



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

## **Working Paper 9 English Case Study Findings**

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## Summary

### 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 groups can enhance CYP's confidence to participate in other contexts.

### 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.

## 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 SEND 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.

### 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.
- 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/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.

# 1 Introduction

The Children and Families Act 2014 (CFA 2014) represents the biggest legislative reform in a generation for children and young people<sup>1</sup> with special educational needs (DfE, 2014). Part 3 of the Act places, through the imposition of a range of duties, significant emphasis on considering and having 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. Children and especially young people are given significant participation rights. Moreover, 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 report concerns key findings drawn from a series of in-depth case studies that sought to explore 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. 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).<sup>2</sup> Working Paper 8 provides a similar analysis for Scotland and also includes a summary of the theoretical framework which has informed the research in both jurisdictions.

Data drawn from 18 case studies of children, young people and their families across three socio-economically representative local authority areas are also informed by the research project's other findings<sup>3</sup>. The analysis contained within this report is shaped by an examination of the following concerns:

- The extent to which children and young people with SEND are able to realise their participation rights effectively.
- The degree to which the autonomy rights of such children and young people intersect with those of parents/carers and are driven by, or influence, the decision-making of schools and local authorities.
- The way in which capacity for autonomous decision-making is understood and acted upon in different social contexts.
- The factors which promote or inhibit the realisation of autonomy rights by children and young people with SEND including those who are looked after by the local authority.
- The impact of a children's rights-based approach on the broader education and social policy landscape.

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<sup>1</sup> A child is someone who is of 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.

<sup>2</sup> 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.

<sup>3</sup> The full collection of working papers can be accessed at <https://www.ed.ac.uk/education/rke/centres-groups/creid/projects/autonomy-rights-sen-asn-children/working-papers>



## 2 Methodology and overview of case studies

Data for the 18 case studies was drawn from semi-structured interviews, classroom observations and activities with children and young people and significant adults involved in their SEND support and decision making (i.e. parent/carers, education and social care professionals). Interview schedules and other research activities focused on eliciting accounts of children, young people and significant adults' involvement in decisions on matters such as school choice, educational provision, funding (including individual budgets, where appropriate), the resolution of disagreements (especially through mediation and appeals), curriculum and planning. The analysis of data contained in this report contrasts the views of children and young people with those of adults, as well as examining adults' views of children and young people's capacity to exercise choice, the ways in which disagreements between adults and children/young people are resolved and how children and young people's rights shape, and are shaped by, educational environments.

### 2.1 Selection of LA fieldwork sites

Prior to undertaking in-depth case study research, a questionnaire was sent to all 152 English local authorities (LAs). It aimed to gather evidence on how the 2014 Act has impacted upon LA practice with regard to supporting children and young people's rights of participation in decisions concerning SEN and provision (Davidge & Harris, 2018). As part of this questionnaire, LAs were also invited to take part in further case study research. Twenty-five LAs expressed an interest in being involved in this phase of the research and three LA fieldwork sites were chosen after careful analysis of the administrative and survey data of all prospective fieldwork sites.

Our case studies are drawn in equal numbers from the three LA areas we refer to as Bigtown, Northshire and Greenshire.<sup>4</sup> These LAs were selected as being representative areas in terms of high, medium and low levels of socio-economic deprivation respectively and of urban and rural populations. A summary of the socio-economic profile and SEN within the school population are shown in table 1. Further demographic details and an outline of the SEND policy and provision context of each local authority can be found in appendices 2-4.

Table 1: LA profiles

	Bigtown	Northshire	Greenshire	Great Britain
<b>Social and Demographic Factors (NOMIS, 2017)</b>				
<b>Total Population</b>	545,500	1,201,900	317,500	64,169,400
<b>Type of LA</b>	Urban	Urban/Rural/C oastal	Urban/Rural	N/A
<b>IMD 2015 Quintile</b>	1 <sup>st</sup> Quintile	3 <sup>rd</sup> Quintile	4 <sup>th</sup> Quintile	N/A
<b>Workforce (NOMIS 2017/18)</b>				
<b>Economically active</b>	72.9%	79.6%	81.0%	78.4%
<b>In employment</b>	69.1%	76.5%	77.7%	75.0%
1-3: Professional/manager	44.1%	40.2%	41.8%	45.9%
4-5: Admin/skilled trade	18.7%	22.0%	23.2%	20.4%
6-7: Sales/service	18.3%	21.0%	16.4%	16.7%
8-9: Manual	18.9%	16.8%	18.5%	17.0%
<b>Education (NOMIS, 2017)</b>				

<sup>4</sup> The names of LAs have been changed in order to preserve the identity of LA fieldwork sites and ensure participants' anonymity.

NVQ4 and above	39.9%	33.2%	31.9%	38.6%
NVQ2 and above	72.7%	75.9%	75.5%	74.7%
No qualifications	11.1%	6.7%	6.6%	7.7%
<b>SEN (DFE, 2018)</b>				<b>England</b>
<b>School population with SEN</b>	15.9%	12.9%	14.5%	14.6%
<b>School population with EHCP</b>	3.1 %	3.0%	3.5%	2.9%
<b>School population on SEN Support</b>	12.9%	9.8%	11.0%	11.7%
<b>SEND appeals registered (rate/10,000 school pop.)</b>	44(4.9)	60 (3.4)	2 (0.5)	4725 (5.5)

## 2.2 Selection and recruitment of case study participants

The authors visited each LA fieldwork site and interviewed senior LA SEND officials in order to negotiate access to children, young people, parents/carers and professionals working in a range of mainstream and special educational settings. During initial interviews with LA gatekeepers, SEND managers suggested a range of participant sampling opportunities which were based on the social and geographical profile of the SEND population as well as offering assistance with introductions to key members of local support and advisory groups (for example, local SEND parent/carer forums).

Within each authority, we adopted a purposive sampling strategy in order to ensure that case study participants included children and young people with different types of SEN situated in a variety of family/care and primary school, secondary school and FE college contexts. Across each authority a range of recruitment methods were used which included the recruitment of families via promotion of the project on parent/carer forum websites; and education and third sector professionals facilitating contact with children, young people and parents or carers who might be interested in the project. It is important to note therefore, that there is a 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 with respective institutions. However, this risk is mitigated to some degree by the inclusion of families who were introduced by third sector organisations or who had self-selected through parent/carer forums; of which some had significant experience of utilising dispute resolution mechanisms.

In all, there are 18 case studies, six per authority. They are focused on children whose primary needs tended to fall within the four most common overall official categories of SEN in England (Riddell et al., 2016): (1) social, emotional and mental health difficulties; (2) moderate learning difficulties; (3) speech, language and communication difficulties; and (4) autistic spectrum disorder. Three of the case studies were drawn from children and young people with SEN who also had experience of being looked after by the local authority. In addition, the selection of case study participants has taken account of other variables such as level of social deprivation (IMD quintile), ethnicity, and age group, and has aimed to reflect an equal gender balance wherever possible. (See Tables 1 & 2.) There has also been an attempt to draw cases from as wide a range as possible of different types of educational setting. (See Tables 3 & 4.) A short description of each child or young person participating in the study is provided in Appendix 1.

Table 2: Case study participant profile

	BIGTOWN	NORTHSHIRE	GREENSHIRE	TOTAL NUMBER OF CASES
<b>GENDER</b>				
Male	3	5	3	11
Female	3	1	3	7
<b>ETHNICITY</b>				
White British	4	5	6	15
African Caribbean	1	0	0	1
Japanese British	0	1	0	1
Pakistani British	1	0	0	1
<b>AGE</b>				
Primary	3	2	4	9
Secondary	2	1	0	3
16-24	1	3	2	6
<b>Primary SEN</b>				
SEMH	1	2	1	4
MLD	0	2	0	2
ADHD	1	0	0	1
ASD	2	2	2	6
SLD	1	0	0	1
SLCN	0	0	1	1
SpLD	0	0	1	1
Sensory Needs	1	0	1	2
<b>FSM</b>	4	0	2	6
<b>LAC</b>	1	2	0	3
<b>EHCP</b>	5	5	4	14

Note: SEMH = social, emotional, mental health difficulties; MLD = moderate learning difficulties; ADHD = attention deficit hyperactivity disorder; ASD = autistic spectrum disorder; SLD = severe learning difficulties; SLCN = speech language and communication needs; SpLD = specific learning difficulties; FSM = free school meals LAC = looked after child; EHCP = education, health and care plan.

Table 3: Family data

	BIGTOWN	NORTHSHIRE	GREENSHIRE	TOTAL NUMBER OF CASES
<b>IMD quintile</b>				
1	4	2	0	6
2	0	0	1	1
3	1	0	3	4
4	1	1	2	4
5	0	3	0	3
<b>Family Composition</b>				
Lone parent	1	0	2	3

Two parents	4	3	4	11
Foster Care	0	2	0	2
Leaving Care	1	0	0	1
Disabled lone parent	0	1	0	1
<b>Parent/Carer/YP Occupation</b>				
1-3: Professional/manager	2	3	1	6
4-5: Admin/skilled trade	2	1	4	7
6-7: Sales/service	0	1	1	2
8-9: Manual	0	0	0	0
Unemployed	2	1	0	3

Table 4: Number of cases drawn from different educational settings

	BIGTOWN	NORTHSHIRE	GREENSHIRE	TOTAL NUMBER OF CASES
Mainstream primary	2	1	1	4
Resourced provision within mainstream primary	1			1
LA maintained, special Primary		1	2	3
Mainstream secondary academy	2			2
Independent special school		1		1
LA maintained special secondary School			1	1
Mainstream FE college			2	2
SEN unit in mainstream college		2		2
Independent, special FE college (residential)		1		1
Supported internship	1			1

Table 5: Number of cases drawn from different governance structures

	BIGTOWN	NORTHSHIRE	GREENSHIRE	TOTAL NUMBER OF CASES
<b>Mainstream settings</b>	4	1	3	8
<b>Resourced provision within mainstream</b>	2	2	0	4
<b>Special school/college settings</b>	0	3	3	6
<b>LA settings</b>				
<b>LA settings</b>	5	2	4	11
<b>Independent settings</b>	0	1	0	1
<b>FE</b>	1	3	2	6

The range of case study profiles and settings outlined above (See Tables 1-4) have informed conclusions regarding how the new framework of rights may be working across different social groups, ethnicities, gender, age and type of SEN or disability. However, it should be noted that due to the small sample size (n=18), it is not possible to make strong correlations between children's, young people's, parents' and carers' experiences and relationships and socio-economic factors. Nevertheless, it is possible highlight issues we have identified as potentially enhancing or impeding the effectiveness of the new framework for children and young people's rights.

### 2.3 Case study research activities

As recommended by Fraser (2003) and Davis (2009), the case study activities and methods adopted for interviewing children and young people aimed as far as possible to be as participatory, non-intimidating and responsive to the particular child or young person's age, type of difficulty and learning environment.

Prior to visiting children and young people in their homes or educational settings, pilot exercises informed by the work of Claire O'Kane (2008) were also undertaken in a mainstream primary school. During the pilot, six children with a range of SEN engaged in up to five prototype activities that aimed to elicit their views and feelings about their rights and promote discussion around their participation in decision making. Discussions with children during the pilot exercises and later consultations with the school SENCO and headteacher enabled the lead case study researcher to refine and adapt activities and interview schedules according to responses to the pilot activities. In addition, proposed activities and interview schedules were often discussed and adapted in collaboration with significant adults who had sufficient knowledge of the child or young person's disposition or difficulties prior to visiting the individual in his or her settings.

Semi-structured interviews and other research activities were also supplemented with half a day's classroom observation per child/young person in order to further understand the ways in which school environments can support the rights of children and young people with SEN.

Children or young people with a range of communication difficulties were sometimes supported by a key worker or parent/carer who assisted them with engaging in research activities or expressing their thoughts and feelings during interviews. Each child or young person was offered a choice of research activity and participated in at least one research interview or activity regardless of communication difficulty, age or cognitive ability. Children and young people were made aware of their rights to withdraw from the research at any stage and one child and one young person communicated their wishes to cease taking part during interviews. Despite this, it is also important

to point out that there remains the possibility that some children and young people participated as a result of compliance with a teacher's or parent/carer's request.

During the course of the case study fieldwork, 40 education, social care and health professionals, 18 children and young people aged between 7 and 22 years and 19 parents or carers were interviewed. Reports written by a range of education, health and care professionals and data drawn from children and young people's education, health care plans (EHCPs), Individual Pupil Plans and Personal Education Plans were also taken into account during the analysis. In some cases, families also voluntarily shared a range of supporting documentation relating to dispute resolution activities.

### 3 Findings

Initial thematic analysis of the case studies identified a range of significant factors influential to children and young people's autonomy in SEND decision-making in a range of contexts. The analysis presented in this report is structured according to the following key themes:

- 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 participation in their own case
- Children and young people's experiences of collective participation

#### 3.1 Individual factors affecting children and young people's ability to participate

**The key factors we identified as potentially impacting upon a child or young person's ability to participate in decisions about their education and care were:**

- **Their level of confidence in their own decision-making skills;**
- **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 groups;**
- **Their knowledge of rights to participate in decisions about their support.**

Below are a number of empirical examples which illustrate some of the inherent factors which can affect children and young people's ability to participate.

##### 3.1.1 Difficulties in making choices

A number of case studies revealed that some children and young people with SEN find the process of making autonomous decisions stressful and that being given extensive choice in decisions was not always helpful. Some of the children and young people considered the presence of familiar adults and the limited choices that were available were important factors which assisted with decision making processes.

*Noah's* case provides a good example of this issue. Noah is nine years old and has SEMH difficulties. He was removed from his birth mother and siblings when he was five years old and is currently living

with a foster family. He described how his condition can sometimes cause difficulties in his relationships with others and can affect his ability to make decisions about his own or other people's safety. He finds that his difficulties around understanding the consequences of his actions can impact upon his confidence to make autonomous decisions safely. His view, as set out in his EHCP, is:

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.

Another child, *Samuel* is also aged nine and has SEMH difficulties. He has some autonomy in decision making at home with his foster carer but this is also limited by his need for structure and security. This underlines the extent to which difficulties in deliberating a number of choices may also inhibit children and young people's autonomy in other decisions about their education and support. For example, *Samuel's* foster carer pointed out that he can experience difficulties coping with any major changes to routine and as a consequence of this she tries to ensure that there are always firm boundaries with regard to his behaviour and explained that she only offers limited choices in terms of his engagement with the rest of the family when planning new leisure activities:

There's a much greater need for boundaries for *Samuel*, without the boundaries he tends to get very wobbly, if things go out of routine, he'll tend to get very wobbly and struggle to cope, so I have to keep it quite fixed.

Other cases illustrated examples of how children and young people's SEN or disposition impacted on their ability to make a choice or challenge an adult's view in their everyday lives. In addition to this, significant adults often remarked that these children and young people could be very compliant and were sometimes heavily reliant upon other adults making decisions on their behalf. The examples below illustrate typical comments made by adults about children and young people who had difficulties making decisions independently.

Regarding *Peter* (16 yrs, ASD):

Because he struggles to make his own decisions, he sort of goes along with what mum and dad suggest and what they say goes, really. (Learning Support Assistant)

I literally could say to him, right you're going to [local college] and you're going to do that, and he'd go okay. 'Cause he'd want to be told, 'cause he literally cannot make those decisions yet. (Peter's mother)

Regarding *Ben* (10yrs, SLCD/MLD)

He will say if it's something that he doesn't want to do, but he doesn't always find the decision making easy... [At home] I suppose he just goes with the flow of the family so, yeah if we're going for a walk, yeah he'll get his shoes and his coat and off he goes. (Ben's mother)

The father of *Kei* (17yrs, MLD) also drew attention to the fact that some children and young people may be less likely to challenge another person's view and tend to be more compliant with significant adults:

He's very easy-going, very placid. He doesn't like--, he's not confrontational at all or anything like that.

His key worker also added that Kei has grown in confidence during his first year at the college and concurred with his father in that:

He never expresses any dislike or if he does find things difficult, then he doesn't complain about anything or say he doesn't like it. He just kind of gets on with things.

### 3.1.2 Degrees of confidence

*Maleeha* is a twelve year old girl with albinism who has impaired vision. Her case illustrates how children or young people's level of autonomy can also be impacted by factors which appear to be unrelated to their SEN. In this example, Maleeha's self-consciousness and lack of confidence in her own ability to make autonomous decisions affect her capacity to make autonomous decisions and express her need for support independently. For example, despite Maleeha's father considering his daughter to be 'responsible and mature beyond her years', in discussions around how she might choose which FE college to study at in the future, she indicated that she lacked confidence in her ability to make such a decision independently:

I'd go with my parents, I can't make such a decision like that on my own, I'm not--, I'm a bit--, I can't... I'm just, I don't think I know.

Maleeha also found it difficult to ask the class teacher for adjustments to be made in terms of her support needs and explained that she sometimes relies upon her learning support assistant to do this on her behalf. Her father also commented that there have been occasions where Maleeha has expressed reticence in voicing her need for additional support on account of feeling that she, 'didn't want to waste the rest of the classes' time, just because of me'. He also highlighted that although Maleeha understood that she had a right to express her need for additional support to access class resources, she was very self-conscious about expressing her needs due to concerns about what her peers might think.

Conversely, *Jacob*, a 22 year old care-leaver with SEMH difficulties and autism, has experience of participating in children in care councils. He explained that as a result of engaging in various participatory groups for young people, he has developed more confidence in expressing his rights and in making decisions around how he is supported.

For children and young people with a limited capacity to communicate verbally, confidence in participating via other means appears to enhance interaction and participation with peers and significant others. *Ben* is 10 years old and has SLCN and MLD. His class teacher stated that Ben was quite resilient and often found his own way of communicating with his friends:

He's quite robust really. He's confident, he doesn't, you know, take himself away. He just mixes with his friends. And there are other ways of communicating by gesture, facial expression. And just by your body language and the way that you act, he will mix with his friends really well. (Class teacher)

In addition, the presence of a significant adult who was very familiar with a child or young person's preferred mode of communication greatly improved the extent to which case study participants with SLCN were able to articulate their views and feelings during research interviews.

The majority of children and young people with some knowledge of their rights expressed some reservations about challenging adults about the degree of support that they receive, although there were also some exceptions. For example, *Laura* (17yrs, SpLD, 3<sup>rd</sup> quintile) has been proactive in asking for additional support at college and demonstrates autonomy and knowledge of her right to



negotiate access to additional support verbally or via email with course tutors and the learning support coordinator. Laura, with her mother, requested the local authority to do an EHCP assessment. However, she expressed unawareness of many of her other rights, particularly in relation to the amount of support to which she is entitled. She appeared to lack both confidence in her ability to challenge decisions and knowledge of her rights regarding redress.

### 3.1.3 Communicating with un/familiar adults

Case studies with children and young people who experience difficulties as a result of lack of continuity with or changes to their familiar routines also highlighted that the presence of unfamiliar adults can sometimes inhibit their ability to participate or communicate their views and feelings. For these children and young people, the support of a significant other helped to ameliorate some of these difficulties, albeit to varying degrees.

