



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

Briefing English Case Study Findings

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Dr Gail Davidge and Professor Neville Harris, School of Law,
University of Manchester



1. Introduction

The Children and Families Act 2014 (CFA 2014) represents the biggest legislative reform in a generation for children and young people with special educational needs (DfE, 2014)¹. Part 3 of the Act places significant emphasis on consideration of and paying regard to the wishes, feelings and participation of children and young people with SEN and disabilities (SEND) in decision-making processes that concern individual support and the provision of local SEND services.

The independent rights of young people with SEND are now considered as equivalent to those of their parents or carers and reflect a key ambition which has the potential to afford young people with greater autonomy in the field of SEND decision making.

The CFA 2014 also reflects an aim of enabling any dispute or disagreement that a young person or parent of a child with SEND has with a local authority or school to be resolved less adversarially than it would previously have been. There is also a statutory responsibility for local authorities to ensure that young people and families are able to access appropriate information and advocacy support with regard to SEND provision and participation in the dispute resolution mechanisms.

This briefing reports on key findings drawn from 18 in-depth case studies that sought to explore whether a new era of children and young people's participation rights is materialising in practice in this field in England.² It forms part of our broader study of the impact of key legislative and policy reforms affecting children and young people's autonomy contained within the CFA 2014 and reflected in the *SEN Code of Practice 0-25 Years* (2015).³

The case studies were drawn from three local authority (LA) areas which were selected as being representative areas in terms of high, medium and low levels of socio-economic deprivation and of urban and rural populations. Within each LA, six case study participants were recruited with the aim of reflecting as wide a range as possible of children and young people with different types of SEND situated in a variety of family/care and primary school, secondary school and FE college contexts. We aimed to include participants reflecting differing levels of deprivation, as well as a range of ethnicities and ages and a representative gender balance. Eighteen children and young people took part in the case studies, aged between 7 and 22 years.

This briefing contains a summary of the views and experiences of children and young people, parents and carers and professionals which were shared with us during the course of the case study fieldwork. Key findings that highlight a range of significant factors

¹ A child is defined under the legislation as someone who is not above compulsory school age; and a young person is someone (aged 16 or over) who has ceased to be of compulsory school age but is under the age of 25.

² The case studies were conducted as part of the wider ESRC project on Autonomy, Rights and Children with Special Needs: A New Paradigm? (ES/ P002641/1).

³ Under Section 77 of the CFA 2014, local authorities, schools, governing bodies, colleges, clinical commissioning groups and a range of other bodies must have regard to the 2015 SEN Code of Practice.

influential to children and young people's autonomy in SEND decision-making in a range of contexts are summarised below.

Individual factors affecting children and young people's (CYP's) participation in SEND decision making

- Regardless of age or the nature of their SEND, some CYP tended to lack confidence regarding autonomous decision making and prefer that adults act on their behalf.
- Limited choices can help to make decision making less stressful for CYP.
- Regardless of age, CYP with limited communication skills can participate to varying degrees via a range of non-verbal methods. Support from a significant other who is familiar with a child or young person's specific communication difficulty is also an important factor that enables greater levels of participation.
- Regardless of age, some CYP are considered by significant others not to have a sufficient level of maturity or control over their emotions or behaviour to make autonomous decisions safely.
- Regardless of age or SEND, some CYP encounter difficulties expressing their views and feelings to unfamiliar adults or within unfamiliar contexts. The presence of a significant adult who has a close relationship with a CYP is often helpful in this respect.
- Some CYP are able to express their own views independently and succinctly, and this was particularly the case with CYP with autism or SEMH difficulties.
- In one case a young person with specific learning difficulties demonstrated tenacity in seeking out appropriate SEN support independently, despite limited knowledge of her legal rights.
- Experience of participating in 3rd sector or LA SEND participatory spaces can enhance CYP's confidence to participate in other contexts.

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.

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.

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

Here, I know I'm entitled to an hour a week, 'cause I don't have a statement and that is what everyone is allowed... I don't know an awful lot about it. I know as a person, that if you need help, you go find it. I also believe that good things don't come to those who wait; you have to find them. But those are my morals, not what I know. **Laura, 17 yrs** on her knowledge of her rights.

