

My Life at School

Understanding the experiences of children
and young people with special educational
needs in residential special schools

Elizabeth Pellicano, Vivian Hill, Abigail Croydon,
Scot Greathead, Lorcan Kenny and Rhiannon Yates
with Wac Arts





My Life at School

Contents

3	Foreword
5	Executive summary
9	Preface
9	Terminology
10	Abbreviations
11	Chapter 1: Setting the scene
19	Chapter 2: My family life
36	Chapter 3: Being part of my local community
43	Chapter 4: Having my say
57	Chapter 5: Feeling and keeping safe
65	Chapter 6: Preparing for my life after school
71	Conclusions
I	Appendices
X	Glossary of terms
XIII	Notes
XVI	About us





I am pleased to issue this important report on the wellbeing and rights of children and young people educated, and living, in a residential special schools in England. The number of settings on which this research study focused was small, but we consider the findings, and the strength of the voice of the children concerned, make what we say in the report applicable across many settings and many more children's lives.

The United Nations Convention on the Rights of the Child guarantees every child, including those with any kind or any degree of disability or difficulty, an education that helps them to fulfil their potential, alongside support that means they are both helped to deal with their difficulties, and to develop their skills and talents to the maximum possible extent. Because children with disabilities and special educational needs face particular challenges they are explicitly afforded additional rights under the Convention. Article 23 states very clearly that a child with a

disability is first and foremost a child, who has the right to live a full and decent life in conditions that promote dignity, independence and an active role in the community. If they have the right, then we adults have a duty to ensure it is fulfilled.

The Convention, under Article 12, also says that every child has the right to be heard, and more to the point, to have what they say taken seriously. They have the same right, whatever their life circumstances or difficulties, to have their wishes, feelings and best interests placed at the heart of decisions that adults make about their lives. This report seeks to allow the voices of children and young people living in residential special schools in England to ring in our ears. It asks a simple question of us all: are we listening, and if we are, are we acting on what we hear? I would ask another, based on what you will read in the pages that follow: if a child is hard to communicate with, how much harder should we try to do so, if we take their rights as one of society's most vulnerable groups seriously? The answer is in all our hands.

For too long, too little has been known about the views and feelings of our children who, because of their range and complexity as well as the seriousness of their needs, are educated at residential special schools. They come from all kinds of family and community backgrounds, bringing with them a wide range of needs and life experiences. They are as characterful and as fascinated by life as their peers who do not share their disabilities,

and they are all as unique as those peers. They have one vital feature in common: all of them spend time living away from home, and in addition, often in connection with their disability and their families' struggles to see their needs properly met, many have experienced big challenges in their lives. It is important that their wishes are understood – both in their daily life, and by those who make policy and decisions which affect them. Where children cannot articulate their concerns easily, this places an even greater responsibility on adults to work hard to understand what children's wishes and interests are. It is not for the child to make the adjustments needed if we are to pay them due respect and listen to them. That is our task.

As Children's Commissioner for England, listening to what children have to say, and bringing their views to the attention of decision-makers, is a key part of my role. I would like to thank

the 83 children and young people from 17 participating schools who took part in this work, who so generously and enthusiastically shared their time and their stories with the research team, alongside their parents, carers and school staff. They have contributed enormously to our understanding of the issues they face, and what they tell us about their lives should contribute to both sides of this debate.

These children are the experts in what it means to live their lives. Often that expertise, and that wisdom, exceeds that held by their teachers, care and support staff, and even their parents and families. Surely, it is time we listened to, and acted on, what they have to say.



Dr Maggie Atkinson
Children's Commissioner for England

Executive Summary

Protecting and enhancing the rights of children and young people with special educational needs (SEN) and disabilities living in residential special schools is an important duty on society. These children possess the same rights, including under the United Nations Convention on the Rights of the Child, as all other children: the right to family life, the right to participate in their communities, the right to shape the decisions that influence their lives, the right to be and feel safe and secure in their environment, and the right to an education which develops their potential and prepares them for adult life. Living in a residential school, however, presents potential challenges to the maintenance of these rights, especially when the child also has physical, sensory, mental and emotional needs above and beyond those of typically developing children.

Given these challenges, it is particularly important that society hears the voice of these children so that we can all become aware of the ways in which they themselves feel that their key rights are respected and their interests protected and promoted. Remarkably little is known at present about how children with SEN and disabilities in residential schools feel about their care, education and resulting life-chances. The absence of their voice from on-going debate is, however, deeply troubling. We will all, after all, only be able to protect the rights of these children effectively when we know how they themselves feel about their current experience and what they believe needs to change.

This report, therefore, aimed to reveal the views and experiences of these children and to compare their reflections with those of their carers,



- Children and young people with special educational needs and disabilities living in residential special schools face many challenges when it comes to having their rights protected and their wellbeing enhanced.
- Children in those circumstances interviewed in a report commissioned by the Office of the Children’s Commissioner had varied experiences but many reported positive experiences with their care and education in these residential schools.
- Key challenges nonetheless remain, including of maintaining family and other crucial relationships while living away from home, ensuring that the child’s own perspective is listened and responded to particularly in the selection of a residential school and ensuring that children have proper care and relationships within their home communities and are well-prepared for life after school, especially when they have been educated and looked after often many miles away.

teachers and families. It did so in order to present a detailed picture of the ways in which their key rights are currently respected and to provide insights for policy-makers, parents and the broader community as they seek to enhance the wellbeing of all children and young people with SEN and disabilities in residential special schools.

Methods

We set out to achieve this aim by working with children, carers, teachers

and parents at 17 residential special schools from across England, including by setting up a Young Researchers’ Group to enable the children themselves to play a key role in shaping the research process.

Children were interviewed in-depth, observed in the school environment and invited to participate in focus group discussions and individual interviews. The interviews were conducted around the key topics of (1): living at school; (2) how things

are run; (3) having your say; (4) staying safe; and (5) life after school. Drawings, photocards and *Playmobil* were used to elicit responses from children where appropriate and British Sign Language interpreters supported access for deaf children. Children were invited to write *post-it!* notes about their experiences and some were also involved in the production of a short film about the challenges and opportunities presented by life in residential special schools.