For example, *Maria* is nine years old and has a diagnosis of severe persistent learning difficulties. She attends a mainstream primary school and is supported by a teaching assistant for 25 hours per week. Maria is described as a confident member of the class who is very able to express her views with familiar adults and peers but struggles to articulate her views and feelings in unknown contexts or with unfamiliar adults. For example, Maria's class teacher describes her as 'quite feisty' with her peers:

Like I say, she's really confident, she knows her own mind, she's quite a strong-willed little thing. She's quite feisty... She won't take any messing, as small as she is... (Class teacher)

However, Maria's teaching assistant also drew attention to how Maria requires consistency with support staff and that she could be shy and quiet with strangers. (Shyness with unfamiliar adults is highlighted in Maria's EHCP.) This was also evidenced during research fieldwork when Maria was able to articulate her views in much more depth when her teaching assistant was present.

A number of cases also confirmed that the presence of a well-established relationship with a significant adult who has an understanding of a child's social and emotional difficulties can sometimes help a pupil to avoid conflict or reduce the risk of further exclusion from participating in everyday school life. For example, *Alice* (10 yrs old, ADHD) has difficulties participating in unstructured times with her peers and can also struggle with conforming to expected behaviour within the classroom. The understanding of the class teacher appears to be crucial factor in managing conflicts between Alice and her peers or in pre-empting difficult social situations.

It [getting into trouble] usually starts when [class teacher] is not in class. It's always I'm getting into trouble... I feel really upset, because I don't like it, I get in trouble all the time when [class teacher] is out of class. (Alice)

Another case, concerning *Claire*, who is 18 years old and has SEMH difficulties, illustrates how some children and young people feel much more able to assert their independent opinions. Claire also said that she felt confident enough to challenge a teacher if she felt that something was unfair.

R: I'm quite, like, strongly opinionated...

I: If there's something you feel is unfair, would you feel able to talk about that?

R: Yeah, I let my teachers know.

The case of another younger pupil illustrated that being articulate and having the confidence to express oneself with ease does not always guarantee full realisation of one's participation rights. *Chloe* is eight years old and has a diagnosis of ASD and MLD. Chloe regularly contributes to

classroom discussions, indeed dominates at times. She is encouraged to express her views and opinions and occasionally the class teacher needs to remind her to give her peers a chance to speak as well. During the research interview and activities, Chloe was very articulate and demonstrated a sound appreciation of her rights. For example, she demonstrated confidence in expressing her feelings of boredom and realised her right to end the research activity with ease. Chloe's teacher described her as a, 'very talkative child' and explained that Chloe's tendency to dominate conversations and talk 'non-stop' was a factor that prompted reservations about inviting her to her forthcoming EHCP review:

I don't know whether I'll take Chloe because, you know, like Chloe can talk. We could have a review that will last all afternoon if I took Chloe in, so I'll sit them down and talk to them about it and I think as they get older, then they do [participate]. (Class teacher)

#### 3.1.4 Understandings of social norms/cues

A number of parents, carers and teachers frequently remarked that children and young people with autism were often 'very literal' in both their understandings of particular concepts and also in expressing their views and feelings. However, in cases where the children and young people were not inhibited by responding to traditional social norms, they appeared to have an enhanced capacity to express themselves frankly and this could be viewed as facilitating a more authentic experience of participation in certain contexts. For example, when asked about *Frank's* ability to express his views, his teacher commented that he was 'quite literal' and candid about his feelings about particular tasks or subjects and that this strengthened his ability to assert his views and challenge the relevance of elements of the curriculum:

Regarding *Frank* (9 yrs, ASD/MLD)

He's quite literal, so if he was being taught something specific, he would probably turn around and go, 'Well what's the point of that? What do I need this for?' So, he will challenge and he will ask, and he's actually quite succinct in how he says it, so sometimes he'll go 'I don't want to do that, so why do I need to do it? That's a silly thing to ask.' Which fair enough, he knows his own mind. That's fairly understandable. (Class teacher)

Frank will, he's not going to hold back. If he does want to do something, you know, that's great, so he's very vocal. (Mother)

#### 3.1.5 Values and knowledge of rights

Although *Laura* (17, SpLD) demonstrated varying degrees of confidence in speaking to different adults regarding the level of support she was able to access whilst studying for her A-levels at sixth form college, she had strong views about her capacity to navigate a number of other obstacles that she felt had inhibited her access to additional support. Both *Laura* and her mother demonstrated that they valued the importance of 'finding a way' to participate as fully as possible in any decisions concerning access to SEN support, despite acknowledging that they only had a limited knowledge of their legal rights. When asked what she understood by her rights, *Laura* said:

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'm sure that somewhere there is someone with a bit of paper that says that if you need help there should be more. But I don't know. 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.

Some children and young people drew attention to inequalities between adults' and children's rights and felt that adults were more likely to be listened to or successfully challenge over the types of support provided in school. For example, *Peter* (16yrs, ASD, 4<sup>th</sup> quintile) understood his right to be listened to and to be treated equally to adults. He was aware of the school rules around pupils not using their mobile phones in lessons and viewed it as unfair when teachers used their phones in lessons sometimes. He also expressed the view that it was important for people to know how he is feeling in order to understand if he 'was not feeling right', and accommodate his support needs. Peter also highlighted the importance of free-speech and understood this as meaning having the right to express his views, but not 'being racist'.

## 3.2 Family relationships and dynamics

- 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.
- The importance of consistent advocacy support was underlined in cases where a child or young person did not have support from a parent/carer.

This section concerns the ways in which children and young people interact with their parents and carers, particularly in relation to articulating their views and contributing to decision-making. The analysis considers the extent to which the intervention of parents and carers can either inhibit or extend children and young people's autonomy and participation in decision-making processes.

Two-thirds of the children and young people lived with other siblings, and in some cases with siblings with SEND. One parent also shared a diagnosis of autism along with her son and highlighted the extent to which she felt that this enabled her to relate to her son's difficulties. Two children were on long term foster placements and one young person was also a carer for his disabled mother. Another young person lived independently and was supported by a care leaver worker.

### 3.2.1 Parent/carer perceptions of their child's 'best interests'

A number of the parents were particularly keen to support their child's autonomy in order to advance the child's 'best interests'. Parents and carers of children and young people who have difficulties with understanding the consequences of their actions or difficulties coping with changes to routines highlighted a number of challenges around supporting their child to develop greater autonomy with independent decision making. One of them was the mother of *Peter* (aged 16). She gave the example of a recent decision about who is authorised to manage his DLA (Disability Living Allowance):

I've just had to be interviewed by the DLA about whether he can have control over his DLA... Well no he's not having control over his DLA because--, they said it automatically transfers into his name when he's 16 unless we filled in a form to say that we didn't think it was a good idea. Which I don't because he's terrible with money and, you know, he's in the past stole money, spent thousands of pounds on computer game points and stuff so there's no chance that's he having that until he's 18.

However, she added that she and her husband are also beginning to try and teach their son to be able to engage in other decision-making activities in preparation for adulthood:

Actually, my husband and I include him in everything because we want him to start to make those decisions, which is why I force the decisions of 'what do you want, this or this?' You know, [he's] got to start making decisions.

Other parents of younger children with different types of SEND highlighted that concerns about how their child's health, safety and well-being can affect the child's ability to participate in decisions about their care. For example, although *Jack's* parents felt that they supported him to have a say on decisions regarding general everyday matters such as what to wear or eat, they also considered some issues regarding his health to be non-negotiable:

There are certain things like he hates having blood tests; absolutely hates them. And he has always said, 'I don't want them. I don't want them. I'm not having them done.' But he has to have them done. He hates having eye drops, because when he has eye drops, they dilate his pupils and then he has seizures. And he doesn't want them because of that... So there are decisions that we make, that we kind of say to him, 'Well no, you've got to have this done.'  
(Father of Jack, 7 yrs, visually impaired)

Other parents and carers also indicated that they intervene in other decisions that concern the 'best interests' of their child, despite the child or young person expressing opposing views. For example, *Aiden's* parents stated that they fully support their son to contribute to family decision making and regularly consider his views and wishes. However, they said that they also go against their son's view in matters important to his development or that might impact upon his safety.

### 3.2.2 Families supporting CYP's autonomy in the home

A number of parents stated that their child was very able to express views and opinions and had much autonomy at home. For example, *Chloe's* mother considered that her daughter had a lot of say in decision making:

She chooses everything she wants, what she wants for tea, when she wants to get up, what she wants to wear. She is very much her own boss at home... Yeah, she chooses where she wants to go at weekends and she doesn't always get her way because it's usually shopping and spending money that she wants to do but yeah, she does have a lot of own say and she has a lot of her own rights at home. (Mother of Chloe, 8yrs, ASD/MLD)

A parent of another child, *Aiden*, commented that being the only child in the extended family, her son had a say in 'everything':

Because we're a small family, *Aiden's* in the middle of everything really. And rightly or wrongly, we put *Aiden* at the centre of everything. Not to say that we spoil him, you know, but yeah. (Mother of Aiden, 13yrs, ASD)

*Claire's* mother, although she has strong opinions about some of the decisions her daughter makes, considered that the *Claire* has a large degree of autonomy at home and ultimately makes her own decisions:

Well she decides, I strongly guide her... I mean she basically makes all her decisions in the house in a way because she doesn't like change...if she won't do something, you know, she

decides she doesn't want to do something, she won't discuss the future. (Mother of Claire, 18 yrs, SEMH)

### 3.2.3 Parents/carers advocating of behalf of their children

A number of case studies also highlighted occasions in which a child or young person actively sought out a parent or carer's support with communicating their needs and wishes or supporting their wider participation in activities when they felt unable to do this independently. For example, *Maleeha* (12 yrs, visually impaired) referred to occasions when she had asked her parents to advocate on her behalf when she was having difficulties at school. She gave one example in which she had been unable to complete a test within the specified timeframe on account of not having magnified materials to work with. She explained that she was able to voice her need for some additional support when this happened but that she had needed to speak with her Learning Support Assistant and parents about it after the event in order to be able to elicit their support with negotiations to re-sit the exam.

There were also a number of cases in which children or young people reported that they had experienced difficulties arising from educational professionals' poor understanding of their condition and support for their needs. In these cases, parents or carers often liaised with key members of staff on their child's behalf. For example, one parent described how she occasionally intervenes on behalf of her daughter at college when the latter is experiencing mental health difficulties. The college does not usually communicate with parents to discuss a student's support needs once they reach the age of 18. However, *Claire's* mother continues to liaise with her daughter's personal tutor to ensure that other members of staff at the college are also aware of her difficulties in order to prevent further exclusion.

Whenever I've had difficulties, someone's been upset, someone's been rude, someone's been like threatening her, the teachers to kick her out again, I emailed this head of student services, and she said, "Don't worry, I'll have a word. She was getting threatened with being expelled, and [personal tutor] was there, and I said to her, "Listen, Claire's getting quite anxious again, she's got PTSD," ... These people [other members of staff], they don't get it, and she starts pulling her eyebrows off, but [personal tutor] understands that, and [personal tutor] talked, you know, they go, "Oh well that's different, oh that's different then, if you're saying Claire has these difficulties". (Mother of Claire, 18yrs, SEMH)

In another example, *Kei* explained that his father had helped him to voice his need for 'the right help' after he experienced difficulties in school:

Well there were [difficult] times but I got through it and my dad helped me sort it out and stuff. The amount of support [at school] wasn't that great. The last year one [teacher] didn't have a clue at all so my dad said if he could talk about my support. One of the teachers in Year 11, she was very interested about them and she chatted to my dad about it. She learned all about my coordination problems and she helped me the best way she can in it. The right help. (Kei, 17yrs, MLD)

Another parent felt strongly about being proactive in promoting her child's rights and has been instrumental in articulating her daughter's SEN support needs since primary school. She drew attention to the close relationship that she has enjoyed with her daughter and highlighted how much the dialogue between them has enabled the two of them to work together and find alternative means of accessing the support that she needs:

We've always sort of said that... talk to me about anything. I can't promise that I'll like what you tell me, but I'll always try and help you, always try and work it out. And I think because of the way we've tried to access things; giving Laura this toolbox of how to manage things and how to process things and do, we've always had a very good dialogue. And I'm really proud of that.' (Mother of Laura, 17yrs, SpLD)

The case of *Jacob* (22 yrs, SEMH/ASD), who is also care experienced and does not have a family member to support him, highlights how even when young people appear confident in making their own decisions, assistance from other adults who acknowledge and support their rights can still be important to support the development of greater autonomy. Jacob said it was also important to him to be able to have some consistency and agency around who he chose to support him and with regard to which professionals had access to information about his life. His leaving care worker (LCW) explained that she has known Jacob for over six years and that they enjoy a close relationship. Jacob said the LCW had offered significant support, especially during periods of insecurity regarding decisions about where he is placed and when he wanted to have a say about where he lives. Jacob's LCW also underlined the importance of listening to Jacob and trying to emphasise that he had a stake in decisions about who had access to information about him and his past. This case also underlined how changes of support structures and redeployment of staff can also impact negatively upon the level of assistance available to children and young people who are care experienced receive for realising their rights. Jacob found coping with a recent redeployment of staff with whom he had developed good relationships was especially difficult for him to manage in light of his SEN.

### 3.3 Socio-cultural factors and awareness of SEND matters

Among CYP and their parents or carers there appeared to be some correlation between levels of deprivation, access to cultural resources and degree of knowledge and awareness of SEND matters. However, this was 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.

On the whole, most parents or carers appear to have at least some, albeit often limited, knowledge of their legal rights although quite varying degrees of cultural awareness of SEND matters more generally. There are a number of statutory duties placed upon LAs to produce, publicise and consult with young people and families regarding the area's 'Local Offer'. A local offer displays information about local SEND services. Just over half of parents and carers consulted as part of the case study research were unaware of the local offer<sup>5</sup>. There appears to be some correlation between social deprivation and parent/carer awareness of legal rights. For example, almost all parents and carers living in the 1<sup>st</sup> and 2<sup>nd</sup> quintiles of the IMD 2015 had very limited awareness of SEND matters or of the local offer and tended to rely upon advocacy services or education professionals to navigate SEND issues. However, there were also a few exceptions to this. For example, a foster carer of a

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<sup>5</sup> The CFA 2014 (s27) sets out a duty on LAs to keep the local provision of education, training and social care for children and young people with SEND under review and also requires LAs to prepare and maintain the 'local offer'(s30). LAs also have a duty to consult with young people and parents/carers in the development of the local offer, invite comments from users of the local offer and to publish these (at least annually) along with details of any action taken by the LA in response to these views. (See further SEND Regulations, 2014 (SI 2014/1530), Part 4, which sets out the LA's statutory duties regarding the local offer)

young person with autism appeared to have a good understanding of SEND matters and corresponding rights and lived in the 1<sup>st</sup> quintile. Parents and carers living in the 4<sup>th</sup> and 5<sup>th</sup> quintiles were more likely to have heard of the local offer and had some knowledge of their rights. Families living in the 3<sup>rd</sup> quintile demonstrated some awareness of their rights and half of these parents were aware of the local offer. However, given the very small sample size (n=17) it is not possible to draw substantive conclusions regarding relationships between socio-cultural factors and awareness of rights. Nevertheless, we found good examples of how intersecting factors appear to contribute to parents' or carers' knowledge of their rights and other SEND matters.

### 3.3.1 Factors affecting parent and carer's cultural awareness and knowledge of rights

#### *Access to information and resources*

A sufficiency of time, capacity and cultural resources to access professional and/or informal SEND networks contributed significantly to the level of awareness of rights among parents/carers. Moreover, families able to access appropriate information autonomously or with the support of a range of third sector or educational professionals appeared to be better equipped to challenge aspects of their child's education and support. For example, *Peter's* mother believed she had had good support with realising her rights but had also been very proactive in ensuring that she could 'manipulate the system' through being heavily involved in the life of a school as a chair of the PTA. However, *Peter's* mother also went on to add that if she had to work full-time she was unsure whether or not she would have had the same opportunities to research her rights and network with other parents or consult with professionals:

I got off to a good start with the primary school... I made myself heavily involved so that I could get access. So in that way I've sort of manipulated the system as well so I was sort of chair of the PTA for eight years and became a really key part of the school so then I had access to SENCOs just all the time, not in terms of oh can we have a meeting, but I'd be at a Christmas fayre and the SENCO would be working with me and I'd be like oh blah, blah, blah. I did that on purpose so that I could sort of understand the school better and, you know, the teachers saw me differently because I was giving a lot back to the school so in a way I sort of manipulated the system as well. (Mother of Peter, 16yrs, ASD, 4<sup>th</sup> Quintile)

*Peter's* mother also considered that the support that she has received from a number of charities and professionals, alongside her background and education have been instrumental in her being able to press her son's rights:

You have to fight for everything I don't feel like it's made obvious and I think it helps that I'm educated myself and I know what I'm allowed, I'm entitled to. And I talk to a lot of other educated people who've been through it and are like you need this, you need to get that...other parents, friends who have got older children or... I think he's lucky to have somebody behind him who knows what he's entitled to because I think if you weren't as educated or, you know, maybe we didn't have access to the same things you would miss out on a lot of stuff.

Access to requisite financial resources for obtaining advice and information from independent professionals was also highlighted as important. For example, the parents of *Lizzie*, a 21 year old with MLD/ASD, living in the 5<sup>th</sup> quintile, explained that despite the financial burden, employing an independent third party enabled them to draw upon information and expertise that challenged the LA in a manner which they could not have achieved by themselves. *Lizzie's* mother was aware of the

local offer, but did not trust the sources of independent support it listed and had relied mainly on Barnardo's and their independent legal advocate.

The case of Maleeha offers a counter example, however. It demonstrates that higher levels of cultural capital and education do not guarantee parents' and carers' ability to access appropriate information relating to their rights. Maleeha's family live in the 3<sup>rd</sup> quintile and her father has a doctorate. Despite numerous requests to his daughter's primary school, her father only became aware that he had the right to request an EHCP assessment as a parent (rather than rely upon the school to do this on a parent's behalf) after a chance conversation with a colleague who has a child with SEN. Maleeha's father went to considerable lengths to find out more about how he could enable his daughter to access additional support from a teaching assistant. He felt that he had to be 'very stubborn' in his approach to ensure that his views were listened to and for his daughter to be able to access her rights. He stated that he did this 'completely unsupervised, with no script'.

In another example, the mother of *Lyron*, a nine year old boy with ASD living in the 1<sup>st</sup> quintile explained that she had hoped to be able to retrain and find employment once her son started nursery school. However, as a single parent she has been unable to study or work due to her son experiencing many difficulties adapting to a mainstream educational environment, which eventually resulted in him being put on a part-time timetable and subject to numerous exclusions. *Lyron's* mother commented that, alongside support received from SENDIASS<sup>6</sup>, her position as a full-time carer has afforded her the time to advocate for her son's rights and eventually secure a place for him within a resource provision. She also demonstrated that after receiving support and information from SENDIASS, if she felt the need to challenge any aspects of her son's support, she now had the confidence and a sufficiency of knowledge of her rights to do so.

#### *Engagement with parent/carer and other support groups*

Other parents were a source of helpful information to case study parents/carers with regard to SEND matters, as were parent/carer support groups and third sector organisations such as Barnardo's which had participatory groups to which their child belonged. For example, *Lizzie* (MLD/ASD, 21yrs, 5<sup>th</sup> Quintile) belongs to such a group and her parents liaised with members of staff within the group to enable their daughter to lobby the Children's Commissioner for England regarding her appeal to be placed at her preferred FE college. In another case, despite not being aware of the local offer or any advocacy services for parents and children with SEND, the mother of a ten year old boy with SLCN living in the 3<sup>rd</sup> quintile explained that she had become aware of the CFA, 2014 and new rights for young people aged 16-25 through one of the local parent and carer forum magazines. Another parent, of a seven year old visually impaired boy living in the 3<sup>rd</sup> quintile commented that he had found 'mumsnet'<sup>7</sup> and the advice gained from other parents more useful than the local offer.