Factors concerning family dynamics and decision making

- Their perceptions about a child or young person's capacity to understand the consequences of decisions impacts upon the extent to which parents and carers intervene in decision making processes.
- The best interests of the child or young person were considered by parents and carers to be paramount and although most parents felt that supporting a child or young person to participate was very important, this was often a secondary concern.
- CYP often had some, or a considerable, say in everyday decision making within the home.
- A young care leaver highlighted the importance of being able to draw upon consistent advocacy support from trusted adults with whom they had a good relationship, in the absence of other family support.
- In most cases, parents and carers helped their child to express their views and acted upon their wishes.
- Parents and carers often advocate on their child's behalf when the child or young person is perceived to lack capacity or has asked their parent or carer to do so.

Well there were [difficult] times but I got through it and my dad helped me sort it out and stuff. The amount of support wasn't that great... My dad asked if he could talk about my support. One of the teachers learned all about my coordination problems and she helped me the best way she can in it. The right help. **Kei, 17yrs** on help with voicing a need for appropriate support.

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

Parents

- Most parents or carers appear to have some limited knowledge of their rights and their child's legal rights and demonstrated varying degrees of cultural awareness of SEND matters more generally.
- Just over half of parents and carers were unaware of the local offer.
- Limitations of time, capacity and cultural resources impact on parents' and carers' access to professional and/or informal SEND networks and this affects awareness and knowledge of rights.

- Access to information directly or via third sector or educational professionals appeared to make parents/carers better equipped to challenge aspects of their child's education and support effectively.
- Engagement with formal and informal parent/carer networks can increase families' awareness of SEND matters and rights.
- Some parents and carers are unsure about or unable to access the information needed to understand and realise their rights.
- Parents or carers with SEND themselves can experience difficulties accessing information about SEND matters and legal rights.
- In some cases, school support is vital to ensuring that parents become aware of how they can act to support their child's SEN.

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.
- CYP demonstrated tacit understandings of their rights and often gave examples that related to their experiences of voicing an opinion in school or of everyday decision making at home.
- Very few CYP were aware of the local offer.
- Access to participatory support groups and support received from significant adults appeared to be influential in terms of raising cultural awareness of children and young people's rights.
- Some CYP are entirely reliant upon a parent, carer or professional's advocacy in relation to their rights.
- Unequal relations of power between adults and CYP can impact upon the extent to which CYP feel able to challenge adults about their rights or access to support.

I feel that my rights are right, but sometimes people like argue against it. So say that I wish that we went on a trip to Disneyland, people will say, 'Oh no, Disneyland is for babies' ... it's up to your parents if you don't want to go, and it's up to you as well. **Alice, 10yrs**, expressing her understandings of children's rights.

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.
- Sometimes educational psychologists and senior managers of schools and colleges support parents and carers by raising awareness of their rights and those of their child or with making applications for alternative provision or additional support.
- Parents and carers reported that they had obtained practical or emotional support from independent advocacy services or 3rd sector organisations at some point during their child's education and had found this to be very useful.
- 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 be useful sources of support for parents and carers in terms of raising awareness of legal rights and other SEN matters.

Issues affecting how settings build children and young people's capacity to participate

- Some settings considered that offering an environment conducive to CYP's participation was integral to the wider inclusive ethos of the school.
- Some schools and colleges host events such as coffee mornings or parent voice conferences which signpost information on SEND provision and independent advocacy services.
- Flexibility around the timing of EHCP meetings can be an important factor in facilitating attendance from other education, health and social care professionals.
- There is variability in the extent to which pupils are invited to attend EHCP meetings.
- Some settings have adapted the language and layout of EHCP forms to enhance CYP's engagement. More generally, person-centred practices are considered helpful in building CYP's capacity to engage in EHCP processes.
- Staff in schools and colleges commented that they have encountered problems securing input from health and social care professionals.
- Some institutions considered that there can be inconsistencies in their staff members' understanding and appreciation of children's rights.
- Lack of time and additional resources can impact upon professionals' ability to facilitate CYP's or parent/carer's views.
- Education professionals tended to be committed to supporting a young person's view even when it conflicted with that of a parent or carer.