Key Findings

Despite the serious challenges they face, on the whole, the majority of children reported a high degree of satisfaction with their care and education in their residential schools. They often reported that their schools were better able to respond to their needs and protect their rights than either mainstream or special day-schools in which they had previously been placed or their immediate families. Many displayed deep bonds with carers, teachers and other children within their schools. There were also very few on-going concerns expressed with regards to safety and security.

The children, carers, teachers and parents who participated did, nonetheless, report a number of serious concerns in each of the five key rights discussed.

First, with regard to family life and other relationships, there was some anxiety about the depth and sustainability of relationships with residential carers and teachers. Children living away from their family felt a strong need for close

relationships, but these were not always forthcoming from staff anxious to maintain professional boundaries.

Second, with regard to participation in the community, children and parents noted that it was often difficult to maintain connections with a child's home community, and that made it especially hard for children leaving school to find a place for themselves at an already difficult moment of transition.

Third, with regard to having an influence in shaping key decisions, children often reported feeling as if their voice had not been heard at key moments, especially when it came to decisions about school placement itself or arrangements for care and work experience once school came to an end. Children also appeared often to be caught in an adversarial decision-making structure with local authorities and other professional agencies in a way that could be damaging to their wellbeing and their participation in such decision making.

Fourth, with regard to safety and security, although schools appeared to make excellent provision for the physical and social wellbeing of children in their care, provision for complex mental health needs was much less well-advanced. Parents, teachers and carers all reported finding this shortage of support distressing and detrimental to the wellbeing of the children concerned. Furthermore, although bullying was not raised as a major concern overall, many children expressed worries over the impact of their peers' or their own behaviour on their and others' safety.

Finally, with regard to the support and planning for their future lives, while residential special schools offered stability and security for young people with SEN and disabilities, ensuring that they can transition to often less structured and less predictable environments in a way that enables them to flourish is a major challenge. Such challenges are further exacerbated in some cases by the perceived lack of planning by local authorities and by delays in receiving requisite information and support. Children who are looked after and attend a school in a community some way from their home local authority face particular difficulties as they return to a context where they

have few or no connections or existing relationships.

Conclusion

All children and young people with SEN and disabilities in residential special schools have preferences and feelings that must be taken into account, and many have strong and clear views about their rights and about the provision needed to protect and enhance them. If we work to understand children's wishes and feelings, and listen attentively to these views, we will be able to further develop and improve the often excellent provision that residential special schools make to the quality of these children's lives.

To assist in the protection and promotion of the rights of children and young people in residential special schools, we need to:

- promote stable, trusting, nurturing relationships
- foster connections with the community during the schools years and beyond
- place the child at the centre of decision making in school and prepare them for decision making in life after school
- pay ongoing attention to keeping children and young people safe and secure, including their mental and emotional wellbeing.

Preface

This report was commissioned by the Officer of the Children’s Commissioner (OCC) to understand the views and experiences of children and young people with special educational needs and disabilities in residential special schools, with the aim of ensuring that their rights are being protected and promoted.

We are very grateful to the OCC for giving us the opportunity to work on such an important, yet much neglected topic, particularly to Frances Winter, Ross Hendry, John Connolly and Shaila Sheikh, for all their support and guidance during the various stages of the project.

We were also supported by an Advisory Group of external stakeholders, including David Abbott, Amanda Allard, Claire Dorer, Jean Haigh, David Miller, Andrew Ross, Alison Ryan and Jacqui Shurlock, who provided advice and support throughout the project. The final methodology, report and conclusions do not necessarily reflect the views of all members of the Advisory Group. We also benefited from the experiences of a Young Researchers’ Group formed of young people with SEN and disabilities all currently attending residential special schools. They provided excellent insights throughout the project, advising in particular on aspects of the methodology and making sense of the results.

Thanks also to Chas Mollet, Thomas Edwards and Nathan Greenwood from Wac Arts for their co-production of the young people’s short film, to Margaret Lankester for transcription, to Ben

Connors for illustrations, to Dan Sinclair for design and production and to Marc Stears for constructive comments on a previous version of this report. Research at the Centre for Research in Autism and Education (CRAE) is supported by The Clothworkers’ Foundation and Pears Foundation.

We are also indebted to all the children and young people, their parents and carers, headteachers, teachers, teaching assistants, care staff, support workers and therapists who so generously invited us into their schools and gave up their time to take part in this project. Your stories so clearly illustrated the realities of being a young person, caring for a young person, or supporting a young person who is schooled often far away from home. We feel very privileged to have heard them. We have done our very best to convey these stories as accurately as possible. Any omissions or errors are entirely our own.

Terminology

A child or young person is considered to have a **Special Educational Need (SEN)** “if they have a learning difficulty or disability which calls for special educational provision to be made for him or her” (Children and Families Act 2014, p.19). In the revised SEN Code of Practice, children’s SEN are included within four broad areas of need and support: (i) communication and interaction, (ii) cognition and learning, (iii) social, emotional and mental health, (iv) sensory and/or physical needs. Many children and young people with SEN may also have a disability as defined under the Equality Act 2010 as “a

physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities.”

Special schools provide education for children and young people with complex learning needs that are unable to be fully met within a mainstream school setting. **Residential special schools** are defined here as offering boarding, which can range from part-time (1-2 nights per week) to full-time (up to 52 weeks) care for children and young people with SEN and disabilities. The schools may be situated either within the local authority area or out of authority. They may be non-maintained schools (run as not-for-profit, usually by a charitable body) or independent schools (either profit or not-for-profit), maintained schools (maintained by local authorities) or academies (independent schools where the contract is between the proprietor and the Secretary of State). Schools offering accommodation for more than 295 days a year or offering residential provision to young people not on the school roll must be dual registered as children’s homes.

In certain communities, especially the deaf and autistic communities, **disability-first language** (e.g., “deaf person”, “autistic person”) is often preferred to **person-first language** (e.g., “person with hearing impairment”, “person with autism”). In this report, we use both person-first and disability-first language to respect the wishes of all individuals.