#### *Difficulties navigating information about SEND and legal rights*

The mother of a ten year old girl with ADHD living in the 1<sup>st</sup> quintile commented that she was unaware of the local offer or of any advocacy groups that might be able to assist her with supporting her daughter to realise her rights. She explained how she relied upon the knowledge of a friend:

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<sup>6</sup> Special Educational Needs and Disabilities Information Advice and Support Service or SENDIASS is a free, confidential and impartial service for parents and carers, children and young people. See for examples, [www.kids.org.uk/sendias](http://www.kids.org.uk/sendias)

<sup>7</sup> This is a popular parenting forum and website. See <https://www.mumsnet.com/> for examples.



R: I'm quite lucky that my best friend, she's got a son with ASD. So, we're always together... 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, do you know?

I: Where would you have turned, do you think?

R: I haven't got a clue. I really don't.

In addition, this parent also commented that as a mother of two children with SEN, finding the time to access appropriate information was a challenge. She said that despite accompanying both of her children to a substantial number of SEN appointments, she still lacked knowledge of many of her rights. The child's school's SENCO explained that parental reticence to accept that their child may have a special educational need can also be obstructive to the taking up of participation rights in relation to the child's support needs:

The parents that we have, you know, here, they're more bothered about the child getting a good education... they don't really seem to take into consideration if they do have needs or they don't want them to have, you know, have needs and things like that... They're quite in denial sometimes... and the ones that have, I don't think it's not because they don't want to know, it's just they probably wouldn't know where to look to find out the information of what their rights are... I feel if they did have the information, then a lot more might actually probably do something with it.

In another case, a young person acknowledged that as she has matured, she has taken a much more independent role in voicing her own views and opinions about decisions relating to the level of additional support she receives in college. However, despite this, her mother expressed regret that, due to a prolonged period of ill-health, she had felt unable to support her daughter with negotiating additional support at college:

I've not quite engaged enough for it to have worked in the way that perhaps she would have liked it to have done... I feel responsible that I should have been able to... I'm fairly intelligent, but I just haven't cracked this nut at all... Well I get exhausted. Post-stroke, I don't quite have the stamina that I did before. And I try very hard, but I just can't always do it, unfortunately.  
(Mother of Laura, 17yrs, SpLD)

*Aiden's* mother highlighted that another barrier to knowledge for some parents was their own SEN. She explained that while being aware of the local offer and of local initiatives that encouraged parents to attend forums to express their views and learn more about local provision, she felt very anxious about attending events in unfamiliar contexts and felt too daunted to join the local parent and carer group:

I receive emails about going to meetings and [sighs] I have to be honest, I've never been... The reason being it's quite daunting. It really is quite daunting to go along to something like that because as a special needs mum and 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)

*Aiden's* mother discovered alternative ways of accessing the information she needed and spent a considerable amount of time independently researching her rights and the SEND Code of Practice online in order to ensure she had the necessary information. However, despite acquiring a better knowledge, she still felt undermined by one particular staff member at the LA who questioned her

understanding of the SEN Code. This parent said that her difficulties as a parent with autism herself were not considered or respected whilst trying to advocate on behalf of her son.

#### *Confidence to challenge professional expertise*

There were a number of cases that highlighted a parent or carer's reliance upon the expertise of educational professionals. In these cases, parents or carers had little knowledge of their rights and often lacked confidence in their ability to navigate EHCP processes. For example, *Chloe's* mother was not aware of the CFA 2014 and also felt very unsure about her rights as a parent of two children with SEN. She found it difficult to articulate her understanding of children's rights and felt she had not had much of a say about her children's education. *Chloe's* mother also acknowledged that she has the opportunity to comment upon the type of support that her daughter receives at school through the EHCP review process but had never heard of any advocacy services such as SENDIASS and lacked confidence in challenging the expertise of educational professionals:

You can comment back on it and send it back in if there's anything you want changed or doing differently. But I think they know better than me with things like that... I [know that] you can take people with you. 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)

Likewise, *Ben's* mother was unaware of the local offer and added that she does not feel well informed about the EHCP process and has tended to rely on professionals as, 'they know what they are doing'. She felt unable to challenge her son's SALT provision due to lack of confidence and a resignation borne out of a feeling school resources were already overstretched:

Maybe that's a little bit of ignorance on my own behalf by not looking into it further. I tend to let the school lead the way because I think they're the professionals and they know what they're doing. (Mother of *Ben*, 10 yrs, SLCN/MLD, 3<sup>rd</sup> quintile)

Other parents also expressed reticence to challenge their rights due to concerns about being seen as interfering, as a 'parent that's always on the phone':

Have we got rights? I don't know. I think we're all just trying to do our best for our kids. And if you happen to have a child that has a particular need, you're that parent that's on the phone, aren't you?... we're determined to help *Laura* the best, but I don't know that us sort of banging fists on tables is actually going to be delivering enough for *Laura*. (Mother of *Laura*, 17yrs, SpLD, 3<sup>rd</sup> quintile)

In contrast, one class teacher based in an area of high deprivation observed that, although most parents were largely unaware of their formal rights under the legislation, many did not lack confidence in pushing their child's rights and their right to be treated fairly. For example:

I don't know if they know they actually do [parents know about their rights]. But the parents round here... they're not nervous to approach anyone. So they're quite forward, and they'll just come and say things to you. I don't know whether they realise it's their right, but they do it anyway. So, it's not... they're not nervous of coming to speak to us. (Class teacher)

### 3.3.2 Factors affecting CYP's cultural awareness and knowledge of rights

Regardless of parent/carer socio-economic status, the majority of children and young people felt that their views, wishes and feelings were taken into account within their respective educational

settings. However, there were also a number of children and young people with experience of formal exclusions who felt very strongly that their views and feelings had not been respected. Very few children and young people were aware of SEND matters or their legal rights, and those that demonstrated some awareness tended to have experience of participating in LA or 3<sup>rd</sup> sector SEND participatory groups or had received support from significant adults informing them of their rights.

#### *Access to collective SEND participatory groups*

Almost all of the children and young people participating in the case studies were not aware of the local offer. The two exceptions to this were drawn from cases in which young people regularly engaged with third sector participatory voice groups and had been involved in LA consultations around the design of the local offer website or had engaged in LA youth councils. Unsurprisingly, these two young people were also much more knowledgeable about their legal rights. In the case of *James* (16yrs, ASD/SpLD, 4<sup>th</sup> quintile), his extensive knowledge of his rights and engagement at an international conference on children's rights also led to his mother developing greater awareness of her rights as a parent of a young person with SEND. Most children under the age of sixteen tended not to have extensive knowledge of their rights or engage in participatory groups.<sup>8</sup>

#### *Parent/carer's support and knowledge of rights*

There were only two cases of children (aged 12 and 16 years old respectively) who themselves had a particularly high awareness of their rights, and their parent had been instrumental in this. Both families lived in the 3<sup>rd</sup> and 4<sup>th</sup> quintiles and had dedicated significant resources in support of their child's access to SEND support.

A number of parents and carers demonstrated that they have actively supported their child to become better acquainted with their rights by encouraging them to join local SEND participatory groups. For example, Lizzie's parents said that their daughter's involvement with Barnardo's and their own support contributed to her understanding of her rights:

I'm really sure that, without the sort of building blocks of what we've done as parents, and of what places like Barnardo's had done to empower Lizzie a lot ... 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, MLD/ASD, 5<sup>th</sup> quintile)

Frank (9yrs, ASD/MLD, 4<sup>th</sup> quintile) was unaware that he has an EHCP and stated that he had not attended nor been invited to any planning meetings. Frank was also unaware of having any input into completing 'Section A- All about me' of his EHCP or a 'one-page profile', although the plan does state his views. Frank was also unaware of any children's rights or of the local offer. He was unsure what he might do if he felt that something was unfair about his education but added that if he was feeling unhappy about school he would, 'tell my mum and try to fix it or something'.

In contrast, *Maria*, a girl with SLD requiring substantial one to one support within the mainstream classroom appeared to feel unable to challenge the type of support that she received and could not

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<sup>8</sup> Some 3<sup>rd</sup> sector organisations such as Barnardo's offer a range of participation services which bring together groups of children and young people with SEND or who are care experienced. These groups aim to inform them of their rights, facilitate discussion groups as well as undertaking work on behalf of LAs and other organisations in order to support children and young people to have a say in the provision of local services. Participation services are also sometimes commissioned by LAs as a means to facilitate wider strategic consultation with children and young people about local care and SEND provision.

rely upon her parents to do this on her behalf either. Both she and her mother appeared to be fully compliant and accepting of any 'help' that was offered:

I: if you weren't happy, for example, and you went home and said, 'Mum, I really don't like [TA] helping me.' Or, 'I don't want to come out of my classroom and have my help, I want to do it in the classroom' do you think your mum and dad would come into school and talk to somebody about it?

R: No. (Maria, 9yrs, SLD, 1<sup>st</sup> quintile)

### *Capacity to understand the concept of 'rights' and ability to realise rights*

Children and young people's differing levels of ability and understanding about their rights stems from a difficulty with the concept of a 'right' or a lack of familiarity with rights more generally, including rights under the CFA 2014 or the United Nations Convention on the Rights of the Child, with the exception of those who regularly engaged with specific SEND participatory networks.

Nevertheless, a number of children and young people demonstrated tacit understandings of their rights to be respected and have their views and wishes taken into account and often gave examples that related to their experiences of voicing an opinion in school or of everyday decision making at home. For example, when *Alice's* understanding of her right to express her views and for these views to be taken seriously was illustrated by her expressed desire to visit Disneyland and her awareness that she had a right to her own independent opinion even if the parent also had an important say in decisions:

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. Are you a baby?' And I'll be like, 'No.' But it's not... that's your opinion. So it isn't up to you, it's up to your parents if you don't want to go, and it's up to you as well. (Alice, 10yrs, ADHD, 1<sup>st</sup> Quintile)

*Jack*, however, 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. However, when engaged in an activity creating a decision-making chart he appeared to have a much sounder grasp of how he was positioned to make decisions about different aspects of his education and support and was able to state areas in which he felt that he had more or less say in decision making.

And for other children, the act of being listened to or of being involved in making a decision or instigating a change to school policies supported a deeper understanding of the consequences of realising their rights, despite not fully understanding them. For example, *Lyron* (8yrs, ASD) was not aware of his legal rights and did not know that he had an EHC plan but had attended his EHCP review and presented his views about how he would like to be supported. He had felt that staff at the school listened to him during his last EHCP review and he believed that people were listening on the basis that they 'actually responded to what I was saying'.

## 3.4 External sources of support

- Case studies indicated that independent advocacy services provided by independent advocates such as SENDIASS, as well as key educational professionals, can offer important practical and emotional 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.

This section considers the importance of different sources of support for children, young people, parents and carers in engaging with schools and local authorities regarding SEN matters. Analysis highlights empirical examples of key professionals and organisations that have offered vital support in this respect.

### 3.4.1 Key professionals

A number of parents and carers found the expertise and information provided by SENCOs or their child's class teacher to be pivotal in raising awareness that their child was entitled to SEN support and supporting them with negotiating the initial EHCP assessment application process or with choosing appropriate settings for their child.

For example, *Noah* was placed in foster care at the age of five and struggled to cope when he was moved to a mainstream primary school closer to his foster family. Noah was subsequently excluded from this school in the first term and was placed in a pupil referral unit (PRU). Noah's foster carer explained that the intervention of the SENCO at the PRU had proved to be vital in securing an EHCP which ultimately resulted in Noah securing a place at his current special school:

R: The SENCO at [PRU] got his EHCP through...I do very strongly feel that if he hadn't been there, he would not have got his EHCP because he didn't have a diagnosis at this point.

I: Did the school apply for the EHCP?

R: Yes, school did it and obviously they had lots of children like Noah and they were very clued up on how to get these EHCPs because she did say to me at a normal school, you probably wouldn't get one because they don't know how to do it. They don't know the key words to write...He was under paediatrics, but no diagnosis had been made and sometimes that makes it really hard, when you don't have a diagnosis, but I was really lucky that she kind of knew what she was doing. Once the EHCP was all put through, then that's when he could move on to [special school].

I: It sounds a bit like the EHCP was quite pivotal then in getting some long-term support that suited Noah.

R: Yeah, absolutely. (Foster Carer of Noah, 9yrs, SEMH/ADHD)

Class teachers also highlighted how some parents and carers lack the confidence, capacity or time to complete EHCP forms and remarked that sometimes they completed forms either with a parent or carer or on their behalf.

In cases involving children or young people's transition to other settings, including those with SEN being supported without the need for an EHCP, the foresight and intervention of SEN staff appeared to be important in alerting parents and carers of the need to make an EHCP application to ensure additional support in the next setting. For example, *Alice* has ADHD, struggles to maintain relationships with her peers and has difficulties managing her behaviour and emotions. The presence of staff who understand her difficulties and are able to support her participation in everyday school activities is important in ensuring that she does not become at risk of being

excluded. The school SENCO has alerted Alice's parents of the need to plan for extra support to be in place when Alice moves to secondary school:

We're going to have the transition meeting with the Educational Psychologists in a couple of weeks. Because we feel that we've managed her in school, and we can manage her in school. But high school, we feel that she's probably going to end up getting, you know, excluded. Which is not what we want for her. So we're going to apply for an EHCP for her next year... you know, staff are very good at knowing the children inside out, you know. And so that's why we've managed it in primary school, because we just know her. (SENCO, re Alice 10yrs, ADHD)

In addition to this, a teaching assistant at the same school highlighted how the persistence of particular members of staff appears instrumental in supporting children and parents who lack understanding of their rights to request additional support through EHC planning:

[Child] should have had this support a long, long time ago and now she's got it and [SENCO] has even got more hours for her. She doesn't let go until she gets what the kids need, which is right. [Child] 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.

Other parents also highlighted examples of other professionals such as educational psychologists (EPs) or headteachers sharing important information regarding their rights, signposting SEN support or making applications for settings appropriate for their child's particular SEN or disability. For example, *Aiden's* parents experienced significant difficulties with their son's support at a military service education setting. An EP advised his parents that the service setting needed to act in accordance with the SEN Code of Practice. Aiden was subsequently excluded from the military service setting and his parents appealed this decision. Their appeal eventually resulted in a tribunal decision in the parent's favour.

One senior curriculum manager at a FE college indicated that she is currently encouraging staff members to be more proactive in advising students with SEN about entitlements to personal budgets and said that, in her experience, very few students or parents are aware of their rights regarding these:

When we're doing our EHCP reviews, even in advance of that I say to staff, you know, just be mindful of you can make referrals... they might not get a personal budget, but they might, you know, it's worth looking at... and I know the services are slightly more limited that we'd like them to be, but it doesn't--, it kind of--, well I think lots of our students probably are eligible for it and don't have it.

### 3.4.2 Independent advocacy support

Just over a third of the parents or carers had recruited support from SENDIASS (formerly Parent Partnership) at some point during their child's education and had found this to be an extremely useful source of support. Some parents and carers stated that it made them aware of their legal rights under the CFA 2014 and others found helpful the assistance with completing EHCP assessment requests or the level of reassurance and practical support they received from being accompanied by a SENDIASS staff member to meetings about their child.

For example, *Claire's* (SEMH, 18 yrs) mother utilised this form of support on a number of occasions such as over disputes concerning her child's exclusion and her daughter's right to be able to undertake work experience. This support had been 'the only way I've been able to have any say or

any right'. Another parent stated while aware their rights, they did not understand the extent to which their rights were 'legally binding' prior to engaging with SENDIASS. A SENCO mentioned that their school had a particularly good relationship with the SENDIASS service and often called SENDIASS to ask for help for a parent.

Some parents and carers mentioned positively the support received from third sector organisations such as Barnardo's with a range of SEN matters, including practical support with understanding and completing the relevant paperwork. For example, *James'* mother lacked confidence completing the EHC forms when her son's statement of SEN was transferred over to an EHCP:

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)

And in other cases, parents were reassured by workers about their rights to appeal a decision made by a local authority. For example, *Aiden's* mother received from Barnardo's much needed reassurance about her redress rights concerning a dispute with the LA about her son's placement at an independent special school:

It was lovely having somebody who was saying you're absolutely right, this isn't good, this isn't how it should be. So to have that seal of approval, that I wasn't going mad, 'cause this is how it makes you feel, like you are going mad, everybody's telling you you're wrong and you're thinking no, I'm not. But you do doubt yourself. And that really gave me the strength to fight on...eventually regardless of the emails sort of to-ing and fro-ing, it went to panel and Aiden got his place. (Mother of Aiden, 13yrs, ASD)

Lizzie's parents expressed a lack of trust in LA processes regarding ascertaining the support needs or capacity of their child to make a choice regarding her preferred setting and explained that they had drawn upon a number of independent sources of support to collate evidence for a forthcoming Tribunal. They accessed Barnardo's services to elicit the opinion of their child regarding her preferred institution:

She was comfortable there [with Barnardo's SEND participatory group], so we tried to get them to get her opinion, so it's not just us saying that this is where is best, so we got those workers to write reports, people who knew her, so we were putting all this evidence together for the trial. (Mother of Lizzie, 21yrs MLD/ASD)

In addition, Lizzie's parents consulted the National Autistic Society and independent legal representatives specialising in SEN appeals. Lizzie's parents found this support offered a degree of emotional support as well as practical assistance in connection with their rights:

Father: She was invaluable wasn't she... she knew the system... she was all hours sending us reports and what we should be doing next, you know, she kept us on the timescale, and told us what we had to have in place.

Mother: She was at the end of an email, the phone... Emotionally she was a good support as well.

Father: She was fantastic, we couldn't have done it without her.

A few parents also mentioned courses run by CAMHS, schools, parent/carer networks or SENDIASS that have drawn attention to useful information contained on the local offer or helped them become better informed of their rights.

Very few children and young people accessed independent sources of support on SEN matters and most tended to rely upon assistance from parents, carers and teaching staff with articulating their views and wishes. One exception was a care leaver lacking family support with engaging with the LA who referred to his leaving care worker's provision of vital emotional support during EHCP review meetings. The care leaver also drew attention to difficulties experienced in navigating new EHCP application forms following the cessation of his original statement of SEN. He said that when he found somebody (with the help of his leaving care worker) at the council, they had been very supportive in helping him to fill out the forms. Additionally, he sought out support from a number of youth advocacy services such as Coram Voice regarding rent arrears and the National Youth Advocacy Service with more general information about his rights.

### 3.5 An enabling environment?

- There is a degree of variability in the ways in which different settings support children and young people to participate in decisions and engage in EHCP processes.
- Time, access to appropriate resources and the commitment of different agencies/staff to person-centred approaches are among the factors that impact upon the extent to which CYP or parent/carer's participation is supported.

This section considers the extent to which different educational settings are able to offer an environment which is conducive to engagement and co-production with children, young people and their families and highlights professionals' attitudes and knowledge of the CFA 2014.

#### 3.5.1 Pedagogy and ethos of schools

One primary school SENCO explained that the subject of children's rights is interwoven throughout the school's overarching ethos and that the school is led by the principles of 'nurturing the whole child' so that more vulnerable students are supported to participate in as much of everyday school life as possible. For example, pupils have some autonomy in choosing which adults they would like to act as their first point of contact when they need additional support:

Every child in school has a designated adult who they choose, if they're chosen, that staff member has a list of children who have especially asked for them. So, they keep an eye out to sort of check in with them. 'Are you okay?' or just a wave in the corridor, you know, just a general look after (SENCO).

