (regardless of age or nature of SEND);
- Their capacity to consider the consequences of decisions;
- Their ability to express views to unfamiliar people or in unfamiliar contexts;
- Access to support with communicating via a range of verbal and non/verbal communication methods;
- Their understandings of social norms;
- Their degree of experience of participating in 3rd sector/LA SEND participatory groups and school/college councils;
- Their knowledge of rights to participate in decisions about their support.



They wouldn't really listen to me as much as they listen to mum, because I'm just young – I'm only nine. My mum is an adult; they'll believe her more than me. **Lyron, 9yrs**, on voicing his need for extra support.

I can't make such a decision like that on my own... I don't think I know. **Maleeha, 12 yrs**, on choosing a school.

I'm quite, like, strongly opinionated. **Claire, 18 yrs**.

It's easier for me to make decisions if a grown up helps me and I have limited choices. It's hard for me to think about the consequences to my choices and I just think about what's good now. **Noah, 9yrs** on things that help with decision-making.

# Family dynamics and decision making


- On the whole, parents and carers support their child to participate in decision making within the home and school.
- Parents and carers went against their child's wishes when they considered he/she lacked sufficient capacity to make decisions or that following the child's view or decision would not be in their child's best interests.


I think that somebody who can't decide what to wear in the morning, he's not going to be capable. He can't decide whether to have toast or cereal if you give him two options... I don't think he'd want that responsibility.  
**Mother of Peter, 16yrs**, views on her son's capacity to realise his rights under the CAF 2014.





# Socio-cultural factors and awareness of SEND matters

- Appeared to be some correlation between levels of deprivation, access to cultural resources and degree of knowledge and awareness of SEND matters.
  - However, not always the case. Analysis of case studies highlighted examples of multiple, intersecting factors which appear to affect a child, young person, parent or carer's awareness and knowledge of SEND matters and corresponding rights.
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I receive emails about going to meetings ... **It really is quite daunting to go along to something like that because as a special needs mum - I've never met any of the parents. You're so isolated that it's really difficult to turn up at these things blind.** You don't know what sort of thing goes on, you don't know what they do, you don't know what they talk about. And for me personally, I mean that it's a huge thing for me. (Mother of Aiden, 13yrs, ASD, 5<sup>th</sup> quintile)

I think they know better than me with things like that... I know of some mums that have a lot of people at the meetings but I never have. **I never pester that much, I just go with it.** (Mother of Chloe, 8yrs, ASD/MLD, 2<sup>nd</sup> quintile)

I'm quite lucky that my best friend, she's got a son with ASD... but **if I didn't have my friend, I'd be on my own with it, you know... I probably wouldn't know where to start.** (Mother of Alice, 10 yrs, ADHD 1<sup>st</sup> quintile)

# Children and young people

- Most CYP felt that their views, wishes and feelings were taken into account within educational settings but were not always aware of relevant professionals' /agencies' obligation to have due regard to them.
- CYP demonstrated differing levels of ability to understand their rights as a result of factors such as levels of maturity, cognitive capacity and prior access to information about them. The abstract concept of a right was very difficult for some CYP to comprehend.

**Jack (7yrs)** struggled to understand the concept of rights. When he was asked directly whether he thought that the school respected his rights, he said that he thought so but then went on to explain this in terms of being able to write neatly. When engaged in an activity creating a decision-making chart he was able to state areas in which he felt that he had more or less say in decision making.

The right to education, the right to a voice, and the right to basically have an opinion. **James, 16 yrs** on his knowledge of children's rights.



# Useful sources of external support

- Expertise and information provided by SENCOs or a class teacher can be pivotal in raising parent/carer awareness of entitlements to SEN provision, offering support with completing EHCP paperwork or with decisions regarding appropriate future settings.
- Practical or emotional support from independent advocacy services or 3rd sector organisations was reported to be very helpful by parents/carers
- Some parents and carers lack trust in LA processes and actively seek out independent support from legal professionals or national charities.
- Courses run by independent bodies or LA services can raise awareness of legal rights and other SEN matters were highlighted as useful sources of support for parents and carers.
- No children and young people reported accessing advocacy support independently except in the case of a young person who was a care leaver.