Abbreviations

AAC: Augmentative and Alternative Communication

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

BESD: Behavioural, Emotional and Social Difficulties

BSL: British Sign Language

CAMHS: Child and Adolescent Mental Health Services

DfE: Department for Education

EHC: Education, Health and Care plan

HI: Hearing Impairment

IRO: Independent Reviewing Officer

LAC: Looked After Child

MLD: Moderate Learning Difficulties

OCC: Office of the Children’s Commissioner

PD: Physical Difficulties

PECS: Picture Exchange Communication System

PMLD: Profound and Multiple Learning Difficulties

SCERTS: Social Communication, Emotional Regulation, Transactional Support

SEN: Special Educational Needs

SENDIST: Special Educational Needs and Disabilities Tribunal

SLCN: Speech, Language and Communication Needs

SLD: Severe Learning Difficulties

SpLD: Specific Learning Difficulties

UNCRC: United Nations Convention on the Rights of the Child

VI: Visual Impairment

VOCA: Voice Output Communication Aids

1. Setting the Scene

Local authorities are committed to ensuring that children and young people with special educational needs (SEN) and disabilities are educated and have access to health and social care services within their local communities. But there is a significant minority of children and young people with SEN and disabilities who live and are educated away from home – many some distance from their families – in residential special schools. These can range from part-time placements to those receiving around-the-clock 52-week care.

Residential placements are made for a variety of reasons, including a lack of suitable alternative local educational provision and inadequate support for parents to care for their child at home [1, see also 2]. They present parents with very challenging placement decisions. The children identified for residential placements are often the most vulnerable and marginalised children – those who are most severely disabled, who have the most complex needs and the greatest dependency on others. They are also among the least visible young people in the education system. Professionals and parents therefore need to be especially attentive to ensure that these children’s rights are protected and promoted – including the rights to a family life, to be part of the local community, to be consulted and listened to, to be protected from harm and to receive an education that prepares them adequately for adult life [3-6; see also 7].

The very limited research in this area suggests that children and young people living away from home and

educated within residential special schools face particular problems. It has repeatedly raised concerns about the impact of children growing up so far away from their family and home community, often out of authority; about the effectiveness of joint working between parents and schools and often several agencies, particularly regarding safeguarding and young people’s welfare; about the nature of young people’s post-school placement and the support and planning provided for the transition process; and about the high financial costs of many of these placements [1, 8-17; see also 18].

Some also have gone so far as to suggest that the “[then] current legislative framework is not adequately protecting and promoting the interests of disabled children” at residential schools [1, p. 114]. Although legislative and monitoring changes have since been made, these sentiments remain worrying for the children and young people, their parents and for the teachers and administrators at the schools concerned – especially at a time of repeated high-profile reports of abuse and misconduct in care homes and schools around the country [19].

This research project was therefore designed to understand in greater depth the experiences of children and young people currently placed in residential special schools.

The most important way to address this question is to elicit the views and perspectives of the children and young people themselves who attend residential special schools. While there is a dearth of research on the school



– and indeed life – experiences of children and young people attending residential special schools, as reported by school staff and parents [e.g., 10], there is even less research directly eliciting the views and perspectives of the young people themselves. This is partly due to the fact that the young people supported in these schools often have high levels of need, including severe and complex conditions, autism in particular, and limited use of speech to communicate [12], raising issues regarding the best ways to elicit these young people’s experiences of life at school.

Nevertheless, this absence of research is still surprising, given the stated intentions of government policies and legislation, including most recently in the revised SEN Code of Practice [20] and Children and Families Act 2014, which places children

and young people at the heart of decision making, emphasising the importance of seeking the views of children with SEN and disabilities in decisions related to their education, health and care. This person-centred approach puts an increased emphasis on their right to express preferences and to participate in planning for their outcomes and transition to adulthood. The extended age range (to 25 years) embraced in the new legislation further acknowledges the importance of young people with SEN and disabilities participating in the decisions related to further education, employment and adult services as they transition to adulthood. The strong focus on children and young people being listened to and having a voice challenges professionals to facilitate all children, regardless of their needs, to participate in the decisions that affect their lives.

There are very few studies that have directly accessed the views and perspectives of children and young people attending residential special schools. One such study found that the children were often not consulted as to their own experiences as they were deemed to be too disabled to offer any distinctive insights, including in the school placement process [1]. The researchers' interviews with 14 children and young people who had very recently been placed in residential special schools yielded mixed experiences. Young people were not often involved in the decision-making process regarding school placement [see also 9] and many would not have chosen to go to a school so far away from home. The majority expressed homesickness but some reported that residential school allowed them to make friends and be more independent. The nature of young people's relationships with their care workers was also crucial to how young people felt about school.

Another more recent study used online survey methods to elicit the views and perspectives of 338 children and young people attending 40 different residential special schools [13]. Generally, children painted a positive picture of their lives at these schools. Although many felt homesick and were worried about bullying, children nevertheless reported enjoying the activities schools provided and being with friends. They also very much valued school staff, especially their understanding, their help and support with problems and personal issues and their commitment to keeping them safe.

While these findings and those of similar reports [14] are informative, the methodology used only scratches the surface of these children's lives and also necessarily excludes the views and experiences of those children and young people with limited communication and complex needs. Indeed, the limited in-depth data in this area – both in terms of the number of children taking part and the nature of their SEN and/or disability – precludes a detailed understanding of these children's views, both negative and positive.

About this study

The current research did not aim to provide a complete picture of the work of residential special schools, to evaluate their performance or to assess whether it was appropriate for children to be educated in those settings. Instead, it focused on the experiences and views of children and young people. It had four aims. It sought to establish:

1. How children and young people understand their rights and feel those rights are being protected and promoted in residential special schools;
2. What differences there are between the experiences of different groups of children and young people;
3. How children and young people's views, experiences and feelings are accessed, heard and taken account of; and
4. The best ways for the Office of the Children's Commissioner (OCC) and other relevant organisations to understand and listen to the views of children in residential special schools.