This school has also been proactive in supporting its more vulnerable pupils to become better acquainted with their rights and develop their capacity to participate in decisions about their education and care by hosting SEND participation group meetings at the school. These groups are run by representatives from Barnardo's SEND participation groups every half term and are attended by all of the pupils with SEND or who are care experienced.

Some professionals highlighted pupil/student councils as environments in which children and young people can develop understandings of decision-making practices within their setting. For example, a special school teacher drew attention to pupils' involvement in staff recruitment as part of pupil council roles. The headteacher of another independent special school was also keen to point out that the school's approach to children's rights and policies was integral to the overall ethos of the school. He explained how pupil engagement with the school council offered an example of this in practice:



That fits pretty well with our overall raison d'etre, right from the word go because it is about empowering young people to lead enriching and fulfilling lives and you can't do that without taking risks with them and allowing them to have some say. I mean, from day one, we've had a pupil council and it's not a showcase thing. It's real. Our kids [now] have a school uniform, that was their decision, not mine.

A special education FE college leader also drew attention to the importance of allowing students significant amounts of time and freedom when making important decisions about achieving greater independence in preparation for adulthood. For example, the wishes of *Lizzie*, a 21 year old young woman with MLD and ASD who hopes to be able to live independently in the future, were listened to by her college and she was supported in considering moving out of the college residential unit. Lizzie currently lives with a 'shared lives' provider during term-time.

Other FE colleges have also acknowledged students' involvement in extra-curricular participatory activities as being of high importance and authorise student absentees to attend events such as SEND voice conferences or LA SEND Board meetings. *James'* mother particularly valued the college's support and encouragement for her son to be able to continue to attend SEND participatory group meetings whilst studying at the college:

They've said that they fully encourage him to continue to do everything. They will support him and back him because they say that they believe in him... Because he does quite a lot for the participation groups and I didn't want him to suddenly say I can't do it any more, but I also want him to get an education. (Mother of James, ASD/SpLD, 16yrs)

### 3.5.2 Building CYP's capacity and maximising opportunities for engagement in EHCP processes

Different settings reported mixed policies in terms of respective commitments to supporting pupil attendance at EHCP meetings. Some schools and colleges advised that pupils are always invited to attend them regardless of perceived capacity or maturity. For example, one mainstream secondary school SENCO advised that she considered that it was important to ensure that pupils attended at least part of the review meeting:

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, they've lost the plot, so they let them go. I always insist that they come at least to the five, ten minutes at the beginning.

One class teacher explained that she takes the lead in preparing EHCP reviews for all of her class and highlighted examples of support that is offered to students with SLCN in order to maximise their engagement. This particular school has developed a 'shield' document in order to facilitate greater participation in which pupils can annotate the document with written or drawn examples of their aspirations and what is important to them in terms of support. Other schools supported pupils to create a short film or presentation to express their views.

Larger special schools with entire school populations that have EHCPs expressed that the organisation and timing of EHCP meetings presents a significant challenge in terms of ensuring maximum participation of all interested parties. Some staff members remarked that ensuring that all relevant staff and invited professionals are available at the same time as parents, carers and pupils can be an almost impossible task and that this can sometimes impact upon opportunities for pupils and their families to engage. Other members of staff highlighted how pupils can often elect to miss

their EHCP meeting due to a clash with a preferred subject lesson or after school activity. And in the case of one school, dates are allocated for EHCP meetings well in advance and if parents, carers or other professionals are unable to attend meetings, the school has a policy of going ahead with the meeting in their absence. Teaching staff at one special school also highlighted that they are responsible for leading EHCP meetings for an entire class, and often the only available time to do this is during their allocated Planning, Preparation and Assessment (PPA) periods. One teacher explained that due to her PPA time clashing with Forest school activities, pupils are rarely able to attend EHCP reviews:

Unfortunately, most of my reviews take place during my PPA time, which is when this class are off-site at forest school, so they can't always attend the meeting. If they could attend, they would be there in person and they can contribute to it, but because they're off site at the time, it's usually quite difficult. (Special school class teacher)

The importance of allowing a child or young person autonomy in their level of participation at EHCP meetings was underlined by a mother of a sixteen year old boy with ASD. She explained that despite her son finding these meetings difficult and being offered multiple opportunities to leave if he wished to, he usually managed to listen to other people's input and remain for the entire meeting.

Other settings adopted a less uniform approach, citing numerous factors which can sometimes preclude a pupil's attendance at a review. These factors included a child expressing dislike of meetings, concerns about creating undue anxiety or stress for a child who might find it difficult to hear others talking about their vulnerability or disability, parents raising objections, as well as common concerns about a child or young person's capacity or maturity.

### 3.5.3 Supporting CYP to articulate their views

Many settings remarked that the layout and language used in EHCP processes can be very difficult for children and young people with SEN, regardless of age or capacity, to access and understand. One FE college personal tutor said that staff often have to explain the purpose of the review and re-word many of the questions contained within it in order to ensure that students are able to understand both the process and the importance of it. A special school advised that they were currently consulting with the pupils, parents and staff in order to re-design the forms that are used to express pupil's views as part of the EHCP, 'Section A: all about me' section:

They've all had a look at it and had a hand in designing it, and then we've put the design together so that it's suitable for passing around... The student council were involved in it and they kind of some of it was good, this is not good. They were very vocal in saying we didn't like this bit and things like that. (Pupil Voice Co-ordinator)

Conversations with staff members at one special school revealed that decisions regarding the capacity of pupils and ways in which they might be supported to engage in EHCP reviews is considered on a case by case basis. They also gave examples of a range of issues that contribute to decisions about a pupil's involvement and concluded that on the whole, a parent or teacher often makes this decision on behalf of the child or young person:

I: Who has responsibility for deciding on a young person or child's capacity to be present in the review, for example?

SL: That's a difficult one, actually, because there are some times that I've brought a young person in and the parents have gone, oh don't...

AP: I think ultimately it would be parents, unless...

I: Would you, by default, invite the child into the review?

SL: Sometimes what I'll do is I'll start a review and then I'll say to everyone present I'm going to invite Joe Bloggs in, shall we do this bit first and we'll get them in. Then I'll tend to invite them in to go through their bit of the paperwork, their shield or their display. Some students do a PowerPoint and they want to present that. That's the appropriate bit. If they want to stay, then they can stay but more often than not, they don't want to miss out on what's going on.

AP: I don't think that by default we would...There's loads of things to think about, each situation's individual.

PV: I think that would be the class teacher and the parent to really decide what's best for that young person.

AP: Very individual needs...[W]hat doesn't kind of get catered for is the capacity to communicate and understand the, very abstract, non-tangible concept. Most things that we teach are.

SL: This is where the PFA [Preparing for Adulthood] is a very difficult document to work with when you're trying to say to students, 'What help do you need in the future?'... They're like 'what's the future?'

PV: They can't understand the concept of tomorrow, let alone...

SL: Well their future is, I want to stay here 'cause this is the here and now, this is all they know. The thought of leaving something and not knowing, that's really difficult.

PV: That sets massive high anxiety levels for our students. (PV, Pupil voice co-ordinator, AP, Assistant Principal & SL, Sixth Form Leader.)

#### 3.5.4 Person-centred practices

Staff at a special school advised that they had recently engaged with SENDIASS representatives who have delivered training on supporting engagement with children and families. The sixth form leader drew attention to the ways in which this has impacted upon practice and highlighted how 'a person-centred' approach can be helpful in building children and young people's capacity and enhance engagement opportunities for those with more profound learning difficulties:

I suppose that's where the person-centred approach comes in because it is difficult to capture, different diversities... This is where we rely on the staff working with that young person... so when it comes to filling in paperwork and what works best for them... You're using the people around them to be the voice for them, a lot of the time... We also have good practice and the training was that you share slideshows with the parents, so for PMLD [profound and multiple learning disabilities] students, it might be that you're sharing video clips, you're showing engagement, you're showing things that they've participated in. (Sixth Form Leader, Special School.)

A special school teacher considered that there have been some positive changes following the CFA 2014 and remarked that although supporting a more 'person-centred' process required more time and effort, it was 'much more relevant in terms of supporting the young person' and pupils were, in her view, able to 'contribute more now' than under the previous statementing system.

A number of settings also highlighted that they have recently started to offer a more personalised approach to signposting parents and carers regarding their rights and SEN matters through hosting events for IAS or introducing LA SEN staff via more informal coffee mornings. This approach is intended to supplement information available on school or LA websites and was considered by some to be more effective than the local offer. A number of schools and colleges also indicated that they intend to offer much more events like this in the future.

Some settings indicated that support staff regularly observe prospective students or attend EHCP review meetings in their current settings in order to build relationships, understand a pupil's SEN and family background or personalise a student's support prior to arriving at a new setting. In some cases, families also requested assistance from IAS or other advocates to assist with enabling a child, young person, parent or carer to participate in such reviews. Parents highlighted that it was important to feel that that host settings welcomed the presence of independent advocates or new support workers during such meetings.

### 3.5.5 Professionals' attitudes and knowledge of rights framework

Educational professionals reported mixed experiences in accessing training and information regarding the CFA 2014 and supporting children and young people's participation. Class teachers and support staff tended to be less aware of the CFA 2014 than senior leadership team members and LA SEND staff and very few teaching staff were aware of wider children's rights frameworks such as the UNCRC or had heard of UNICEF's Rights Respecting Schools. For example, some teaching staff referred to recent policy emphasis on 'British Values' in the curriculum or mainly pointed to the school council as an example of how the school supported engagement with children's rights. When asked about their knowledge of children's rights some teaching and support staff admitted that they knew very little about the CFA 2014 or UNCRC but were able to articulate some examples of listening to children's views and respecting their wishes as part of regular classroom practice.

Professionals working in the FE sector displayed some awareness of students' rights regarding SEN support and EHCP processes and in some cases, staff also drew attention to examples of teaching students about students' rights as a consumer or future employee.

Almost all of the families involved in the case studies were unaware of personal budgets, and in one case a parent encountered difficulties with the LA's response to their request for one. However, some educational professionals appear to be more proactive in ensuring that parents or young people are aware of alternative ways of securing funding for their child's support. In two of the case studies, professionals had tried to ensure that families were aware of their rights regarding this.

EPs, SENCOs and senior school leaders appeared to have a greater awareness of the statutory implications of new legislative frameworks. One Principal EP drew attention to the ways in which communication with children, young people and families has improved following implementation of the Act. There was considered to be a significant improvement in CYPs' and parents' engagement with the LA:

I think what the Act has done, which I think has been very positive, is opened up communication with parents and the need for the local authority to respect and engage with parents and young people; and I think that has been quite phenomenal in terms of local authority and parent partnership working together. And I think that's been a real positive shift.

Another LA primary phase SEND case manager considered the most important aspect of the CFA 2014 has been the transition towards person-centred practices and the impact that this has had upon the agency of children and families to steer decision making processes:

From sort of parents', young person's perspective I think they feel that they're more empowered, they've got more control over their future decisions that are being made about them, that directly affect them. The whole person-centred thing is, has got to be a positive. They feel involved, you know, about it all. And they can also steer it in a direction that they feel it needs to go, and not what everybody else, the experts think.

A very experienced foster carer considered that the new rights accorded to young people over the age of 16 included as part of the CFA 2014 were important in terms of 'giving voice', but she also had some reservations about young people with SEN who have also experienced significant trauma being able to realise these rights:

If you think about some of the young people I know in terms of, you know, severe ADHD, sometimes autism as well or very traumatised so a lot of developmental delay, when they reach that milestone [age 16] they'll be completely lost, very, very lost. It's very good in terms of it's giving them the voice, but it needs to be able to give them the voice with the knowledge and recognition of their developmental stage.

At an institutional level, teachers also underlined the importance of *all* staff having a wider appreciation of children's rights and listening to pupil's views consistently. For example, in the case of *Alice* (10 yrs, ADHD), the child enjoyed a close relationship with her class teacher and felt that her teacher understood her difficulties in managing her emotions and behaviour in the classroom and made time to listen when she expressed her views and feelings. Alice's class teacher underlined the extent to which difficulties can arise between Alice and other teaching assistants with whom she does not share the same kind of relationship. She also highlighted challenges around supporting children's rights within the school in a more consistent manner and underlined the importance of ensuring that all staff members respect a pupil's right to express their views:

They [teaching assistants] won't sit and listen to them... I can see why the children get wound up. Because it is just, 'What you doing? No, I'm right, you're wrong' with them. They don't let them explain, like, 'I was just telling her what to do.' Or, 'I was helping her.' If it's silent and they speak, that's that.

One primary school SENCO considered that the potential benefits of the CFA 2014 were also greatly restricted by pressure on school resources, balancing heavier workloads and difficulties accessing sufficient EP support:

I know the idea behind it was to get everybody together but that just hasn't happened at all really. Because budgets are just tighter. Everyone's workloads are just so much heavier and so there just isn't the capacity for it. I feel as though people are paying lip service to it, you know, and they're saying, yes, we'll do this and do that ... But I feel as if we're just like, we're just ticking that box and I'm thinking I wish I could have a bit more time to involve parents.

### 3.6 Children and young people's participation in their own case

A number of important factors that affect the extent of children and young people's participation in decisions and support to express their views were identified:

- adults' concerns about a child or young person's capacity, maturity, and mental health and well-being;
- CYP's knowledge of EHCP processes, rights and available advocacy services;
- their prior experience of adversarial contexts; and
- lack of trust in professionals and LAs to listen to CYP and take their views seriously.

This section outlines a range of ways in which children and young people have been able to express their views, wishes and feelings and participated (or not) in decision making processes about their

education and support. Case studies highlighted examples of children and young people’s direct or indirect participation in review meetings, school selection or appeal hearings.

### 3.6.1 Children and young people’s participation in reviews

The analysis presented in preceding sections suggests that there is a degree of variability in the extent to which children and young people are considered to have the capacity and/or are invited to attend EHCP meetings and reviews. Fourteen children and young people participating in the studies were holders of an EHCP. Eight of these CYP had attended all or part of the EHCP meeting and six of these eight were aged between 12-22 years of age. The other six children or young people were considered not to have sufficient maturity or capacity to attend or there were concerns that attending the meeting might cause them undue anxiety or stress. Of the four other cases which involved children or young people who did not qualify for an EHCP, one young person refused to be assessed, two children were being considered for an EHCP application in the future and the remaining case involved a young person who had been advised by the LA that her support needs should be met via existing college resources.

Table 6: Attendance at EHCP reviews (n=14)

	Primary	Secondary	16-25	Total number of cases
Attended all or part of EHCP meeting	2	3	3	8
Did not attend	5	0	1	6

Being well informed of one’s rights and having an understanding of EHCP processes was highlighted as a factor that enhanced a child or young person’s ability to participate. For example, *James* (16yrs, ASD/SpLD) explained that prior knowledge of his rights gained through participating in various LA and third sector groups for young people with SEND strengthened his understandings of the EHCP process as well as helping him to manage expectations of what might happen during review meetings. He recalled that at his last EHCP review he ‘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’* mother also advocated for her son to be included in his last EHCP review despite feeling that the school ‘didn’t want him to be there’. She had also felt that the school ‘wasn’t very happy’ that she’d asked a Barnardo’s representative to be present at the meeting. A Parent Partnership member had also helped both *James* and herself to fill out all of the EHCP review forms and she had found this extremely useful.

In another case, *Maleeha*, a twelve year old girl with a visual impairment, was able to recall attending meetings where she could discuss how she is supported in school. She ‘sometimes’ attended the entire review meeting and people had asked her ‘if there's anything you can improve, or how you're doing, are you struggling with, any problems, how's the iPad working?’ When asked if she felt able to express her views and feelings with other adults present during her EHCP review meetings, *Maleeha’s* response was fairly indifferent and she simply explained that, ‘it’s alright’. She went on to say that her mother and father were usually present for these reviews and that teachers also attended along with sensory impairment advisers from a nearby specialist school.

Another child, *Peter*, was also unaware that he had an EHC plan but remembered going to meetings at school to discuss his support. He also felt that he had had some agency in deciding whether or not he wanted to attend and that he was able to express his views freely:

I: So when you're in these review meetings, do you have to stay for the whole thing or can you just not go, or how does it work?

R: Yeah, I can choose whether to go or not. Usually choose to go.

I: When you're in the meeting and talking to the other adults in the meeting, how is that? Do you feel like people listen to you?

R: Yeah. Yeah it's fine. They ask like how my progress is going at home and if I'm getting on with everyone.

I: And the people that are in that meeting, do you feel okay to say exactly what you really think?

R: Yeah. (Peter, 16yrs, ASD)

The SENCO was particularly pleased with Peter's progress in terms of being able to voice his needs and referred to his developing confidence and independence over the last few years to the point where he was now also able to voice his needs outside of the EHCP meetings and was able to instigate a change in the school uniform policy:

Peter has been brilliant. Again, he's grown and developed into telling us what he needs. He is developing independence, his choice and what he wants to do, that's what he's choosing. He's very vocal and in fact, I'm really proud of Peter because last summer, he struggles with wearing the uniform and always has done, but last summer he took a presentation to the head teacher, he spoke up and then he went to the governors and gave his presentation to the governors. He gained the right for [all] students to wear shorts... It was taken up and in the summer when it was so terribly hot, we had at least five or six children, most of whom were autistic, going round wearing shorts. That was amazing.

### 3.6.2 Factors affecting CYP's lack of participation in EHCP processes and reviews

#### *Lack of trust in educational professionals and local authorities*

A number of factors may reduce the extent of a child or young person's opportunity to participate in EHCP processes and reviews. We saw examples of how they and their families may choose *not to engage* with educational professionals or local authorities or decline additional SEN support via an EHCP.

*Claire* (18yrs, SEMH) demonstrated a high level of confidence in presenting her views and opinions and was able to realise her right to choose her preferred FE setting against the wishes of her mother. She also said that she did not want to participate in meetings regarding SEN support. Claire's experiences of multiple exclusions and difficult encounters with health and education professionals in the past have contributed to feelings of mistrust and anger regarding discussions about her SEMH support needs. Claire also talked about enjoying greater freedom to express her views and wishes about the way that she is supported at college and that this made her feel more respected and empowered. As a college student, she also felt much more able to articulate her belief that she did not require any additional support and she enjoyed an element of agency in choosing whether or not to engage with the curriculum:

I: What do you like about college?

A: Freedom. A lot different to high school... if you want to pass the course, then the teachers will help you; but if you don't want to do anything, they'll just leave you to it. They don't care. So it's literally just up to you... Since all of this nonsense in high school, they've literally left me to myself in college. I don't need support. I don't need anything

Claire's mother also explained that her own previous experiences with her daughter's exclusion from a number of different settings and her lack of trust in some educational professionals and the local authority made her reticent to explore formal channels of securing additional SEN support. For example, despite the local Behaviour Support Service (BSS) suggesting that Claire would benefit from the additional support available as part of an EHC plan, her mother refused to grant permission for the application. She reasoned that this was on account of having concerns about granting access to her daughter's medical records and not 'trusting' the college either.

I didn't sign it. And I don't think they [BSS] were very happy about Claire going to college without one in place...I didn't feel comfortable with the healthcare plan, I didn't trust the BSS and as it happened I found out they've had four meetings with the college about Claire without my knowledge and without me being there.