# Useful sources of external support

[SENCO] doesn't let go until she gets what the kids need, which is right. Maria would still be on 15 hours if it weren't for her, you know, fighting for it 'cause you have to fight for funding and that. You need the right people there to make sure that kids do get what they're entitled to.  
(Teaching Assistant)

I didn't even know what an EHC plan was until I got the paperwork... At first, I didn't fill it in. I pretended that I didn't get it, but then I asked Barnardo's and then they came and helped me.  
(Mother of James, 16yrs, ASD/SpLD)



# Building children and young people's capacity to participate

- Variability in the ways in which different settings support CYP to participate in decisions and engage in EHCP processes. Some always invite CYP by default, others do not.

You do have to listen to the child. All our children come into their reviews... Some of them stay for the whole thing, some of them, you know, obviously have had enough by the time you reach the end of it and you're outcome setting and all of that... I always insist that they come at least to the five, ten minutes at the beginning. (SENCO)

I don't know whether I'll take Chloe because, like Chloe can talk. We could have a review that will last all afternoon if I took Chloe in. (Class teacher of Chloe 8 yrs.)

# Building children and young people's capacity to participate

- Hosting 3<sup>rd</sup> sector SEND participatory groups at schools/colleges
- Adapting EHCP forms in consultation with CYP to make these more accessible (changes to wording and layout).
- Use of alternative communication technology (e.g. proloquo) and film to capture CYP's views and feelings.
- Use of person-centred practices. E.g. whole meeting is planned, timed and centred around the CYP's wishes and communication support needs.
- Professionals' commitment to supporting YP's rights as equal to those of a parent/carer in cases of conflict.
- Allowing CYP agency in decisions about which adults support them.
- Meaningful engagement between CYP and school/college councils that leads to demonstrable change.

## Challenges encountered:

- Timing of meeting, clashes with activities/lessons can reduce extent to which CYP are available to attend meetings
- Adult concerns about CYP's capacity, maturity or well-being can result in CYP not being included in discussions about their education and support.
- Professionals' lack of understanding of CYP's rights or commitment to listening to CYP's views within different institutions
- Professionals' lack of access to appropriate resources to facilitate person-centred approaches

# Children and young people's individual participation

- Some CYP choose not to participate in EHCP processes due to a lack of interest or trust in professionals and LAs.
- Common factors which affect CYP's participation at meetings include their capacity/maturity/motivation, the timing/length of the meeting, and parental concerns about their mental well-being.
- Continuity of support, familiar contexts and the presence of familiar adults who understand their needs enhance CYP's confidence and ability to communicate their feelings and wishes.
- In the majority of cases, parents and carers supported their child to make a decision about the most appropriate educational setting.

I used to get very, very, very angry, every day, 'cause they were always mean. So then I said [to foster carer] that I don't want to go to that school. Now I come to this school and it's--, I have never been angry at this school, and I've been here for years. (Samuel, 9yrs, SEMH)

I can choose whether to go or not. Usually choose to go. **Peter, 16 yrs**, on attending EHCP review meetings

# Participation in disputes and appeals

- There was only one case in which a young person went against the views of a parent and made the decision regarding their preferred educational setting independently.
- Parents and carers instigate appeals not only on behalf of children but also often in the case of young people.
- Some parents, carers and independent advocates are able to provide significant support for CYP's involvement in disputes and appeal processes.
- Expressing negative opinions and views can be stressful for CYP and there is a risk that CYP will comply with significant others' decisions in order to avoid conflict.

'If in our case the Council don't particularly want to listen to parents, I can't see how they would suddenly want to listen to 17-year-olds.' Father of Kei, 17yrs


Can you imagine going to so many different staff, and they're all trying to make you out to be a bad person? Why would you want to go into that? **Claire, 17 yrs**, on attending case meetings.