Table 1. Characteristics of participating schools

#	Region of England	Type	SEN	Ofsted	Age range
1	South East	Non-Maintained Special School	SLCN	School: Good Care: Good	7 – 19
2	South East	Non-Maintained Special School	BESD	School: Outstanding Care: Good	11 – 19
3	East of England	Independent Special School	ASD, BESD & SLD	School: Satisfactory Care: Adequate	4 – 19
4	London	Community Special School	HI	School: Outstanding Care: Good	11 – 19
5	South East	Non-Maintained Special School	SLCN	School: Outstanding Care: Outstanding	5 – 11
6	South East	Independent Special School	SLD	School: Outstanding Care: Good	8 – 19
7	South East	Non-Maintained Special School	MLD, SLD, ASD & SLCN	School: Outstanding Care: Outstanding	5 – 19
8	East of England	Independent Special School	SLD & ASD	School: Outstanding Care: Outstanding	4 – 19
9	North West	Non-Maintained Special School	HI	School: Outstanding Care: Outstanding	4 – 19
10	West Midlands	Independent Special School	ASD & BESD	School: Good Care: Adequate	8 – 19
11	South West	Community Special School	MLD, ASD, PD, SLCN	School: Outstanding Care: Outstanding	11 – 16
12	South East	Non-Maintained Special School	Epilepsy & MLD	School: Good Care: Outstanding	5 – 19
13	South East	Community Special School	ASD	School: Good Care: Good	4 – 19
14	South East	Non-Maintained Special School	PMLD	School: Good Care: Outstanding	3 – 19
15	South East	Community Special School	ASD	School: Good Care: Adequate	11 – 19
16	North West	Non-Maintained Special School	VI	School: Outstanding Care: Outstanding	2 – 19
17	South East	Community Special School	ASD, SCLN, BESD	School: Outstanding Care: Outstanding	11 – 16

Notes: ASD: Autism Spectrum Disorders; BESD: Behavioural, Emotional and Social Disorders; SLD: Severe Learning Difficulties; MLD: Moderate Learning Difficulties; SCLN: Speech, Language and Communication Needs; PD: Physical Difficulties; HI: Hearing Impairment; VI: Visual Impairment; PMLD: Profound and Multiple Learning Difficulties.



17

Schools visited



50
boys seen



33
girls seen



43

activities observed

(between 1 and 11 activities per child)



32

parents interviewed



11

children observed

114
staff seen

(29 focus groups)

1,891

minutes observed



To address the aims, we visited 17 residential special schools across England (see Table 1), seeing a total of 83 children and young people (33 girls), ranging in age from 8 years 3 months to 19 years 8 months. Young people had a range of SEN and disabilities as specified in their Statement of SEN, a legal document that details the child's needs and services that the local authority has a duty to provide, and which specifies each child's primary need. The primary needs recorded on their Statement included: attention deficit hyperactivity disorder (ADHD; n=2), autism spectrum disorder (ASD; n=44), behavioural, emotional and social disorders (BESD; n=3), specific learning difficulties (SpLD; n=1), epilepsy (n=3), hearing impairment (n=11), moderate learning difficulties (MLD; n=3), profound and multiple learning difficulties (PMLD; n=2), speech, language and communication needs (SLCN; n=13), and visual impairment (n=1). Many of these children and young people, however, had multiple needs.

Of the 83 children, 13 were looked after by their local authority. Seven were looked after under section 20 care orders. The remaining six children had section 31 care orders, where parental responsibility is shared with the local authority. These latter children may have been exposed to abuse and/or neglect and may be living with foster carers or in care homes when not attending school.

Participation by schools in the study was voluntary. All residential special schools who reported children boarding in April 2014 were contacted and

offered the opportunity to participate in the research. As Table 1 shows, schools from the South East of England, and those whose provision has been judged by Ofsted to be outstanding or good, were over-represented in the study.

Since children and young people are the primary source of knowledge about their own views and experiences, we used a multi-layered approach to understand and promote the participation of all children and young people in residential special schools, listening to them in ways that were tailored specifically to their needs. We elicited the views of 72 young people using focus groups and individual semi-structured interviews, including *post-it!*, drawing and photocard activities (see Appendix A). We asked them about what it is like to live at school, how they feel things are run, whether they get to have their say, whether they feel safe and what their hopes are for life after school. We also asked about their participation in decision-making – from everyday decisions, like what they get to do in their free time, to key educational and life decisions, such as school placement and transition to adulthood. Together with our community partner, Wac Arts, some young people were also given the opportunity to produce their own short film about what their life is like at school.

For 11 young people, who showed difficulties communicating using speech, sign or symbols, we used a combination of ethnography and structured observations to understand their experiences. Researchers spent

time with the child or young person in school and/or at the 'home' part of school to gain information about their experiences, which involved closely observing and recording the young person's activities, interests, interactions and relationships with others. Some observations took place over the entire day – from the moment the child woke up to when they went to bed – so that we could capture a 'day in the life' of the young person living in residential school.

This range of methods and formats was necessary to ensure that all of the young people's 'voices' were heard in some way, even those who have limited or no spoken communication or sign language [21]. Children and young people's names have been changed throughout to preserve anonymity. A Young Researchers' Group consisting of children and young people with relevant current experience from two of the participating residential special schools were critically involved in shaping the design and application of these methods and reviewing the findings.

In many cases, children and young people opted to have a school staff member or an interpreter present at the discussion. Although focused areas were identified for the discussion (see Appendix A for details), follow-up questions depended on young people's interests, which mean that not every possible area was covered during discussions.

We also adopted a multi-informant approach, interviewing children's parents, carers and their teachers, to

gain a fuller picture of young people's lives. We spoke to 114 members of school staff, including teachers, care staff, and school-based therapists, across the 17 schools about the children they support, the strategies that they use to support them and involve them in decision making (and the challenges in doing so) and their perceptions of children's wellbeing and relationships with others. Thirty-two parents also spoke to us in depth about their child's developmental and schooling histories, their perceptions of their child's wellbeing in their current schools, and their hopes and aspirations for their child's future. These interviews provided important context for the young people's views and perspectives about their placement. In some areas covered by the research, adult responses were important in and of themselves.

Data collection for this study included multiple visits to schools by researchers to conduct observations, interviews, focus groups and participatory work with young people and focus groups with school staff during a three-month period (May – July 2014). Interviews with parents were conducted during July – September 2014. Full details of the participants and the methods used are provided in Appendix A. The following chapters present the results of this work, drawing from the full range of methods and informants.

In this report, inspired by the United Nations Convention on the Rights of the Child (UNCRC) [6], we focused on a series of rights that are fundamental both to the immediate wellbeing of



children and which serve necessary functions in enabling children's emotional and cognitive development into adulthood [see also 22]. We discussed these with the children in language appropriate to their needs and experience, informed by the belief expressed by former UN High Commissioner for Human Rights, Sergio Vieira de Mello that for human rights to work they have to "belong to people" themselves [23, p. xv.]. As such, researchers and children together identified a set of rights that were crucially important to them, their families and their own sense of wellbeing. These rights were: the right to family life (Chapter 2); the right to participate in the community (Chapter 3); the right to have a say and shape one's own life (Chapter 4); the right to be safe and secure (Chapter 5), and the right to an education which develops the child's potential to the fullest possible extent and to a well-supported transition to adult life (Chapter 6).