However, as highlighted in previous sections Claire's mother has continued to advocate for her daughter by liaising with the college staff more informally in order to ensure that her tutors understand her daughter's difficulties and are able to offer appropriate support.

Another care experienced young man expressed mistrust of some education and social care professionals but chose to engage with EHCP processes in order to secure the additional support he required to undertake a supported internship whilst attending FE college. *Jacob* (22 yrs, SEMH/ASD) also appeared to be very confident in expressing his views and opinions and demonstrated extensive knowledge of his rights as a care leaver. He had had some autonomy in who was invited to his latest EHCP review meeting and recalled that in front of the social worker he was more guarded about expressing his views and remained 'tight-lipped'. However, despite a degree of agency in relation to the information he chose to share during review meetings, he also felt that staff at the college had tried to persuade him to follow a career in hospitality and catering and stated that he had no interest in this. Jacob described how he was able to gain some support from his leaving care worker during the meeting but was disappointed in the outcome of the meeting. He recalled that he was quite clear that he wished to work for a local council and wanted an office-based job. Eventually he accepted a Supported Internship within the car park department and felt that this was, 'ok' but not really what he wanted to do long term. Due to the fact that Jacob does not have any family members to support his participation in meetings, there is also an explicit recognition of Jacob's right to express his views and participate fully in decisions about his care and support highlighted in his EHC plan.

Jacob must be actively involved in reviewing his plan... Jacob lives independently and does not have a family network to support him. His voice must be heard at the centre of reviews and meetings to discuss his progress and his preferences must be recorded.

#### *Lack of interest in engaging in decision making or attending EHCP meetings*

Regardless of their awareness of their participation rights, some children and young people lacked interest in engagement regarding their education and support. For example, one young woman (Lizzie, 21 yrs, MLD/ASD) voiced a strong dislike for meetings in general. Although she was aware that she had an EHCP she had not read it: 'I didn't really read it, I gave up.' In reference to the EHC planning meetings she also explained that she does not like attending these: 'I hate it, I don't like it, I can't stand meetings like that... I get bored.' Lizzie's case also highlights how, although some children



and young people may feel obliged to engage with EHCP processes, their presence at review meetings does not necessarily guarantee voluntary participation.

Another young man, *Aiden* (13yrs, ASD) recalled that he found the review meeting difficult due to there being 'too many people' present. He was also very candid about paying little attention to what was being said in the meeting and expressed little interest in the process, apart from the biscuits:

I: Can you remember what happened at the [EHCP] meeting? Did you go to all of the meeting?

R: At the end of it, and it was just talk, talk, talk, talk, biscuits, talk, talk, talk, biscuits.

I: Did you talk to the people in the room?

R: Just barely. I just sat there, like...

I: Did you want to be there?

A: I just sat there, drooling at the biscuits the entire time, while the adults talked.

I: Would you like to have said something?

R: No.

I: What kind of things did the adults talk about in the meeting, can you remember?

R: Things... I wasn't really listening...Probably about my plan and that and like...It seemed all good because my mum was smiling.

I: Did you have any say in who came to the meeting?

R: No. I don't really care that much.

#### Parent/carer concerns about a child or young person's ability to engage in EHCP meetings

Although one young person had previously participated in small parts of EHCP meetings whilst at secondary school, his parent explained that concerns about his son's ability to cope with people talking about him and understand what was being said during the review make the young person feel uneasy. Therefore, this young person has not attended any reviews at college despite his father wanting his son to feel included and the college encouraging his presence:

The last one we did at the college, it was just my wife and I went along and did it but I think they'd said obviously he's more than welcome to come along. There's no problem and I think quite a few of the children didn't go along to the reviews, so maybe I think probably for the next one we might ask him, but I suppose the only thing is, that I'm maybe slightly cautious about is I don't really like talking about him while he's there. I want him to feel included and always able to follow and that makes me a bit uneasy, put it that way. (Father of Kei, 17yrs, MLD)

Parents, carers and teachers of younger children or with SEMH or ASD often articulated concerns about a child's ability to participate within the physical space of a meeting. For example, the carer of *Noah* (9yrs, SEMH/ADHD) said that the boy's attendance at meetings very much depended upon the child's 'mood really, on whether he can maturely talk or not.' In the case of a much younger child, with a visual impairment, parents and teachers expressed concerns about his ability to understand the process and considered that including the child in the meeting might cause unnecessary anxiety. The child's parents also explained that they had completed the 'Section A- All about me' section of the plan on their child's behalf:

To be honest, I don't think it would be a good thing for Jack [to attend EHCP review]. Because he over thinks things. He'll probably be sat in there thinking, 'Why is mummy and daddy having a meeting?' (Mother of Jack, 7yrs, visually impaired)

Jack's teacher shared his parents' concerns and clarified that it was unlikely that Jack would attend any EHCP meetings in the near future. The teacher went on to explain that staff have supported Jack to express his views feelings and wishes prior to review meetings and that this information is shared with his parents.

In cases where children or young people attended all or part of an EHCP review meeting, it appeared to be common practice for them to present their 'Section A- All about me' part of the form verbally or to give a short presentation. Presentations often reflected the child or young person's preferred communication styles, what is important in their lives, and their preferred forms of support and aspirations for the future. Pupils also tended to be supported with preparing their contributions by a teaching assistant or class teacher. In some cases, involving children and young people with SLCN, SLD or MLD, views were often articulated via a short film, assistive technology or with the support of an adult familiar with the child or young person's SEN and preferred medium of communication.

A few children and young people indicated that they had some say in whether or not they stayed for the entire meeting and that they felt able to express their needs if they wanted to leave at any point. However, cases involving children or young people with less confidence in expressing their needs expressed difficulties in voicing a desire to stay or leave meetings.

Often, in cases involving primary school aged children or those with more profound learning difficulties, decisions regarding a pupil's attendance at meetings were made by teachers or parents. One case highlighted how adult perceptions of a child's capacity can affect his/her participation. For example, *Maria* (9yrs, SLD) said she valued being able to participate in her EHCP review and talk about her achievements, despite feeling nervous in doing so. Maria was well supported by her teaching assistant in order to prepare for the event and practised her contributions in advance. However, Maria was only invited to attend part of her review and was asked to leave the meeting after her input. When interviewed Maria said she would have felt sufficiently confident to have stayed for the rest of the meeting and discuss her support if given the opportunity to do so. However, Maria's teaching assistant told us there were concerns that Maria would not have understood 'what we were all saying and doing, it might have confused her a bit'. Therefore, after Maria had presented her views she was praised for her contributions and asked to return to the classroom in order to complete her work.

Balancing the rights of children and young people to participate as much as possible against the effects of exposure to situations which might cause distress or anxiety was illustrated as a difficult dilemma within a number of case studies.

It is also possible that children and young people's participation can be affected by levels of confidence in expressing and processing views of a more negative nature. In Lizzie's case the 'what is important to our family' section of the EHCP contained her parents' specific concerns about their daughter's reticence to express a negative point of view:

Lizzie doesn't always say when she is unhappy, in situations which she doesn't like or when she is feeling unwell... Currently Lizzie answers most questions in a positive way and hates mentioning negatives, so we would love her to be able to answer both negatively and positively, enabling her to voice concerns and become less vulnerable to abuse etc.

#### *Difficulties expressing feelings and views to adults*

Children and young people's abilities to voice negative opinions regarding the type of support that they receive can also be tempered by concerns about appearing to be impolite. For example, despite teaching staff considering that Jack was very able to express his views and opinions, when he

engaged in a research activity about 'having a say' in his support he indicated that on occasions where he felt that he would like to be supported in a different way, he was unable to voice a negative opinion on account of not wanting, 'to be rude':

Q: Do you think you'd be able to say, 'Miss, I need you to help me a different way'?

A: Well I don't really want to be rude, but...

Q: Would it be okay for you to say that? Or tricky?

A: Tricky. (Jack, 7 yrs, visually impaired)

The example of Jack's case above highlights the risk that a child or young person may simply comply with decisions made by adults in order to avoid a potential conflict of opinion or in deference to a more powerful adult. In addition, some younger case study participants appeared to be much more likely to assume that a parent's or carer's view might be accorded more weight. For example, *Lyron* voiced an appreciation of being able to speak with staff about any difficulties he was experiencing in school but also considered that if he struggled with getting his point of view across, his mother would be more likely to be listened to due to the fact that she is an adult:

R: You know, she [mother] tells them about what I think is unfair about, about my situation in school. And she really gives them sense; she really knocks sense into them...She, she talks firmly. And she says, you know, about this.

I: What's different about your mum telling the school, as opposed to you telling them?

R: They wouldn't really listen to me as much as they listen to mum, because I'd, I'm just young – I'm only nine. My mum is an adult; they'll believe her more than me. (Lyron, 9yrs old, ASD)

Regardless of age, level of maturity or SEN it appears that many of the case study children and young people could be reticent to voice their need for extra support in some contexts; and the presence of a familiar adult often helped to overcome some of these difficulties. For example, *Laura* is 17 years old and has SpLD. She communicates particularly well with adults that she has a good relationship with but lacks confidence in expressing her feelings with some of her other tutors:

She needs permission to speak, yeah. She's very polite in that way. She just, she will just quietly go off and have a cry about things. (Personal tutor)

### 3.6.3 Inclusion of children and young people's views in EHCP forms

Section A of the EHCP document provides a space in which children and young people's views can be included separately. Older children and young people are more likely to complete it independently. However, the majority of children and young people tended to be supported by a parent, carer or education professional with this task. In a few cases a parent or carer completed it on the child's behalf without consulting the child.

*Maleeha* (12yrs, visually impaired) completed it independently. Her father explained that he offered a small amount of assistance, 'polishing sentences' after his daughter had expressed her views in her own words. In contrast, some parents presumed that a child's teacher would support the pupil's completion of section A but were often unsure about the extent to which their child was involved. For example, *Ben* (10yrs, SLCN/MLD) was not aware that he had an EHCP or any kind of plan in school and was unsure if he had ever attended any review meetings. Ben's mother explained that her only awareness of her son's involvement in EHCP reviews was:

...just a page where, his teacher will say to him, "What do you like, what do you dislike? What are your favourite things?" other than that, I don't know--, no I don't think maybe he is that involved in it.

Ben's mother also remarked that she was unsure if the school ever involved her son in decisions about how he is supported and went on to add that even if the school asked him about this, 'I don't know whether Ben would understand that'.

Other parents assumed responsibility for supporting their child with this task, although some parents found this quite challenging. For example, *Frank's* mother commented that, 'it's quite something to fill out' and explained that she recollected that her son 'didn't really want to' add his views when they had completed the EHCP documentation upon his arrival at his current school. As a parent she felt that, although happy to complete the forms, it was a 'daunting' process and that there are also lots of other demands on her time in terms of ensuring that her son has completed his homework, and so on:

I'm happy about doing it. I think sometimes it's a little daunting because you, you know, if your child isn't enthused about doing it and then you've got homework and other things to do, it sort of feels like, oh, that's another thing to kind of get done. And that's why I think it's been put in a drawer I think... I think Frank would see it as a bit of a chore. (Mother of Frank, 9yrs, ASD/MLD)

Where a child or young person does not have an EHCP but requires additional SEN support, schools often produce a 'one-page profile'. One-page profiles are intended to display at a glance key pieces of information that are useful to support a pupil's additional needs and are aimed informing a wide range of professionals that may come into contact with a pupil, from lunchtime supervisors to casual supply staff. The use of 'person-centred' practices as a means to involve children, young people and their families more fully in participating in decisions about their education and support are also advocated in the SEN Code of Practice (2015). In one case, involving a nine year old child with ADHD, the pupil's profile was created by the child articulating her needs verbally with her main one-to-one support worker acting as a scribe, although it also included feedback from significant others about what they admire and appreciate about the child and how she would like to be supported.

#### 3.6.4 Participation in decisions about preferred educational settings

Every child or young person was asked how independently they made decisions regarding their current or future preferred educational setting. Responses ranged from children and young people considering that they had a lot of autonomy in this decision to having had no say at all (see fig. 1). Likewise, parents and carers supported their child with this decision in varying degrees.

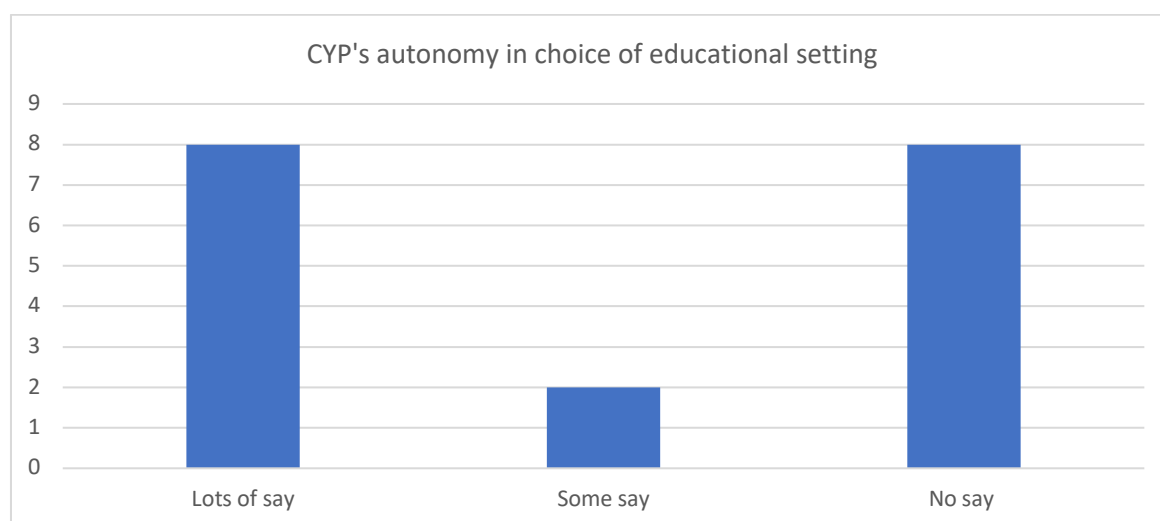


Figure 1: CYP's autonomy in choice of educational setting (n=18)

There was only one case in which a young person went against a parent or carer's wishes regarding their preferred educational setting. *Claire* demonstrated a high level of autonomy regarding the choice of college post-secondary education. Claire's mother did not, however, agree with her daughter's choice due to concerns about its reputation. However, Claire had had the final say. Claire's mother said:

I was totally against [FE College], because they have such a bad reputation, their inspections, they failed Ofsted, I didn't want her to go there, but... she insisted on going there, she refused to go anywhere else 'cause she said she wouldn't suit it, there were other places she could have gone but she just refused because her friends weren't going there. (Mother of Claire, 18 yrs, SEMH)

Very few children and young people referred to not having had some input from a parent, carer or leaving care worker in decisions around choice of educational setting. A common experience was of receiving support from parents and carers in order to be able to make an informed choice, but also feeling able to have much say in the final decision. For example, Catholic College was *Kei's* preferred choice and he described how he had visited three local colleges in the area with his parents and based his final choice upon the fact that drama was included in the curriculum and that the college had the best level of support. Kei's parents said that there was an effort to help him make an informed decision:

He did have a say and we did try to discuss and advise and that kind of thing, yes...we did try to come to the best decision as possible as a family and then also in discussions a bit with his teacher and stuff. (Father of Kei, 17yrs, MLD)

Another child, *Samuel*, explained that his foster carer had listened to him when he had said that he was not happy at his previous school and had supported him by finding another school which was nearer to his foster home. His foster carer liaised with the relevant authorities and eventually secured a place at his current school:

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)

*Maleeha* (12yrs, visually impaired) explained that she had also received some support from her parents in choosing her current secondary school but felt that she had a lot of say in the matter. However, she said she would rely on further support from her parents when making future choices and would, 'go with my parents, I can't make such a decision like that on my own.'

A number of children said that their parents had made the decision about which school they should attend. This was often because of concerns about the child's capacity to make a decision. Parents and carers of children with difficulties managing emotions and behaviour often had very little autonomy in choice of school either. For example, after receiving confirmation that *Noah* qualified for an EHC plan, it appears that he was very reliant upon his foster carers in choosing an appropriate school for him to attend. He recalled that he had an opportunity to visit the school (and liked what he saw) but that his foster mother had made the decision for him to go there:

He didn't have a choice, I'll be honest with you. He didn't have a choice, and neither did I, because it was a pupil referral unit and we were really lucky to get a place. When it came to [special school], we did go and look round it, me and [foster father] went. We didn't look for

somewhere else because I felt it was right for Noah... a lot of the staff at the PRU were all very positive about it, so I didn't feel the need to look anywhere else. (Foster carer of Noah, 9yrs, SEMH/ADHD)

Noah is currently in year 5 and explained that he has also been thinking about which high school he would like to attend. This is a decision that he will make with his foster mother and he would only like to look at one high school and will then rely upon his foster mother's views and observations about other potential schools before they make a final decision together. He felt he lacked sufficient capacity to decide on whether or not he would be able to cope in a mainstream secondary school, but trusted his foster mother's judgement on the matter:

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, SEMH/ADHD)

*Ben* (10 yrs, SLCN/MLD) did not know why he was attending his current school but assumed it was his parents' preferred school. Even if unhappy at his present school, he would not, he said, be able to change schools, because 'mum would choose'. Similarly, *Lyron* (9yrs, ASD) said he had little say in the matter of which high school he will attend and that his mother would choose: 'I'll just like have to learn to deal with it I guess'.

A number of other primary school aged children felt that regardless of their views about their current setting, their parents had the final say. For example, *Aiden* had not been involved in choosing his school but did, however, express confidence in his parent's ability to choose the most appropriate setting on his behalf:

I didn't have a clue what was happening. I might be going to [X] High School, I might be going to, [Y school] something like that. I just thought I were going to everywhere and when the staff heard me say I might go to [Z school], they were like, 'You are not going to [Z school]'. It didn't have a very good reputation at all with the staff in my old school. They thought it wouldn't fit me whatsoever. (Aiden, 13yrs, ASD)

A parent of *Peter*, a child with ASD, did not consider that her son had a sufficient level of maturity to choose the most appropriate secondary school but she felt that as he matured, he would be more able to have greater input:

We took him round the schools, but he, [didn't choose] no, not really. We didn't let him make any of the decisions. I mean he was really immature then. I mean he has a bit of developmental delay now, so he probably works at a year nine emotionally, so there was no chance he would have any idea. (Mother of Peter, 16yrs, ASD)

### 3.6.5 Children and young people's participation in disputes

Children and young people indicated that they had very little direct involvement in disputes concerning their SEN support or placements at preferred settings. In none of the case studies the child or young person had experience of engaging with mediation services but in half of the cases there had been an involvement at some point in appeals regarding a child or young person's exclusion, placement at a preferred setting or level of SEN support. However, no young people had experience of realising their right to appeal to First-tier Tribunal independently and in all cases involving appeals, parents and carers invoked this right. However, there were a number of cases in

which a child or young person alerted a parent or carer to the fact that they were unhappy at their educational setting which led to a parent or carer either independently securing a placement at an alternative setting or instigating an appeal.

In the majority of cases involving some form of dispute, the parent or carer referred to having tried to protect their child from undue anxiety and distress by limiting their involvement in any disputes. For example, *Aiden's* parents have been involved in a number of appeals and in his interview Aiden explained that he had only recently become aware that his mother had been 'battling [for a year] to get me to come here because it's really hard to get kids in here and that.' Aiden said was glad that he had not been involved and considered that his mother's efforts to challenge his right to be educated in an appropriate setting made him 'think that my mum will never give up'.