# Collective Participation

- Just over half of CYP were aware of their school/ college council; some children had misunderstandings about its purpose.
- On the whole, CYP engaging with collective consultation mechanisms (for example, school councils or LA/3<sup>rd</sup> sector SEND participatory groups) felt that their views were taken seriously.
- In cases where CYP participated in collective decision-making processes leading to demonstrable change, this tended to enhance their confidence in expressing their views in the future.
- Educational professionals recognised that students with SEND were often under-represented on school/college councils. Some settings have adopted measures to rectify this.
- Among CYP, a lack of opportunity to voice negative views can engender a sense of disenfranchisement and lack of confidence in consultation mechanisms.
- A young care leaver highlighted the importance of feeling valued and that they had a voice via membership of participatory groups.





**For example, Aiden sometimes found it difficult to cope with the length of school council meetings but felt his involvement with the school council has enhanced his confidence to participate in collective decision-making contexts. This experience has encouraged him to make more suggestions in the future.**

R: We've made a change that I put forward to the previous pupil council member, for the chef for the school, to put like chillies on the menu, so children would know how hot it is because when we didn't have that, I got something, it was like that Thai green curry and I had it and it burned my mouth a lot 'cause I have a really sensitive taste to spice, and it burned my mouth. When I put that forward, he did it, so they must have agreed to it.

I: How did it feel to know that you'd suggested something and they listened to you?

R: It made me feel like the pupil council, it's not just there so you can just have a chat... It makes me feel like they actually listen to what you have to put forward and it made me confident to think about other things to put forward as well. (Aiden, 13yrs, ASD)

# Conclusions

- Still a long way to go before CYP and their families are able to access the information and support they need to realise their new rights consistently and uniformly.
- Families living in areas of high levels of deprivation or with limited time and access to other resources often rely upon the expertise of professionals involved in their child's care to access information about SEND matters and their rights.
- Regardless of socio-economic background, just over half of parents and carers were not aware of the local offer, and of those that accessed it, very few found this a particularly useful source of further information and support
- CYP had some knowledge of their rights to have their views and feelings respected, but very few had experience of collective decision making regarding SEND matters, except for a few young people who regularly accessed LA or third sector participatory groups.
- Majority of CYP relied heavily upon their parent or carer's having access to sufficient information and support in order to realise their rights, and parents and carers often advocated on behalf of their child.

# Conclusions

- CYP with SEND are not always informed about their rights or are able to participate in discussions and decision-making processes regarding education and support.
- Professionals' access to resources to deliver a consistent person-centred approach to the planning and delivery of EHC processes alongside other competing institutional demands and increasing workloads can limit the extent to which children and young people are supported to achieve greater autonomy.
- CYP's autonomy limited by a lack of clarity with regard to who has responsibility for ascertaining participatory capacity at a number of different levels of decision-making, ranging from choosing to attend an EHCP meeting to more long-term decisions regarding their preparation for adulthood.

# Next steps...

- Improve and extend opportunities for CYP to engage in individual/collective decision-making contexts and learn about their rights. (SEND groups, school councils)
- LAs and schools/colleges ensuring that clear information on SEND matters & rights is provided.
- Further work on adapting EHCP forms & adopting creative responses to include CYP's views within EHCP processes.
- Extend parent/carer and YP's awareness of advocacy support available via SENDIASS/3<sup>rd</sup> sector groups.
- More training for education and social care professionals on children's rights and person-centred practices.
- Greater clarity and consistency regarding who is responsible for ascertaining CYP's capacity, across institutions and agencies. Some institutions and professionals appear to be much more proactive than others in trying to elicit views of CYP with different levels of maturity or SEN.
- Allocation of sufficient resources to adopt person-centred approaches consistently.
- Better communication and provision of information from LAs or DfE to support FE institutions with the inclusion of YP up to 25 years in EHCP processes.