We found widespread agreement with parents, carers and school staff

that these rights were essential to wellbeing. They are, of course, not exhaustive. Children who are educated at residential special schools are entitled to full protection and promotion of all their UNCR rights without discrimination, and many other themes, including children's rights to privacy, to developing independence, the highest possible standard of physical and mental health, and access to play and leisure were recurrent themes across many of the discussions. In this study, we did not examine what might be called children's technical understanding of their legal and administrative rights, beyond their direct relationship to the rights described above. Children may have specific entitlements, for example, if they have a Statement of SEN or if they are looked after, which require complex legal action to be enforced. There remains a need for further studies to assess children's appreciation of, and approach to, their broader set of legal entitlements.

2. My Family Life

A secure and fulfilling family life is an essential right of any child and is widely recognised as such [6]. Family bonds generate a sense of security and stability that can be vital to many core aspects of a child's development. Living in a residential school presents many possible challenges to this fundamental right to a family life, as it has the potential to disrupt the emotional bond between parents and child and to cause distress in both the short and the medium term.

The UNCRC [6] recognises that “the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding”, with a “right to know and be cared for by his or her parents” (Article 7). It requires States to “render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities” (Article 18). The United Nations Convention on the Rights of People with Disabilities [24] also mandates States Parties to ensure that “children with disabilities have equal rights with respect to family life”, requiring them to put in place “early and comprehensive information, services and support to children with disabilities and their families” (Article 23).

In our conversations with children and young people, there were differences in the extent that they reported missing their family and home life. Some young people reported missing “home a lot”, indicative of strong family bonds. They talked about getting “really upset at school” and not liking to stay

over “because I’ve got no parents [at school].” The younger, primary age children were particularly upset about being away from their family: “I don’t like ... makes me sad. Miss mummy.” This 9-year-old boy with SLCN – one of the youngest in our sample – wanted to attend a different kind of school where he did not need to board.

Other young people were more mixed in their feelings. One young woman with autism described how “living at [current school] makes me feel at home really” but that sometimes she gets “very homesick when I’m away from home. I like it there but I like having my own room and my own place. And I like it when I have someone to talk to.” Another girl with autism also spoke of how she enjoyed boarding but also how she feels “free when I’m at home because I can go anywhere I want.” A 10-year-old boy with SLCN said “sometimes it’s easier at home to sleep because I can sleep in my own room ... I don’t have any people sleeping with me.”

Others still were more definite in their preference for living at school either due to their families’ turbulent lives or to the support they received at school: “I don’t like going home; I like staying here ... I get more help and support here, because at home I don’t get any of that” [16-year-old girl with autism].

Parents also spoke of homesickness in their children: “He always tells me he misses me when he comes home.” One mother spoke of how her 14-year-old son with autism was “still not a hundred percent settled still now. [Child] still doesn’t unpack



his suitcase; it stays packed and he gets what he needs out of it, but it stays packed.” This young man, while he did not speak of homesickness directly, appeared to be as unsettled as his mother described. He noted that packing was quite difficult and that school is “very different [from home] because you’re in a different atmosphere in a different building

even.” During a tour of this young man’s bedroom, the researcher indeed came across his neatly packed suitcase open on the floor, full of his clothes for the week. One father also spoke of his 18-year-old daughter’s initial homesickness and that while she still misses her family, “as time’s gone on, she really looks forward to going back to school.”

Box 1. Lily's story

Lily is a 12-year-old girl, with a range of complex and challenging needs, including autism, ADHD, Tourette's Syndrome, learning and communication difficulties and challenging behaviour. She has attended her residential special school for 3 months. An interview with Lily's mother elucidated the processes and events that led to Lily's placement. Her mother described how, having been relatively settled at primary school, Lily's needs changed dramatically as she approached adolescence. Transition to her first secondary school was particularly difficult. Her mother explained that, "because her behaviour was going downhill quite rapidly ... she was really struggling with transition, going from home to school, school to home. And when she was at school, her behaviour was just going off the wall because she wasn't coping in that environment." This school placement rapidly broke down: "The secondary school was going to throw her out and then she didn't have anywhere to go. It was extremely stressful, it was awful."

As the family struggled to manage Lily's needs at home, they were also trying to find a suitable school placement. Lily's mother explained that the decision to consider a residential placement was very difficult but in the end was based on Lily's needs and those of her family: "It was the right thing for



It was the right thing for her and the right thing for the family ... at the end of the day we don't want the family unit split up because of not being able to cope.

Lily's Mother



her and the right thing for the family because otherwise we would probably all be in meltdown. And at the end of the day we don't want the family unit split up because of not being able to cope. So it wasn't easy. Certainly, there's a bit of a weight lifted off because you feel like she's now going to be supported a bit more."

When describing how Lily managed the transition to residential school, her mother explained: "the fact that she was going to residential was something completely new to her and actually she found that quite fun I think and something different." Lily's mother also noted that her behaviour at school has since settled: "I just think now she feels like, now she's somewhere where she's feeling supported, less anxious, and there are others

around her that are similar.” Lily spends each weekend at home but “she finds it more challenging because there’s not so much structure at home, and then she gets more anxious.”

The family feel the residential school placement was the right choice for Lily because “they are going to be able to help her the most. The schools I’d put her in before, they’d always be ringing me up asking me what should we do, and I don’t know. We just cope as best we can. But I’m just hoping that now she’ll have all the therapy she needs that’s going to start to make her feel a lot calmer, less anxious, good about herself, raise her self-esteem, so I just feel that that is the right place for her now. They’re going to be looking at her as a whole and helping her as a whole.” Her mother also reported feeling that the residential placement has helped reduce the stresses and pressures on the family: “It’s a much needed rest to be honest, because she’s very demanding at the weekends and her little sister doesn’t get much time. So in the week we can give her that time back.”