In another case involving *Jack* (7yrs, visual impairment), his parents considered themselves best placed to argue on behalf of their son in a dispute about his medical needs at school. Although they felt it was important for a young person aged 16 or over to be able to realise their rights to appeal, they considered that the young person would need considerable advocacy support in order to do this. They based this opinion on their own recent experience of trying to resolve a disagreement with Jack's primary school:

I think things like tribunals and things like that, even at sixteen, they would probably need a parent or someone there with them. We've had problems with schools before, the people like local authority and the schools and things are big places, and they don't tend to listen. And you do have to go to outside agencies to get them to listen to you sometimes...I found it stressful. I found it stressful. And there's a lot of people to ring, and a lot of different departments, a lot of different people to speak to. And it takes a lot to keep on top of it all and speak to them all and get them to communicate with each other. So I think they would probably struggle at sixteen.

This view was shared by another parent with recent experience of a dispute with the LA who explained that, '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.'

Another case concerned *Claire* (18yrs, SEMH), in which both mother and daughter attended an appeal meeting with the school's Board of Governors following Claire's exclusion from secondary school. Claire considered that her views and feelings were not respected or taken into account and she felt unable to go through that process again when a subsequent appeal meeting was held at the LA offices:

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's mother also added that due to her daughter's previous negative experience of attending an appeal meeting she decided not push her to attend any subsequent appeals:

You were too traumatised, I think, by the first one... They were very rude. They were very, very rude... The head was rude. The chair of the board was downright insulting. And then the inclusion officer, she was so rude. It was... you know when you just feel as though it's fixed? And she was, the chair of the board was just mocking me.

Although the appeal was decided in Claire's favour, it appears that she had little choice over whether or not to return to the school in question, since the appeal resulted in the school being

given two options: to either take Claire back, or pay a fine. The school decided to pay the fine. Claire described the effect that this decision had on her mental health as ‘devastating’.

Another case involving *Lizzie* (21yrs, MLD/ASD) highlighted some tensions around the extent to which parents and carers support their child to participate in appeal processes, whilst at the same time wanting to limit their exposure to adversarial contexts. In 2016, Lizzie and her family were involved in a First-tier Tribunal which eventually resulted in her securing a place at her preferred educational setting. Her parents had tried to support Lizzie to express her views and wishes and to enable her to participate as much as possible in the appeal process. Various sources of independent advocacy support had been helpful in that respect. Lizzie’s mother explained that Lizzie had been indirectly involved in the decision to appeal. She described how Lizzie’s participation in the process was also limited by a number of factors:

Lizzie was involved in the decision, but only in the sense that we asked her which college she’d prefer, we kept her informed of the process but she wouldn’t have known how to appeal, we didn’t, so we sought information from friends, Barnardo’s, Parent Partnership, National Autistic Society, Northern College, NATSPEC, solicitors and online parents etc. We had tonnes to learn in a short time, the process would have been too difficult for Lizzie and she hates conflict. She would have also found it difficult to fund, I think she would have been eligible for legal aid, but again I don’t think she could have applied without support and the process would have taken a lot longer, meaning she would have been out of education for a longer length of time. So I think without our help she wouldn’t have accepted the LA’s decision to go to [LA’s preferred] College, she probably would have stayed out of college.

Lizzie’s mother went on to explain that as parents, she and her husband had tried to protect their daughter from unnecessary distress concerning the decision to appeal the LA’s refusal to fund a place at the [parent and YP’s] preferred college:

She didn’t voice anything relating to seeing if we could help her get into [parent and YP’s preferred] College initially, as we had asked her not to worry about how we were going to get her there, we assured her if her wish was to go, we would try and make it happen. We asked her if she was happy for us to appeal on her behalf, which she was, she didn’t like having to be assessed or talked about.

Lizzie’s parents and advocacy workers from Barnardo’s also supported her to make contact with the Children’s Commissioner as part of another Children’s Rights initiative called ‘Takeover Challenge Day’<sup>9</sup>. The ‘Takeover Challenge day’ was originally launched in 2007 by the Office of the Children’s Commissioner as an activity that aims to encourage organisations across England to open their doors to children and young people to take over adult roles in order to be put into decision-making positions. It also aims to encourage organisations and businesses to hear their views. During Lizzie’s visit to the Children’s Commissioners office, which was organised by Barnardo’s as part of this initiative, she handed in a letter to the Commissioner outlining her difficulties in securing her preferred choice of educational setting. Lizzie’s letter is copied below:

*My Name is Lizzie, thank you for letting me meet you today.*

*I really like going to Barnardo’s and they help me a lot.*

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<sup>9</sup> For examples regarding this initiative see, <https://www.childrenscommissioner.gov.uk/2017/08/23/takeover-challenge-next-generation/>



*I am trying to get ready to go to college, but my Council have named a college on my EHC plan that I don't want to go to and is not suitable, so I have to go to a tribunal court this year and it feels very scary. The college I want to go to and can support my communication needs is residential and out of my local county.*

*I am autistic and like to plan and at the minute I can not plan my future. This whole appeal process is very stressful.*

*Thank you for reading, Lizzie.*

The Commissioner responded by supporting Lizzie's case in a letter addressed to the LA's Education Panel which drew attention to Lizzie's right to have her views, wishes and feelings considered in the panel's final decision.

Once the appeal reached the tribunal, Lizzie's family listened to her views about whether or not she wanted to attend the hearing and tried to facilitate her participation in a manner that respected Lizzie's feelings and wishes. Lizzie explained that she had chosen to 'come to the day' and wanted to visit the city and be with her family for the event but that she had not wanted to 'go into the court room'. During her research interview Lizzie demonstrated how the tribunal continues to remain a difficult subject to talk about:

...when the subject of the tribunal came up Lizzie whispered to dad that she had, had enough and wanted to stop. 'I want to go, I want to, I don't want to hear it anymore.' Mum confirmed that it was ok for Lizzie to leave as she became distressed and wanted to end the interview. Lizzie went off saying 'why me?' in relation to having to go through the process of the tribunal and eventually went inside. Mum and dad continued with the interview and spoke on her behalf. (Fieldwork notes – Diamond Ranking activity during home visit, 18-07-18)

The majority of parents and carers of young people considered that their child would have great difficulty in realising their rights of appeal independently. They based this pessimism on their own experience of difficulties with understanding and obtaining appropriate information, engaging with LA officials and realising their rights to appeal as parents or carers.

For example, when asked about her son's capacity to realise his rights under the CFA 2014 upon reaching the age of 16, *Peter's* mother felt that despite his age Peter was insufficiently mature and anyway would not want to be given responsibility to act on his own behalf:

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, so I think there--, and I don't think he'd want them, I don't think he'd want that responsibility. (Mother of Peter, 16yrs, ASD)

Kei's father also drew attention to concerns for young people with SEN who did not have a family to support them and felt that they would struggle to navigate the appeal process without significant support:

I would fear for children or young people who don't have parents to advocate for them. I would really worry because I just think, you know, our experience has been probably not even half as bad as quite a few other people, but it still often is, it's tricky to navigate and basically what ends up happening is you as parents end up doing an awful lot of it. Now if people don't

have-- , maybe they're in care or that kind of thing, they're not going to have that so who's going to do it for them? (Father of Kei, 17yrs, MLD)

Education professionals tended to offer a more optimistic view and demonstrated a commitment to supporting a young person's preferences. For example, one SENCO drew referred to instances where a pupil and parent may have a conflict of views about how they might be best supported:

As the students get older, often they don't want somebody with them all the time, and you can see that their progress isn't particularly good but they're being very vocal that they don't want somebody with them in the classroom. The parents are saying if you drop that support back they're not going to make the progress, and so it's trying to navigate through that, really, is often very tricky. You have to listen to the students' voice. Another example was a student who chose not to wear a radio transmitter to help them with their hearing in the classroom. The parent was absolutely adamant that they needed it and I said, you know, it's her choice if she doesn't want to wear it, and so we came to the decision that if her progress dropped off, she would then consider using it again.

### 3.7 Children and young people's experiences of collective participation

Examples of CYP's experiences of collective participation illustrated the extent to which feeling listened to and being able to instigate demonstrable change as a result of engagement led to children and young people having greater confidence in realising their rights and feeling valued.

This section highlights examples of how children and young people voice their opinions and contribute to collective consultation mechanisms such as school councils and LA SEND groups.

#### 3.7.1 Knowledge of school councils and engagement with them

All of the schools and colleges that case study participants attended had some sort of formal mechanism to elicit pupil voice, although pupils were not always aware of this. Just over half of the case study children and young people were aware of a school or college council and number of them had experience of participating as a school councillor at some point during their education. Primary school age children were less likely to know if there was a school council than secondary age pupils or college students (see fig.2).

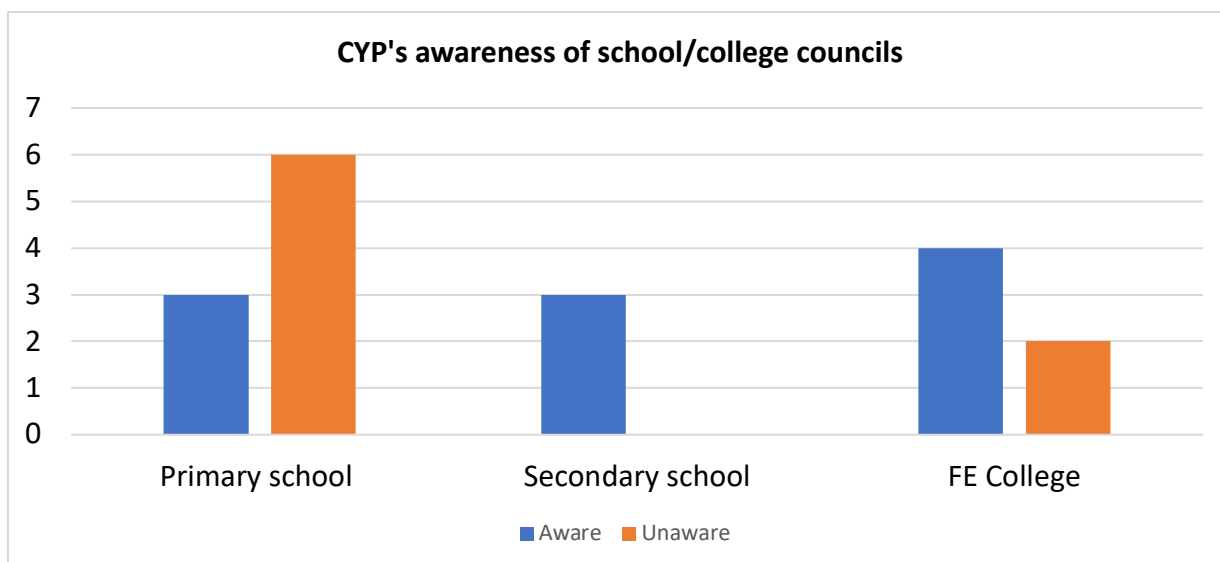


Figure 2: CYP's awareness of school/college councils (n=18)

In some cases, primary school children had misunderstandings about the purpose of the school council. For example, some pupils in faith schools conflated the aims of the school council with those of the worship group and litter picking duties.

One primary aged pupil demonstrated a lack of trust in the pupils elected onto the council, commenting that *'the people that are on the council, they are absolute snitches'*, although he had participated in school council elections.

In contrast, some primary school age children who regularly engaged with the school council felt confident that their views and feelings were listened to. For example, *Noah* (9yrs, SEMH/ADHD) was very proud of the fact that he is now a school councillor and explained that he attends school council meetings every Friday to discuss 'what we want to happen [in school]'.

Case studies provided illustrations of children and young people's experience of collective consultation mechanisms and illustrated the impact that 'having a say' and in some cases of being involved in instigating change had on their levels of self-confidence and understandings of participation.

For example, one young woman with SEMH stated that she appreciated having some say in decision making as a student representative on her college council. Despite encountering difficulties with other students being largely apathetic when she tried to elicit their input, she felt that the college had listened to the council on the subject of the provision of food and had made changes after listening to the council's views. *Claire's* mother also commented upon the positive impact that being listened to as a member of the student council and taking part in instigating change had upon her daughter's confidence and well-being:

Yeah, and she really liked that [being a student rep], she loved that... she really seemed to enjoy that, you know, giving her opinion and, you know, being involved, having a say. (Mother of Claire, 18yrs, SEMH, 4<sup>th</sup> Quintile)

Another pupil, *Aiden*, had a similar experience, and although he sometimes found it difficult to cope with the length of the meetings, he regarded his involvement with the school council as having 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)

A number of educational professionals recognised that, although their institutions provided spaces for students to engage in collective decision making, students with SEND were often under-represented. A few colleges and schools had tried to redress the balance in this respect and had taken steps to try and encourage more students with SEND to serve on student councils. One FE college has recognised that existing mechanisms to enhance 'student voice' are not always fully inclusive. The college is attempting to create a more inclusive, accessible space for its SEND students to contribute. The curriculum manager described how the college has recently employed two 'ambassadors for inclusion' with the aim of making student council meetings and activities more accessible and encouraging more students with SEN to join the student council:

We haven't historically [included SEN students on student council] and being honest it hasn't been a totally accessible set-up...I think our students have always said well, you know, we've been based off campus so it's a bit difficult for us to kind of attend 'cause we don't want to disrupt students' placements either... we've now recruited two Ambassadors for Inclusion looking at how actually they can engage with the student rep process. Some [SEND students], they want to be a rep but can't attend or take part in the standard format because it doesn't meet their needs, or it isn't accessible, or they find it too challenging to attend.

A secondary school SENCO explained that the school council also had a number of representatives with SEND and her department had actively tried to encourage pupils with SEND to participate.

One case, that of Laura, (17yrs, SpLD), also highlighted the need to actively engage with children and young people's views and drew attention to the problem that not taking a young person's view seriously can impact upon their levels of confidence in participating in consultation initiatives. When asked to comment about her experiences at college, Laura felt that the college was much more receptive to hearing positive views and did not support her to be able to voice other views and this contributed to her sense of disenfranchisement:

I: Does the college ever ask you about your rights?

R: We fill in a form once a year that says, 'Do you feel happy at college?' And most people say, 'Yes.' And I wrote them a short essay about why I said, 'No.' And I was never asked any questions on it afterwards.

I: Do any changes ever happen when you tell people how you feel?

R: I offered to be the geography representative, because I wanted to go and pick my bone with the Head about why I was having to [try and organise additional SEN support] by myself. And it was met with a, 'Well we'll talk about this another time, Laura.' But I want people to know that this is the way I feel and this is not okay.

### 3.7.2 Engagement with LA or third sector participatory groups

The case of a young person with SEND who is also care experienced drew attention to the importance of children and young people who cannot draw upon support from a parent or carer being able to access collective participatory groups in order that they may feel valued and that they have a stake in decision making processes which can lead to positive change:

I like to feel valued and appreciated because I have no family. I like to feel that I belong somewhere. 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, 22yrs, SEMH/ASD)

Another young man (Kei, 17yrs, MLD) became more aware of his rights as a young person with SEN after joining a local SEND participatory group. He explained that during one of his recent meetings he had become more aware of different cultural understandings of children's rights and forms of disability support. He added that as a result of the information shared at the meeting, he became more aware of differences between children's rights in other countries and was able to express an opinion about this.

Another young person, James, who is also a young carer for his disabled mother, was a member of the LA SEND partnership board and had had some input into deciding on the group's logo and some contact with important decision makers. He spoke about being able to offer candid opinions at these meetings and was keen to ensure that there was always a young person representative at every meeting at times when he is unable to attend. He also explained that participating within LA consultation groups has enabled him to make suggestions about improving the LA's communications with other children and young people:

R: One is the media group, so we'll look over the LA's [local offer] website... We'll liaise that back to them, saying it's not child friendly, can you do this, change this, or make it easier.

I: Do they listen to your suggestions?

R: Most of the time, yes. (James, 16 yrs, ASD/SpLD)

### 3.8 The role of the local authority (LA)

Our three LAs' areas differed in terms of size, levels of deprivation and distribution of SEND populations. This does not appear to be a significant factor in terms of CYP's knowledge of their participation rights or experiences of autonomous decision-making. Whilst most LA staff considered the ambitions of the CFA 2014 to be a positive move forward, difficulties in establishing a consistent and meaningful person-centred approach to EHCP processes, alongside managing increases in the volume and scope of SEND related workloads in times of austerity, was highlighted as a challenge across LA contexts.

Although the local authorities differ in terms of size, levels of deprivation and distribution of SEND populations, this does not appear to be a significant factor affecting the extent to which children and young people with SEND are able to access and realise their participation rights effectively. As noted in the preceding sections, the influence of individual and familial factors, access to socio-economic resources and availability of support from schools and third sector advocacy groups appears to be more influential in this regard.

Across each LA, frontline and senior SEND personnel appear to be conscious of the principles and statutory functions contained within the legislative framework set out within the CFA 2014. All of the LAs involved in the case studies drew attention to challenges that surround establishing cultures of co-production and developing greater consistency in person-centred practices across agencies

and institutions in times of austerity, increased workloads and high staff turnover. A summary of other issues that have been highlighted as working well or as areas that require further improvement, irrespective of type of LA, are summarised below.

What's working well?	What could be better?
'Draft meetings' with parents before EHC plans are written improves understandings of the process and reduces instances of conflict between the LA and parents.	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.
The focus on 'Preparing for Adulthood' is considered to be a useful mechanism to ascertain and include CYP's views and feelings about their future aspirations.	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.
LA Commissioning of 3 <sup>rd</sup> sector SEND participatory groups appears to enhance CYP's knowledge of rights and offers opportunities to develop skills and experience in collective decision making.	Provision of more dedicated groups for CYP to participate in collective SEND decision-making processes (e.g. 3 <sup>rd</sup> sector SEND participatory groups) in order to extend CYP's awareness of, and access to participation rights.
Signposting of independent advocacy services is welcomed by parents and carers as a very useful source of support; especially in cases of conflict or where there is a lack of trust in the LA.	Lack of consistency between education settings regarding the level of professionals' awareness of CYP's rights and understandings of EHCP processes.
Continuity of support from dedicated points of contact at LA SEND teams has been highlighted as improving communication between parents, carers and education professionals.	Parent, carer and YP's awareness and access to relevant information on rights and SEND provision made available through the local offer.

### 3.9 Conclusions

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.

As might be expected, each child or young person's SEND and capacity to understand and realise their participation rights as well as the level of support available to them from family members and

professionals is unique to him or her. However, a number of generalisations can be drawn in identifying the important factors which may affect the extent to which they can be better supported to understand and access their rights. Table 7 below adopts a person-centred focus in highlighting important factors that may promote or inhibit children and young people’s autonomy and access to information about SEND matters and corresponding rights.