CYP's participation in their own case

- 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.
- 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.
- 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.

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.

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

I want people to know that this is the way I feel and this is not okay. **Laura, 17 yrs** on the importance of acknowledging negative views.

If you're getting a say in what school you want to go to, which I am, and I really, really, really want to go to a mainstream school but me and mum decided that, deep down inside of me, down there, right in the bottom of your belly. Yeah, I know that I can't, I won't be able to manage. **Noah, 9yrs.**

- In just under half of cases, across the full age range, CYP had no say in which school they attended.
- 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.
- Negative experiences of attending meetings with professionals can deter YP from subsequent engagement in resolving disputes and attending mediations/appeal hearings. It can also impact upon a YP's mental health and well-being.
- 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.

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/3rd 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.

Barnardo's were brilliant in that they could provide her with lots of groups to empower her as a young person. So, rather than her being taken advantaged of type of thing: 'I have rights you know, mum. I don't have to do that if I don't want to, mum.' **Mother of Lizzie, 21yrs** on supporting her child to understand her rights.

I didn't find it too hard but that's 'cause I've been around it [through contact with participatory groups], so I kind of understand what's going on. **James, 16 yrs** on EHCP review meetings.

I like to be given time to devote to my committee. I like to feel that I have a voice and can make a difference. **Jacob, 22 yrs**, on participating in decisions about LA SEND provision.

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.**

Conclusion

Analysis of eighteen in-depth case studies indicates that there are a wide range of intersecting factors and complex issues which affect the extent to which children and young people with SEND are able to access and realise their participation rights effectively regardless of the LA in which they reside. A number of important factors appear to influence children and young people's ability to understand and realise their rights:

- their maturity, disposition and capacity;
- their relationships and family dynamics;
- their and their family's access to resources and knowledge of rights;
- the attitudes of professionals and initiatives which help to build CYP's capacity;
- their prior experience, if any, of collective participation.

Our analysis of children and young people's participation in SEND decisions within the case studies suggests there is still a long way to go before they and their families are able to access the requisite information and support 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. Moreover, regardless of their particular 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.

Children and young people 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. The vast majority of children and young people 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. This underlines the importance of ensuring that children with SEND who are also looked after by the local authority are able to access a comparable level of support from care professionals and independent advocacy services.

The case studies also highlighted that children and young people with SEND are not always afforded an equality of opportunity in being informed about their rights or to participate in discussions and decision-making processes regarding education and support. Issues surrounding professionals' access to resources sufficient to ensure a consistently 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 in these contexts. The levels of autonomy that children and young people are afforded by both parent/carers and professionals are also sometimes limited by a lack of clarity with regard to 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.

The new legal framework and policy have been welcomed by parents, carers and professionals working in the field. There is a broad recognition that an increased focus on person-centred practices and commitment to children and young people's rights to participate in decisions about their education and support constitutes a positive development. However, there are tensions that surround institutional aspirations to offer a more participatory approach which is flexible enough to treat every case according a child or young person's individual circumstances and needs, whilst also securing the resources and material conditions for this to consistently take place across a large variety of settings catering for a wide age range and diverse levels of SEND.

Given the risk that the autonomy rights of children and young people may intersect and overlap with those of their parent or carer, as well as possible disparities between the ways in which different professionals and institutions support children and young people's autonomy in decision making, the need to ensure that children and young people are made aware of their rights and are supported to realise them independently becomes ever more pressing.

References

Department for Education (2014, September 1). News and Communications. <https://www.gov.uk/government/news/reforms-for-children-with-sen-and-disabilities-come-into-effect>

Further information

All working papers and briefings relating to the project **Autonomy, Rights and Children with Special Needs: A New Paradigm?** (Ref. ES/P002641/1) are available at <https://www.ed.ac.uk/education/rke/centres-groups/creid/projects/autonomy-rights-sen-asn-children> and on the website of the Centre for Research in Education Inclusion and Diversity (CREID) at the University of Edinburgh (www.creid.ed.ac.uk). For any enquiries, please contact Dr Grace Kong (creid-education@ed.ac.uk).