The placement seems to have made a difference for Lily: “she’s happy there. Because it’s the right place ... and sometimes that’s hard to deal with. You think, well why is she happier there than she is here, but I just have to deal with that.”

Other parents acknowledged, sometimes reluctantly, that their children preferred school: “I’d like to think that she doesn’t like [living away from home] but I can’t say that at all. She is absolutely fine.” Another parent of a young man with autism and no verbal language spoke of how her child “loves it there. He gets all excited and the arms and legs start going. It’s structure and the routine and he’s got somebody to meet every need he could possibly have.”

School staff spoke of supporting some young people when they were feeling homesick, particularly during bedtime: “we always find it is a vital part of our night staff role because if it’s going to show up you can guarantee it’s going to show up when they go to bed.” They also reported that young people “have plenty of opportunities to call their parents”, with some schools allowing young people to have their own mobile phones so that they could call their parents at any time. Many schools make use of facilities like Skype, which provides both visual and auditory contact and is a real asset in helping children with a range of special needs to stay in contact with their families. Staff also spoke of differences in the extent to which children were homesick, supporting the children’s descriptions: “Some are on the phone, hello, goodbye, that’s it. Some don’t want to speak to their parents. And if they’ve had a bad day, they’ve got a lot to say.” One mother mentioned that she was so pleased when her son did not want to speak to her in the evenings, for it meant that he was feeling settled at school. For some young people, who have difficulties

with spoken communication, several care staff spoke of how they like to call their parents “just to listen to the voice of his mum and dad. He doesn’t talk much; he can’t hold a conversation but just likes listening.”

Some parents felt that the residential placement was helping them to keep the child within the family, particularly if their child’s needs were becoming more challenging with age and were affecting their siblings. They also spoke of the support that residential placements provided not only for the child but also for the family: “It got to the point where I thought, I have got to place him. I can’t support him. I am so tired. My kids are saying, ‘mum we’re tired of seeing you looking tired. We are so tired mum of seeing this’. It was the hardest decision but I did it because I knew it was what was best for all of us, not just [child], but the whole family” (see also Box 1).

Indeed, many parents said that they were unable to offer the range of opportunities available at school. One talked of the lack of space in the family home, which could not accommodate the child’s need for a “safe place/quiet room”. Several mothers commented on how they could not physically cope with their teenage sons at home, if they were distressed, aggressive or having seizures. One mother said that it was often uncomfortable for her and her son because, due to his epilepsy, she needed to supervise his bath during school holidays.

Staff also spoke about how some children’s family lives were such that

school gave them “breathing space”. Some remarked on how sometimes the increased stress and anxiety at home can exacerbate some young people’s ability to settle in at school: “I know that one of the girls gets upset when she comes back [from seeing her mum]. Because she doesn’t necessarily know when she’s going to see her mum again. So it’s that uncertainty. It must be really hard for them.” One staff member noted that “that’s really why they’re here, because they can’t manage in their family homes.”

For some parents of children with autism and with limited spoken communication, they felt that their children did not miss them at all: “There’s no interest at all. To be brutally honest, I don’t think he even knows who we are. I think we’re people who take him out for Cokes and cake once a month and I don’t think he’s got a clue who we are. It’s very sad, really.” Other parents also described what they saw as a lack of awareness of where real home is: “He doesn’t mind [living away from home]. His disability is such that he would go wherever you take him really. He just needs to get used to it.”



Staff members who worked with these young people also described the difficulties these young people had in understanding their relationship between school and home: “They really struggle with knowing when they’re going home, when they’re staying, and as much as we do to try to help them understand, they’re never going to fully understand.” Other staff, however, reported that children sometimes signalled, in their own way, their understanding of home and of missing home: “We were at the park today and one of the students thought it was mum’s car that I’d parked next to and it wasn’t. But it’s now covered in his fingerprints because he kept trying to get in.” One staff member also described how the young man he works with “is asking for Daddy and home and he knows home contact is coming up, he’ll rush, try and rush through his routine because he thinks that speeds up time to get that.”

Home away from home

Like many children, staff all spoke about how their schools aim to provide a “home away from home” for their young people. Care staff in particular emphasised how they tried to draw a distinction between ‘school’ and ‘residential’: “We try not to make it all educational here because it’s their home away from home. This is where they live.” They also mentioned that if there was an incident during the day at school that they would “try and draw a line under what’s happened and treat it as if you were at home upstairs.” Staff also stressed the need to make it feel like a home: “It is where they live, so it should be homely, it should be nice for them.”



I really didn’t like it (at my old school) ... when I came here I felt like this school is my home and I’ve made lots of new friends since then.

Young woman with autism



While some parents found it difficult to acknowledge that their children felt at home at their school (“Realistically speaking, this [school] is her home and I think that’s something which is harder for you as a parent to take on”), other parents were comforted by the homely nature of the schools: “He had a few wobbles to start with but we kept on with it ... and after no time, he’d settled in. And the staff were amazing at helping with all that. ... And because it’s such a homely environment, we were very comfortable with him staying over” [mother of a 9-year-old boy with SLCN].

One young woman with autism also commented on how settled she was at her school: “I went to a junior school and I really didn’t like it there ... when I came here I felt like this school is my home and I’ve made lots of new friends since then.”

For one young woman with Rett Syndrome, who was observed by

Box 2. A day in the life of Melanie

At the time of our visit, Melanie was one week away from her thirteenth birthday. She attends a full-time 52-week residential school, has a diagnosis of Rett Syndrome, is non-verbal and is a wheelchair user.

The observation of Melanie began at 7.30am at which point she was already awake, dressed and watching television in the lounge, which she reportedly enjoys. The staff explained that morning times are usually a rushed period, as they try to attend to all of the young people's medical needs. Melanie was alone and had started to eat her Weetabix, albeit with some difficulties. After a period of time, a member of staff arrived to provide Melanie with one-to-one support with her breakfast. She explained that, usually, Melanie has three breakfast options to choose from. If Melanie turns her head away to the first, staff may try gently another few times, before trying another type of food. During this process the staff member showed patience, accepting when Melanie chose not to eat.

Melanie's grandma arrived, to which Melanie responded with a smile. She visits Melanie every week and explained how she feels as though she is welcome to join Melanie in school.