*Table 7: Important factors affecting CYP's understanding and access to participation rights*

<b>What’s working well that we want to build upon?</b>	<b>What is not working well that we need to change?</b>
Prior experience of engaging in participatory groups and collective decision-making processes helps inform CYP of their rights and of what to expect from EHCP processes.	CYP’s lack of knowledge about their rights. Difficulties coping with communicating with unfamiliar adults and in unfamiliar contexts.
Personalised support from parent/carers and professionals which is sensitive to a CYP’s SEND, maturity, preferred mode of communication and aspirations can encourage greater participation.	Lack of professional time, resource or available staff to accommodate CYP’s specific support needs/wishes in EHCP processes.
Consistent approach and institutional commitment to involving CYP as far as possible in decision-making processes.	Parental/professional low level of understanding of CYP’s rights to participate and lack of clarity regarding responsibility for ascertaining CYP’s capacity.
Offering CYP autonomy in their level of involvement in EHCP processes/meetings.	Inconsistencies around inviting CYP to EHCP meetings, and the extent to which the CYP’s views are given by parent/carer.
Educational professionals providing information and support for parent/carers who have difficulties accessing information regarding SEND matters and legal rights.	Inconsistencies between settings/professionals in the level of information and support offered to families about SEND matters and their rights.
CYP’s positive experience of engaging in individual/collective decision-making contexts that facilitate change as a result of listening to CYP’s views	Lack of feedback or acknowledgement of CYP’s views within consultation initiatives.
Schools/colleges signposting information on SEND matters & rights. Hosting meetings that offer independent advocacy/3 <sup>rd</sup> sector participatory SEND groups	Local offer – parent/carers’ lack of awareness. Some find the offer inaccessible due to information overload or poor signposting.
Schools and colleges adapting EHCP forms & adopting creative responses to include CYP’s views within EHCP processes.	Language and layout of some LA EHCP forms is difficult for CYP and parent/carers to access.
Parent/carer or teachers supporting CYP to develop confidence in expressing views.	CYP or parent/carer lack of confidence in expressing own views with professionals.
Parent/carers in/formal networks sharing information on SEND matters and sources of advocacy support.	Lack of trust in LA or education professionals.
Commitment and access to training on person-centred approaches across agencies.	Lack of resources/access to training to deliver person-centred approaches in different educational settings.
Parent/carer’s positive experiences of accessing advocacy support. SENDIASS/3 <sup>rd</sup> sector groups.	Involving social care and health professionals in EHCP processes.

Analysis of children and young people's participation in SEND decisions within the case studies has indicated that 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 differential access to a range of socio-economic resources, 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 SEND groups. The vast majority of children and young people relied heavily upon their parent or carer's 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 SEN 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 equality in being informed about their rights, or the same level of participation in discussions and decision-making processes regarding their education and support. Issues surrounding professionals' access to sufficient resources to consistently undertake a 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 by them 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 the responsibility for ascertaining capacity to understand their rights and to participate 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 appears to be welcomed by parents, carers and professionals working in the field. An increased focus on person-centred practices and a commitment to children and young people's rights to participate in decisions about their education and support are broadly seen in positive terms. However, there are tensions that surround institutional aspirations to offer a more participatory approach which is flexible enough to treat every case according to 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 wide 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 the rights 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.



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## ***Appendix 1: CYP case study profiles***

### **Bigtown case studies**

**Alice** is 10 years old. She has a diagnosis of ADHD and a history of difficulties in managing her behaviour and emotions which has led to a number of exclusions. She lives in an area of significant deprivation located within the 1<sup>st</sup> quintile of the IMD with her parents, who are both unemployed, and three siblings. One of her brothers also has a diagnosis of ADHD and attends a local special secondary school. Alice attends a mainstream primary school which is part of a Multi-Academy Trust. Alice does not have an EHC plan and is supported by a TA and class teacher within the classroom at the level of SEN support. There are concerns about Alice's ability to cope when she makes the transition to high school and an application for an EHCP assessment is underway. Both Alice and her parents have very little knowledge of their rights. In her free time, Alice likes to play with her baby doll, watch television and go on YouTube.

**Maleeha** is 12 years old and is a very polite, unassuming young girl who has albinism. Her albinism creates physical difficulties with her vision and also has implications for her social development in terms of her different appearance to that of the rest of her family. Maleeha lives at home with her mother, father and two younger sisters in a small village located on the outskirts of Bigtown, within the 3<sup>rd</sup> quintile of the IMD 2015. Maleeha attends a mainstream high school and has some awareness of her rights but is also reliant upon her parents to support her with advocacy and decision-making. Maleeha's father encountered some difficulties obtaining additional support for his daughter whilst at primary school but eventually managed to secure agreement for an EHCP which included TA support for 25 hours per week upon her transition to high school. Maleeha enjoys being outdoors and participating in outdoor activities such as ball games, cycling (in a controlled environment) and PE.

**Lyron** is 9 years old and has ASD. He is an only child. Lyron lives at home with his mum in an area of significant deprivation. Lyron has an EHCP and attends a resourced provision (RP) with 6 other pupils within a mainstream primary school. Twice a week, Lyron joins the rest of his peers in the mainstream classroom and is supervised by a TA during this time. Lyron's mother has advocated on his behalf in order to gain a placement at the RP after his being at risk of being permanently excluded from his previous primary school. Lyron is currently unable to join his peers at lunchtime or playtimes due to multiple incidents of violent behaviour and continues to be at risk of further exclusions. When Lyron is older he would like to work in football and have his own family and his own house.

**Jacob**, 22 years old, has a diagnosis of SEMH and ASD. He has experienced significant trauma in his life and has been in and out of care since the age of two and was later adopted. He has no contact with his birth parents or siblings. Jacob has an EHCP and has recently completed a supported internship. He lives independently in a supported tenancy which is located within the 1<sup>st</sup> quintile of the IMD. Jacob is an active member of multiple third sector and LA SEND/LAC participatory groups and Trust Boards. He is very passionate and knowledgeable about children and young people's rights. Jacob has a close relationship with his leaving care worker and has been supported by her for the last six years. Jacob has recently secured part-time employment working for the LA and enjoys living independently and spending time with his girlfriend.

**Maria**, 9 years old, has a diagnosis of severe persistent learning difficulties. She is the youngest child in her family and has five older brothers and sisters. Maria lives at home with her parents and three of her siblings in an area of significant deprivation. Two of Maria's siblings also have SEN. Maria has an EHCP and attends a mainstream primary school where she is supported by a TA for 25 hours per

week. Both Maria and her mother have very little awareness of their rights and have relied heavily upon the school SENCO to access SEN information and support. Maria's mother and teaching professionals describe her as a sociable girl and a confident member of the class who is well liked by her peers. In the future, Maria would like to be a police officer during the daytime and a Rockstar at night.

**Peter**, 16, has a diagnosis of autism. He is a cheerful and talkative young man who is currently studying for his GCSEs at a mainstream secondary school. Peter lives in a small affluent village which is situated within the 4<sup>th</sup> Quintile of the IMD with his mother, father and two younger siblings. Peter has an EHCP and is supported by a TA for 20 hours per week. His mother spends a significant proportion of her time supporting Peter and has been a very proactive advocate in support of his SEND rights. Peter has some understanding of his rights and has supported the rights of other students at his school. His mother has a very good understanding of SEND rights and has been involved in an appeal regarding Peter's school placement. When Peter leaves school he would like to pursue a career in computing or gaming.

### Northshire case studies

**Noah** is nine years old and has been living with his foster family since he was five. Noah has witnessed a significant amount of trauma in his early years and has a diagnosis of PTSD and ADHD. He lives with his foster carers in their home located in a small town within the 1<sup>st</sup> quintile of the IMD. Noah's foster mother describes him as a, 'very lively young man who likes to be liked'. Noah has an EHCP and attends a state-maintained special school where he is supported by a high ratio of adults to pupils. He has had limited input in choice of school due to previous exclusions and limited availability of appropriate places. His foster mother and educational professionals have advocated for his right to secure a placement at his current school. Noah is a school councillor and has some understandings of his rights but is very reliant on adults to support him participating in decisions about his education and care. When Noah is older, he would like to be a motorbike stunt rider or a BMX rider.

**James**, aged 16, has a diagnosis of Asperger's Syndrome and SpLD. He also has a history of being permanently excluded from a number of secondary schools. James is a young carer and lives with his mother who is disabled and has limited mobility. They live in a small town which is located within the 4<sup>th</sup> quintile of the IMD. James' mother described her son as 'a really good lad' who likes to please. James has an EHCP and attends a SEND unit within a mainstream FE college and is also very active in a number of LA and 3<sup>rd</sup> sector participatory groups. He has a good understanding of CYP's rights and hopes to pursue a career in family or criminal Law in the future. James' mother has also advocated for her son's rights and has accessed independent advocacy support to assist her with navigating LA appeal and EHCP processes.

**Aiden** is 13 years old and has a diagnosis of ASD. He is an only child and lives with his mother and father in a small town on the edge of the countryside, located within the within the 5<sup>th</sup> quintile of the IMD. Aiden's mother also has a diagnosis of autism. Aiden's mother described her son as very loving and explained that he had a great sense of humour. Aiden has an EHCP and attends an independent, special secondary school with a high ratio of adults to pupils and has access to a range of therapeutic interventions. Aiden is a school council member but relies upon his parents to argue for his rights. Aiden has a history of multiple exclusions and his mother has been very proactive in seeking to uphold his rights. In the future, Aiden would like to follow the family tradition of a having a military career or work as a 'pro YouTuber'.

**Kei**, 17 years old, has a diagnosis of global learning delay. He encounters difficulties with co-ordination, some aspects of communication and memory loss due to Neuronal migration disorder. He lives with his mother and father and sister at their home in a small town in Northshire which is located in the 5<sup>th</sup> quintile of the IMD. Kei, who has an EHCP, attends a SEND unit at a local FE college and is enrolled on the foundation learning course within the essential skills department. He has recently joined a 3<sup>rd</sup> sector participatory group for CYP with SEND. Kei's father describes his son as a very placid, cheerful young man. Kei has some understanding of his rights but continues to be very reliant upon his family to promote them. Kei is not sure what kind of job he would like but he hopes to be able to live independently or with a friend in the future.

**Lizzie** is 21 years old and has global learning delay and autism. She lives with her mother, father and younger brother at their home in Northshire in a small village located within the 5<sup>th</sup> quintile. Lizzie has an EHCP and attends an independent special FE college in a neighbouring LA. During term-time, Lizzie lives with a host family and has recently learnt to travel to college independently. She also attends a 3<sup>rd</sup> sector participatory group and has a good understanding of some of her rights. Lizzie is very reliant upon her parents and significant adults to support her with decision-making and express her views. Her parents have accessed a number of independent sources of advocacy support and were involved in a First-tier Tribunal regarding a dispute with the LA over the FE placement. In the future, Lizzie would like to work in catering or in a library and to live independently.

**Samuel**, aged 9, has difficulties with his social, emotional and mental health, especially with regards to attachment. Samuel is the second eldest of five siblings. He and his elder sister were placed with a foster carer on a long-term placement two years ago. They live with their foster carer in a small village which is located within the 1<sup>st</sup> quintile. Samuel does not have an EHCP and attends a state-maintained, mainstream primary school. He is supported by a TA and accesses a number of therapeutic interventions at the level of SEN support. Samuel is described as a cheerful, energetic boy who is passionate about football. Samuel is unaware of his rights and is reliant upon his foster carer's, social worker's and SENCO's advocacy on his behalf.

### **Greenshire case studies**

**Laura**, aged 17, has SpLD. She lives at home with her parents and younger brother on a farm located in a small hamlet within the 5<sup>th</sup> quintile of the IMD. Laura experiences significant difficulties with reading and writing and this has impacted upon her ability to fully participate in her preferred A-Level subjects. Laura does not have an EHCP and is studying at a mainstream FE college. She is described as a very articulate, determined and independent person by her mother and teaching staff. Laura's mother has been very active in representing her interests throughout her education but has recently experienced a period of ill-health. Laura has some awareness of her rights and as she has matured, she has taken a much more independent role in voicing her own views and opinions about decisions on additional support in college. In the future, Laura hopes to pursue a career in illustration.

**Ben** is 10 years old and has SLCN and MLD. He has limited speech and uses a range of technologies to communicate his views. Ben lives at home with his parents and two siblings in a small village located in the 3<sup>rd</sup> quintile. He has an EHCP and attends a state-maintained special school academy. Ben's mother described him as 'a happy, lovely little boy' who is really determined but can also be very compliant. Both Ben and his mother have very little awareness of their rights and his mother relies on the expertise and opinions of education and health professionals concerning her son's access to SEN support. In his free-time, Ben likes to go swimming and horse-riding and he is very keen on football.

**Jack** is 7 years old and has epilepsy and very poor vision. He is an only child and lives with his parents in a small village on the outskirts of Greenshire within the 3<sup>rd</sup> quintile of the IMD. Jack has an EHCP and attends a mainstream primary school where he receives 15 hours of support from a dedicated TA. Jack is described as very confident and cheerful. He has very little awareness of his rights. His parents have advocated on his behalf on a number of occasions. They have also accessed support from independent advocates and health professionals. In his free time, Jack enjoys swimming, writing stories and watching You Tube on his tablet.

**Frank** is aged 9 and has a diagnosis of autism and MLD. He lives with his mother and two older, adult siblings in a small town located on the outskirts of Greenshire within the 4<sup>th</sup> quintile. Frank has an EHCP and attends a state-maintained special school academy. He is in a small class with a high ratio of adults to pupils. Frank's mother described her son as a, 'sensitive and intelligent boy' and explained that routine was very important to him. Both Frank and his mother have very little awareness of their rights and are reliant upon education and health professionals to understand and realise their rights. In his free-time Frank enjoys playing video games and feels that it is important for him to be happy and to spend time with his friends.

**Claire** is 18 and has SEMH difficulties. She is an only child and lives with her mother in a small town in Greenshire located within the 4<sup>th</sup> quintile of the IMD. Claire has a long history of being excluded, or being on the verge of exclusion and being asked to move from both primary and secondary schools. She has also spent some time at a pupil referral unit before joining her current FE College. She studies BTEC Level 2 Science at college. Claire does not have an EHCP and both she and her mother have refused to grant permission for an EHCP assessment. Claire accesses some pastoral and academic support at college. Claire's mother acts in support of her daughter in times of crisis and has accessed independent advocacy support on numerous past occasions. Both Claire and her mother have been involved in a number of disputes regarding Claire's exclusions. Claire has some understanding of her rights and is very able to articulate her feelings and views. Claire hopes to study for a Level 3 Beauty Therapy course next year.

**Chloe** is 8 years old and has autism and MLD. She lives at home with her parents and older brother, who is also autistic, in a small town within the 3<sup>rd</sup> quintile of the IMD. Chloe has an EHCP and attends a state-maintained special school academy in small class of pupils considered to be the most able in the school. Chloe is described as very talkative, cheerful and bright and demonstrated that she is very articulate and able to understand some of her rights. Chloe's mother has very little awareness of her rights and is heavily reliant upon the class teacher for information and support regarding her daughter's education and SEN provision. Chloe would like to learn how to sing and to be a teacher or work in computing when she is older.

## Bigtown LA profile

### Summary

- The LA serves a predominantly urban area which has a growing population and has some of the most deprived communities in the country.
- The IMD 2015 ranks Bigtown within the first quintile and levels of deprivation are high across the authority.
- The overall proportion of pupils with SEND is 1.3 percentage points higher than the national average.
- Special schools and resourced provisions in mainstream schools are now reaching capacity and a number of children with EHCPs are placed in special schools in other boroughs.
- Requests for statutory assessments are on the increase and this is also resulting in a rise in new EHCP's issued by the authority. The proportion of pupils with an EHCP (3.1%) is slightly higher than the national average (2.9%).
- There has also been an increase in the numbers of EHCPs issued for children in Early Years provision and YP aged 20-25yrs.
- The LA consider that skills and expertise in EHC plan writing are improving as a result of more experience and training. Early EHC plans are in the process of being revised and re-written where necessary.
- There have been almost double the amount of mediations in 2018 than in 2017, but almost a third fewer SEND tribunals in the same period. The number of SEND appeal cases registered in 2018 was reported to be 0.6 percentage points lower (per 10,000 school population) than nationally.
- There is high emphasis placed on embedding cultures of co-production throughout the authority and the LA reports that training around SEND provision and services was a priority prior to the 2014 reforms.
- The LA has extended the reach of its Local Offer to a wider audience but acknowledges that further work needs to be done in terms of enhancing the content and accessibility and is consulting with CYP and families on this.
- There is a Children's SEND Board and a Local Offer Review Board which consults with children, young people with SEND and their parent/carers.
- The LA has a well-established model of co-production for working with parents and carers, the participation of CYP is less well developed. Further initiatives aimed at extending CYP's participation have been included in future strategic planning.
- The city subscribes to the social model of disability and aspires to be a disabled friendly city in the future.

### LA profile

Bigtown city council serves a population of 545,500 residents situated within predominantly urban and densely populated areas. Just under two-thirds of the population fall within the White broad ethnic group. The remainder of the population is made up of a variety of different ethnicities, including a significant proportion of Asian /Asian British residents and Black/African/Caribbean residents. The proportion of pupils attending state-funded primary, secondary or special schools whose first language is believed not to be English is significantly higher than the national figure across all sectors. In secondary and special schools, the proportion of pupils with English as an additional language is more than double the reported national average. Bigtown's population is also steadily increasing due to migration patterns and higher birth than death rates; the increase in its population in 2016 (2.2%) was much higher than that recorded nationally (0.2%). The IMD 2015 ranks Bigtown within the first quintile and levels of deprivation are high across the authority. The local authority has a lower proportion of its population in employment than the national average

and unemployment rates are 0.7 percentage points higher than the national average. Just over a third of households in Bigtown are owner occupiers, compared to 64% of households nationally.

### **SEND provision context**

The proportion of pupils with SEND (15.9%) is higher than the national average (14.6%). There were just over 3500 children and young people aged 0-25 years with an EHC plan in 2018. Bigtown has reported a 61% increase in the number of EHCP's since 2015 and attributes the overall growth in the child population in the area as a significant factor contributing to the increase. Alongside this, there has also been an increase in the numbers of young people with EHCPs that are aged between 20-25 as well as a significant increase in the numbers of early years pupils being issued EHCPs. This indicates that children are having their needs identified at an earlier age than was the case before the implementation of the CFA 2014; 19.4% of new EHCPs were issued for the under-fives in 2017/18. The number of children with needs met through SEN support (12.9%) is also slightly higher than the national average (11.7%).

### **Independent advocacy and disputes**

Parents, carers and young people are able to access a confidential and impartial, dedicated SEND helpline in addition to a range of other advice and support services which are available via face to face meetings or email contact. National and local charities, organisations and advocacy groups are well signposted within the Local Offer on numerous different pages. The LA report that there has been increased demand for IAS services in supporting parents and carers in school meetings. In order to extend the capacity of the current IAS services, parent champions who have undertaken independent support training are also offering additional support to other parents. From January to October 2018, Bigtown has spent £37,495 on 104 mediations. This is nearly double the number at the same point last year. The number of tribunal cases in 2018 was reported to be 0.6 percentage points lower (per 10,000 school population) than nationally.

### **Training**

The LA report that training around SEND provision and services was a priority prior to the 2014 reforms. Since the inception of the 2014 Act, the LA also provides 'Person-centred Practices' training for frontline education, health and care staff and their managers. Training sessions have also included sessions that are delivered by parents and carers. In addition, senior managers from education and social care have also delivered SEND awareness raising sessions with Children's Services staff regarding the LA's statutory responsibilities. Some staff have also received training such as by IPSEA on SEND Law. There are also a number of SEND network meetings that share training provision across a number of agencies, schools and colleges.