This same staff member supported Melanie with brushing her teeth. As soon as they entered the room, the staff put on a recording of Melanie's grandma and grandad singing and saying nursery rhymes, to which Melanie laughed. The staff member continued to talk casually to Melanie and used supports to illustrate what was going to happen next. The staff member then gave Melanie a choice of a toy to take into school by holding two toys next to each other. Melanie was given the toy that she looked at first.

Melanie's first session at school was hydrotherapy in which she is able to take part once a week. She was encouraged to choose a toy to play with in the pool. With hand-over-hand support, Melanie pushed the duck to a member of staff who then pushed it back. This became a repetitive game, which Melanie seemed to enjoy, as she laughed and clapped throughout the game. Halfway through this session, another young person entered the pool. The staff member encouraged interaction between the two children by moving them towards one another and facilitating a game with a ball.

When Melanie left the pool and joined her class, she seemed unhappy. She started to make sharp noises, and eventually began to cry. The staff member now working with Melanie explained that she had not worked with Melanie for long and so was unsure why she was upset. The staff member eventually walked her around the school for a "change of scenery".

On return to class, Melanie was still upset. Her class teacher pulled a chair next to Melanie and imitated her noises, which led to a brief reciprocal interaction, with Melanie looking closely at his face. The teacher wondered whether Melanie was hungry, and held a banana out to her saying, “Hmm, banana?”, which made Melanie smile.

During the next activity, the pupils decorated a flag together. The staff member initially played Peek-a-boo with Melanie to secure her attention and make her smile. She then developed a predictable routine, laying the paper down in front of Melanie and hand-over-hand gluing one strip after another and pouring glitter over the paper. She encouraged Melanie to say ‘Go’ before they poured the glitter together. On the fourth attempt, Melanie said “Ga!” and they poured the glitter again.

Melanie then went back to her bedroom and slept for an hour and a half before lunch. After lunch Melanie’s grandma arrived, to which Melanie responded with a smile. Melanie’s grandma has parental responsibility for Melanie and has looked after her since she was 6 years old. She visits Melanie every week and explained how she feels as though she is welcome to join Melanie in school, or the residential aspect of the school, at any time.

Melanie’s grandma took Melanie back to class and became her support worker for the afternoon. In the first activity, each pupil, including Melanie,

chose a part of the body, using visual supports, that they would like finger tapped, tickled, or massaged when the music started. Throughout this session Melanie was vocalising and laughing, to which her grandma would imitate or comment on with a smile. They then took part in a sensory activity.

After school, Melanie again slept for an hour. At 5.15pm, she was woken to get ready for dinner at 5.45pm. The support worker explained that children are given their dinner at different times and often alone, given their distinct and often complex eating requirements, which resulted in limited interactions with her peers. After dinner, Melanie’s grandma asked if Melanie wanted to watch television by holding the iPad up to her. Melanie smiled and rocked back and forth in response, and her grandma stood her iPad up on the table and put on the Tweenies, a regular choice of programme.

During the Tweenies, Melanie’s grandad phoned and her grandma put the phone to Melanie’s ear. Melanie stayed very still and smiled while her grandad spoke to her. Melanie’s grandma then took Melanie to her bedroom, which her grandma has decorated specifically to include pictures of her family, wall transfers of the Tweenies and Winnie-the-Pooh and many soft cuddly toys. At the end of the observation (7pm), Melanie’s grandma described how they would spend the rest of the evening watching television together and “having a cuddle”.

a researcher over an entire day, the 'homely' nature of school was achieved through partnership between the school and family. The young woman has a cassette player in her room that plays nursery rhymes that her grandmother and grandfather have sung and recorded. Furthermore, the school holds an 'open door' policy for all family members and this young woman's grandmother is able to visit once a week, often supporting her grandchild through school lessons until when she goes to bed in the evening (see Box 2).

"It's just about relationships"

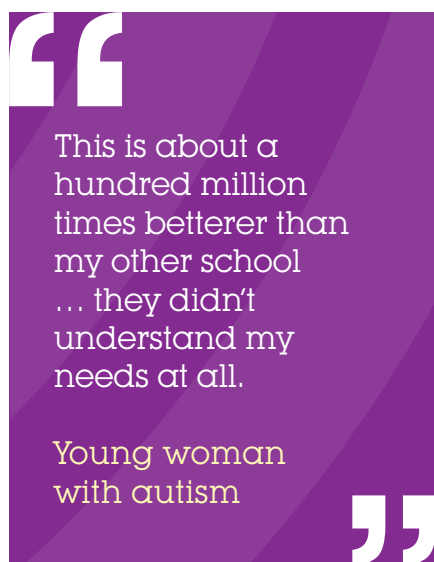
The strength of the relationships between young people and staff that was frequently observed further supported this notion of a 'home away from home'. One young man with BESD valued his relationships with staff: "Because you sort of know all the staff really well here. You get to know them because they're just walking around sometimes; you get to chat to them." He also spoke of how staff understood

him: "They're quite good at knowing whether you're in the mood to talk to them. So that's quite good." Another young man with epilepsy referred often to his support worker during the interview with whom he clearly had a deep bond and saw as his role model.

Other young people described the relief of having adults in their lives who finally understood them and their individual needs. One young autistic man described how people "here understand me better. They just know the way that I like to do things and know that I have to find things out for myself." A young woman described how "This is about a hundred million times betterer than my other school ... they didn't understand my needs at all" while another young woman described how her care worker "is really nice ... she's just knows when I'm not ok because I just don't talk."

The ethnographic work also demonstrated the importance of staff who understand the individual needs and communication signals of young people with complex needs. One young woman had become increasingly upset following a transition to another activity during the school day. Her teacher responded by sitting next to her, in close proximity, engaging with her by imitating her vocalisations – engagement that led to a brief reciprocal interchange (see Box 2). They made eye contact for extended periods of time and the young woman gradually settled and was then ready to engage in the next school activity.

Another young woman with PMLD started to feel discomfort in her



This is about a hundred million times betterer than my other school ... they didn't understand my needs at all.

Young woman with autism



wheelchair at the end of the school day, which she expressed through vocalisations. Two members of staff worked together to move her into a position, lying facedown on a large soft wedge, which medical staff had advised would help her to feel more comfortable. One staff member stayed with the young woman and read her stories from a book whilst stroking her arms and back. The young woman turned her head towards the staff member and smiled and laughed throughout the storytelling.