### **The Local Offer**

The LA's Local Offer (LO) was co-produced with parents, carers, schools, colleges and other agencies who continue to participate in the further development of the LO via the Local Offer Review Board. The LO website has extended its reach to a wider audience since it was first published in 2013 and visits to the site have increased by 87%. The LA acknowledge that one area of concern is that too many families do not yet know about the LO and find it difficult to find the information they need. In response, the local authority is developing a publicity campaign in 2019 which will use traditional methods and social media to publicise the LO and other ways of getting information, advice and support. IAS has been involved in publicising the LO to a wider audience through its helpline and are also actively involved in raising awareness of the LO via the implementation of the parent champion model. Monthly Local Offer drop-in sessions are also offered in a range of local settings which are supported by IAS engagement teams alongside representatives from the Parent Carer Forum, parent champions and early help practitioners. These sessions are aimed at reaching residents who cannot easily access or navigate the LO website.

### **CYP participation in strategic decision making**

There is a Children's SEND Board and Local Offer Review Board which regularly consults with CYP and views are shared with the LA strategy work programme. Since the LO was first published, feedback from young people has led to changes in the overall layout and navigation of the LO and video content has been added in order to enhance access for younger audiences. The LA acknowledges that although it has a well-established model of co-production for working with parents and carers, the participation of children and young people is less well developed. A project manager has been appointed by the LA to develop further initiatives aimed at extending children and young people's participation in strategic planning. The LA is currently working with a local Youth Network to recruit and train eight youth ambassadors by April 2019. They will represent the voice of children and young people at the Local Offer Review Board, the SEND Board and the LA Disability Board.

### **CYP participation in own cases**

The LA considers that the default position is for children and young people to always be invited to attend EHCP reviews. An audit of EHCPs has also been recently completed to see if the voice of the child or young person is influencing the outcomes and provision in their plan and if plans are sufficiently aspirational. The findings are supporting the development of a toolkit for professionals on effectively capturing young people's voice. The toolkit is being co-produced with children and young people, schools, colleges, parents, and SEND teams.

### **LA perspectives**

#### *Views on the challenges of meeting statutory requirements of the CFA 2014*

- Due to the large volume of EHC plans that the LA maintain, this causes significant challenges in terms of having sufficient staff to attend EHCP meetings and that as a result the LA is heavily reliant upon schools to support CYP's participation in EHCP review processes.
- LA SEND staff consider that some settings are more proficient than others in including a child or young person's voice in the EHCP. Schools have subsequently been allocated a dedicated LA SEND case manager contact in order to offer additional support and training for recording CYP's voice and aspirations in EHC plans.
- All staff involved in all aspects of the reforms have experienced a significant increase in workload.
- The LA also expressed concerns about a rise in requests for EHCPs being led by school's being unable to meet SEN support needs within the nominal £6000 threshold.
- The LA also has a high level of population movement and families migrating to the city from overseas. Often children and young people with SEND arrive with no medical records and families do not always speak English. This creates challenges for the LA in terms of planning and allocating SEND resources and also in accessing the voice of a child or young person.

#### *Views on the merits of the CFA 2014*

- There has been a significant focus on embedding person-centred practices throughout the authority and a number of training events have been delivered to LA SEND staff which have been well attended. As a result, the LA considers that schools and colleges are adopting a much more person-centred focus which has led to CYP having more of a say about their education and care.
- Staff working on the LA Statutory Assessment team consider that Preparing for Adulthood and person-centred planning elements of EHCP processes can enable professionals and families to take account of the social needs and future aspirations expressed by young people, rather than just focus educational needs, as was considered to be the case prior to the CFA 2014.



## Northshire LA profile

### Summary

- The LA serves a large and diverse population of CYP with SEND distributed across a variety of urban, rural and coastal areas that include some of the wealthiest and most disadvantaged communities in the country.
- The IMD 2015 ranks Northshire within the third quintile and levels of deprivation are mixed across the authority.
- Significant areas of weakness were identified as a result of a recent joint inspection of SEND services undertaken by Ofsted and the CQC.
- The overall proportion of pupils with SEND is 1.7 percentage points lower than the national average.
- There are a large number of different SEND provisions spread across the LA and the recent inspection drew attention to inequalities in provision based on location.
- The number of CYP with an EHC Plan (3.0%) is consistent with the national average (2.9%).
- The quality of EHCP's has been identified as poor.
- The number of SEND appeal cases registered in 2018 was reported to be 2.1 percentage points lower (per 10,000 school population) than nationally.
- Northshire's IAS was highlighted as an area of strength in the LA's recent inspection as a service which supports parent/carers in resolving disputes successfully.
- Person-centred training is mandatory for SENCo's and provided for most frontline SEND staff. Weaknesses in understanding and adopting practices of co-production were identified in the recent Ofsted/CQC inspection.
- Parents' awareness of the local offer has been identified as poor and it is currently being redesigned in consultation with CYP and families.
- The LA has created a SEND Partnership Board which includes representatives from education, health and social care professionals, CYP, parents and carers, teachers and third sector groups.
- The LA commission a young people's participation group who have created peer resources to support a greater understanding of SEND rights.

### LA profile

Northshire LA serves a large population (over one million) living within some of the wealthiest and most disadvantaged communities in the country which are situated within a variety of urban, rural and coastal areas. The IMD 2015 ranks Northshire within the third quintile and levels of deprivation are mixed across the authority. The majority of the population in Northshire falls within the White broad ethnic group (89.7%). The remainder of the population is made up of a variety of different ethnicities, including a significant proportion of Asian /Asian British residents (6.1%). Some parts of Northshire are much more ethnically diverse than others. The most recent LA Children and Young People's Plan reports that there are over 140 different languages spoken by children attending schools in Northshire. However, the proportion of pupils whose first language is not believed to be English attending a state-funded primary, secondary or special school across the LA is lower than nationally. The authority has a slightly higher proportion of its population in employment (76.5%) than the national average (75.0%). 71% of households in are owner occupiers, compared to 64% of households nationally.

Due to the large size of the LA, administration is split into three areas. There is a wide variety in levels of deprivation and types of need throughout each area and this was identified by LA officials as a particular challenge in terms of developing appropriate SEND provision and meeting diverse

needs. For example, the authority includes seaside towns with very transitional movement of populations, leafy middle-class suburbs and some of the most deprived towns in the country with very high levels of unemployment.

### **SEND provision context**

The overall proportion of CYP with SEND in Northshire (12.9%) is lower than in England as a whole (14.6%). The proportion of pupils receiving SEN Support in Northshire (9.8%) is also lower than national percentage (11.7%). The number of CYP with EHC Plan (3.0%) is consistent with the national average (2.9%). Just under 6,500 children and young people aged 0-25 years in Northshire had an EHC plan in 2018. Across the LA there are differing levels of capacity to meet demand for all school places due to the uneven spread of the population across diverse geographical contexts.

The LA has recently had a joint inspection of SEND services undertaken by Ofsted and the CQC. This inspection found that a 'written statement of action' was required because of significant areas of weakness in the local area's practice. As a result, a SEND Partnership Board which includes representatives from education, health and social care professionals, CYP, parents and carers, teachers and third sector groups has been established to oversee SEND decision making and improve current provision.

### **Independent advocacy and disputes**

Northshire's IAS was highlighted as an area of strength in the LA's Ofsted report as a service which supports parent/carers in resolving disputes successfully. The number of SEND appeal cases registered in 2018 was reported to be 2.1 percentage points lower (per 10,000 school population) than nationally. LA officials reported that the numbers of tribunals have been stable and do not appear to have altered as a result of the new reforms. However, the LA report that the majority of families do not appear to take up opportunities for engaging in mediation processes and often opt to move straight to an appeal. Very few young people engage with mediation or IAS services independently and those that do tend to be supported by parent/carers. National and local charities, organisations and advocacy groups are well signposted within the Local Offer on numerous different pages.

### **Training**

According to the latest Ofsted and CQC inspection, co-production is not happening consistently and there is a lack of understanding within the LA about what co-production means. Person-centred training is mandatory for SENCOs and is provided for most frontline SEND staff. Ensuring that all relevant members of staff receive this training can sometimes be difficult due to high levels of staff turnover. Other forms of related training such as mediation support can also be accessed as part of an individual's PDP on a voluntary basis.

### **The Local Offer/provision of information**

The recent Ofsted inspection reported that parents' awareness of the Local Offer is poor and does not always provide parents with the information that they need to access the right service in the easiest way possible. The SEND Local Offer is currently being redesigned in consultation with CYP and families and members of the SEND partnership Board. There is also a Local Offer Facebook page and a quarterly Family Information Network Directory newsletter which publicises information and signposts sources of advice and advocacy support which is made available to families who have signed up to the directory.

### **CYP participation in strategic decision making**

There is a Northshire Participation Network which is a multi-agency partnership comprising key services, organisations and settings in Northshire. This network links directly to the Northshire

Children and Young People's Trust and includes CYP in partnership to embed and improve participation. There are a number of participation structures and mechanisms by which the LA consults specifically with CYP. Some of these groups are aimed at disadvantaged groups such as looked after children, young carers or CYP with SEND. The LA commissions a young people's participation group who have created peer resources, films and guides aimed at supporting CYP with SEND to be better informed about their rights and about participating in decision making. Within the authority it has been identified that CYP with SEMH difficulties are under-represented in strategic decision-making contexts and CYP with autism tend to be over-represented.

### **CYP participation in own cases**

The LA considers that the default position is for CYP is to always be invited to attend EHCP reviews. Decisions regarding a CYP's capacity and levels of participation are taken on a case by case basis and at multi-agency levels which would usually also include the views of the parent/carer.

### **LA perspectives**

#### *Views on the challenges of meeting statutory requirements of the CFA 2014*

- The LA considers that promoting integration and joint commissioning arrangements presents one of the biggest challenges to meeting the statutory requirements of the CFA 2014. The LA PEP commented that different performance indicators for health and social care contribute to difficulties in joint working across agencies, services and institutions.
- Representing the voices and identifying the needs of CYP with SEND which are spread across such a large and diverse LA population was identified as major challenge in terms of facilitating meaningful participation and consultation in strategic decision making.
- There has been a considerable increase in workload due to transferring statements of SEN to EHCPs; the extension of age range up to 25 and lack of time and resources required to move towards more person-centred practices were cited as factors contributing to increased workloads.
- Lack of understanding around Supporting PfA and post 16 SEND provision was identified as an area for which there is a 'massive learning curve' as with coping with increased numbers of 19-25s included in the EHCP process. The LA also referred to the fact that FE colleges are much bigger institutions than schools and that co-ordinating approaches between the FE sector and LA can be difficult due to the numbers of different personnel involved.
- Accessing CYP's voice meaningfully within EHCP processes and being able to invest sufficient time and resource to adopt a person-centred approach were also highlighted as a challenge.

#### *Views on the merits of the CFA 2014*

- The PEP considered that the PfA element of the new reforms was, 'a great move forward in the current practice'.
- The LA considers that aspirations to place children and families at the heart of SEND decision making and create spaces for CYP to express their views represent a positive move forwards as long as efforts are undertaken to ensure that CYP's engagement is meaningful and led by the principles of co-production.

## Greenshires LA profile

### Summary

- Greenshires LA has a relatively small population which is distributed across a large number of rural areas alongside a number of more densely populated towns.
- The IMD, 2015 ranks the LA within the 4<sup>th</sup> quintile and levels of deprivation are low with minimal levels of unemployment.
- The overall proportion of CYP with SEND in Greenshires is close to the national average.
- Specialist state-maintained SEND educational provision across the authority is limited. Additional specialist provision is provided by neighbouring local authorities and independent specialist providers.
- The proportion of CYP with an EHC plan is higher than the national average.
- The SEN team is organised according to age group rather than specific SEND functions. This has the advantages of enhancing relationships with CYP and families and delivering continuity of support.
- Time-scale pressures to convert existing SEN statements to EHCP's impacted on the extent to which children and families participated in the process and affected the quality of plans. Early EHC plans are in the process of being revised and re-written where necessary.
- The LA have very few SEND tribunal cases. In 2018 the rate of SEND appeals registered per 10,000 of the overall school population was 0.5%. This is 5.0 percentage points lower than the national average.
- The LA has recently introduced a 'draft meeting' with parents before EHC plans are written in order to improve understandings of the process, enhance relationships with families and reduce instances of conflict between the LA and parents.
- Person-centred training has been delivered to all members of the SEND team and has been offered to social care and health practitioners as well as a range of educational settings. The LA is actively trying to encourage more schools to take up person-centred training.
- The 'Local Offer' section of the LA website sets out a comprehensive selection of advice and guidance specifically aimed at a number of different audiences which is easy to navigate and is fairly accessible. CYP were consulted in schools and colleges via a range of mechanisms when the LO was created.
- There is a 0-25 SEND Strategic Board in Greenshires includes representatives from services and organisations who work with children and young people with SEND and their families, including a parent carer representative.
- The LA has a well-established model of co-production for working with parents and carers, the participation of children and young people is less well developed.
- Currently, there are no exclusive children's or young people's forums or groups that provide a dedicated space for children and young people with SEND to participate in LA strategic decision making.

### LA profile

Greenshires LA has a relatively small population (approximately one third of a million), residing within a mixture of urban and rural areas. The population is predominantly white (95.4%), with very few residents of BME heritage. The proportion of pupils attending state-funded primary, secondary or

special schools whose first language is not believed to be English is significantly lower than the national average across all sectors of school. The authority encompasses a number of affluent areas and has a higher proportion of its population in employment (77.7%) than the national average (75.0%). The majority of households in Greenshire are owner occupiers (70%) compared to 64% of households nationally. The IMD, 2015 ranks the LA within the 4<sup>th</sup> quintile and levels of deprivation are low with minimal levels of unemployment. However, there are some small pockets of deprivation, where residents live in the 20% most deprived areas of England.

### **SEND provision context**

The overall proportion of CYP with SEND in Greenshire (14.5%) is close to the national average (14.6%). The proportion of pupils receiving SEN Support in Greenshire (11.0%) is slightly lower than national average (11.7%). The number of CYP with an EHC plan (3.5%) is higher than the national average (2.9%). Just over 1800 children and young people aged 0-25 years in Greenshire had an EHC plan in 2018. Greenshire's population is sparsely distributed across a large number of rural areas alongside a number of more densely populated towns. This presents a significant challenge, in terms of ensuring ease of access to both mainstream and special school SEND services and support. Specialist state-maintained SEND educational provision across the authority is limited. Additional specialist provision is provided by neighbouring local authorities and independent specialist providers; Greenshire has 5.3% of learners with EHC plans attending independent specialist provision. Due to the small size of the LA, the management of EHC plans within the county is organised according to key stage and there are SEND case managers who support CYP and families throughout the whole process from initial request to on-going reviews. Continuity of support has been highlighted by the LA as contributing to fewer disputes and enhanced communication between the LA and children, families and schools.

### **Independent advocacy and disputes**

National and local charities, organisations and advocacy groups are well signposted within the Local Offer on numerous different pages. Greenshire has a very few SEND appeal cases. In 2018 there were just two SEND appeal cases registered, equivalent to a rate of just 0.5% per 10,000 of the overall school population and considerably lower than the national average rate of 5.5%. During the last twelve months Greenshire has also introduced a, 'draft meeting' which is not a statutory requirement but rather a LA initiative where the SEN case manager meets up with a child's parent before the EHCP is written in order to confirm that the plan best reflects the pupil and parental view. The LA considers that although this process has increased workload, the hope is that it will reduce miscommunication and prevent future conflict and is a case of, 'investing time to save time'.

Responses from the members of LA staff interviewed indicate that it appears to be very rare that a young person will instigate formal routes of redress in Greenshire. Staff acknowledged that improving children and young people's attendance and participation in disagreement resolution is an area that the authority needs to consider in more detail. Very few young people engage with mediation or IAS services independently and those that do tend to be supported by a parent or carer. Where CYP are included in some aspects of mediation meetings, the wellbeing of the CYP takes precedence and they often do not stay for the entire meeting or alternatively elect to have their views represented by an adult.

### **Training**

Person-centred training has been delivered to all staff working within the SEN Team and has also been offered to social care and health practitioners as well as all schools and colleges and early years settings. The LA is actively trying to encourage more schools to take up person-centred training in order to navigate difficulties encountered by LA staff in reaching a sparsely distributed SEND

population. The LA has also provided Local Offer training to many schools, parent carer groups and providers to help them to use and understand the SEND Local Offer.

### **The Local Offer/provision of information**

The 'Local Offer' (LO) section of the LA website sets out a comprehensive selection of advice and guidance specifically aimed at a number of different audiences (young people, parents/carers and practitioners) which is easy to navigate and is fairly accessible. The LO also contains examples of EHC plan forms and guidance. The LA is also in the process of establishing a network of 'Local Offer Champions' to support the ongoing development and regular review of the LO, and to address the difficulties of providing a comprehensive service in a large rural county. Champions will be parent carers, people working within related SEND professions and YP with SEND. The LA also provides CYP and parents with advice and information about SEND matters through leaflets, posters, live events and word of mouth. There is an independent parent and carer council which is led by the principles of co-production. This group also offers advocacy services, information and opportunities for parents and carers to inform LA policy and practice.

### **CYP participation in strategic decision making**

Currently, there are no exclusive children's or young people's forums or groups that provide a dedicated space for children and young people with SEND to participate in LA decision making or inform SEND strategy. Nonetheless, the 0-25 SEND Strategic Board includes representatives from education, health and social care services and from voluntary organisations who work with children and young people with SEND and their families, including a parent carer representative. The Board is responsible for carrying out the work of the Greenshires SEND Strategy. CYP have been consulted in schools and colleges via a range of mechanisms in respect of the Local Offer.

### **CYP participation in own cases**

Within the LA there is an expectation that children and young people that are more able to articulate their feelings will express their views independently or with the support of a parent or teaching professional. Children and young people that find this process more demanding are usually able to access support through an educational psychologist. The LA stated that it always seeks to ascertain the views, wishes and feelings of children when carrying out an EHC assessment and does this by requesting information to complete 'Section A' of the EHC plan and through a request for a 'One Page Profile'. However, data drawn from the case study research indicates that CYP are not always invited to attend EHC plan reviews as a default position. According to responses on the LA survey and conversations with SEND staff, the LA appear to advocate and prioritise the view of a young person in cases where there is conflict with a parent, providing that it is in the young person's best interest. In cases where agreement cannot be secured, the LA is guided by the final decision of an impartial official.

### **LA perspectives**

#### *Views on the challenges of meeting statutory requirements of the CFA 2014*

- Motivating schools and colleges to engage with person-centred training events was identified as an area that the LA was finding difficult. The LA is actively trying to encourage more schools to take up person-centred training in order to navigate difficulties encountered by LA staff in engaging with a sparsely distributed SEND population in person.
- The LA considers that schools and colleges are unsure about their statutory duties under the CFA 2014.
- The LA has experienced some difficulties in holding non state-maintained schools to account in terms of early intervention and overall quality of practice around SEN support if a child does not have an EHC plan.

- The inclusion of young people up to the age of 25 has also added more pressure on workload in order to extend provision and services for this age range. The LA is currently considering how to improve the experiences of young people with SEND in further education and enhance understandings of SEND provision for FE sector staff.
- LA staff feel that austerity measures and associated pressures on staffing and other resources across the LA have impacted adversely upon workloads and ability of SEN staff to fulfil statutory functions.
- Greater collaboration with Health and Care services has been identified as an area for future development.

#### **Views on the merits of the CFA 2014**

- The developing person-centred practices are viewed as a positive development by LA staff. It is considered that this way of working enhances opportunities for children, young people and families to have a say and participate in decisions about individual SEND support and provision. However, this has also increased both the level and scope of work that SEND staff undertake in comparison to the previous system of SEN statements.
- There is a positive view of the introduction of the PfA outcomes and the inclusion of young people up to the age of 25 under the reforms.