For the remaining observations with children who had limited or no formal communication systems, we asked the adults supporting them if they were familiar with the children. The majority of these children were supported by adults who “knew them” and these adults were also able to demonstrate some understanding of how that child communicated their needs, ideas, likes and dislikes. The data from our

structured observations also provided evidence that the staff understood these young people and were sensitive to their often-complex needs. We found that, on the whole, adults understood children’s bids for interactions – their idiosyncratic vocalisations, gestures, expressions –, responded to them and also helped promote them through the use of interpersonal and learning supports (see Box 3).

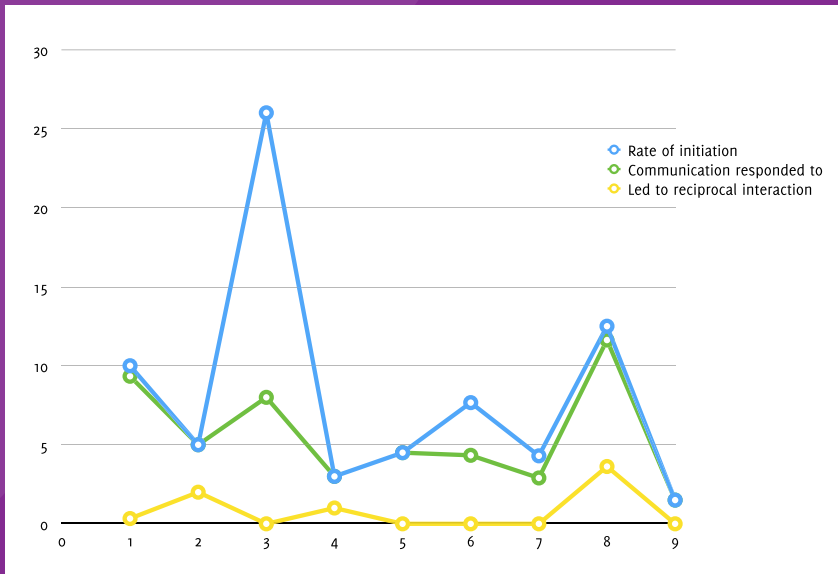
Parents also spoke of the importance of deep connections and “friendships” between their children and the staff: “There’s certain staff he’s really bonded with over the years. His key worker now, she’s been with him since he started and they’ve got a fantastic bond between the two of them” [parent of a 17-year-old with autism and limited spoken language]. They further described that these bonds ensure that the young people know who they can turn to for help and that staff “get the very best out of the

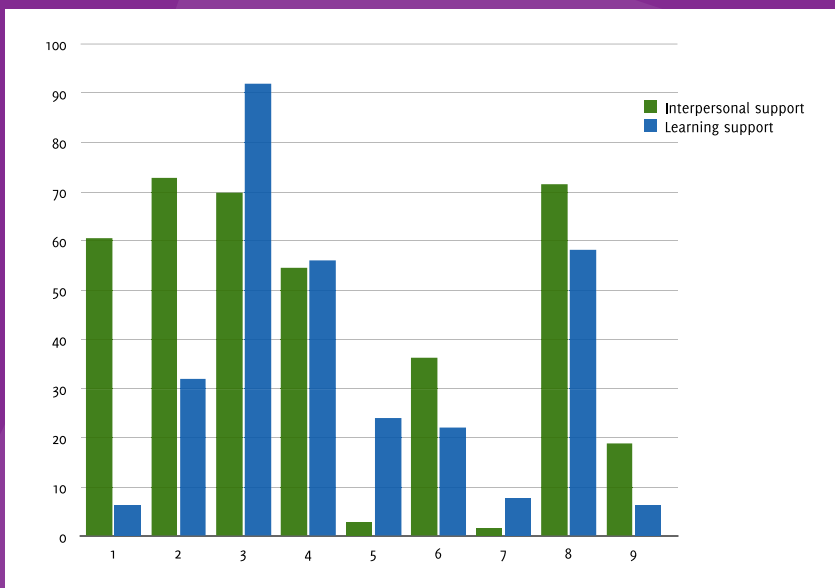
Box 3. Adults respond to young people with limited speech and complex needs.

During the majority of our observations of young people with limited speech and complex needs, we found that when children were engaged in activities with a trusted communication partner, they were more likely to show behaviours indicative of positive wellbeing, such as smiling, choice making, vocalising, and initiating bids for interaction. The figure below shows data for one of our primary target behaviours (see Appendix A) during the structured observation – child-initiated interaction – for 9 of the children observed. The blue line shows the rate at which children spontaneously initiated communication, which varied considerably across children. Some children (e.g., child 3) made many bids for interaction during the activities observed, while others

(e.g., child 4) rarely made such bids. Adults' response to the young person's bids (green line) matched up to their rates of initiation in all cases, with the exception of child 3 and child 6. These initiations and responses, however, seldom led to reciprocal (two-way) interchanges (child 8 is one exception). These data suggest that, for the majority of the children observed, their adult partners were generally responding to their communicative acts and getting them engaged, and this was particularly the case where the adult was a trusted communication partner.

We also examined the nature of the 'in-the-moment' supports that children and young people were offered during the various activities. Young people with





limited or no verbal communication in particular need a variety of supports to ensure that they become active participants at school and at the ‘home’ part of school. Adults need to be flexible and responsive to the individual attentional, emotional and social needs of the child (interpersonal supports) and to the different social contexts and learning environments (learning supports) in order to maximise learning in the classroom and participation in day-to-day activities.

Our structured observations for the most part revealed that adults varied considerably in the degree and nature of the support they offered. The figure above shows that for some young people (e.g., child 5, child 7 and child 9), the number of (learning or interpersonal) supports was

negligible during the activities observed. For others (e.g., child 1 and child 2), adults provided them with more interpersonal supports than learning supports; that is, the adult was able to adjust their own communication style to meet the child’s needs yet made fewer attempts to modify the environment in such a way to enable the child’s participation. For others still, the percentage of learning supports was equal to (e.g., child 4) or surpassed (e.g., child 3) the percentage of interpersonal supports. In these cases, the data suggest that the adults working with these particular children on certain activities were adept at adjusting the environment in an effort to promote children’s readiness to learn and take part in school and home life.

“

(The children) want you to be part of their life, when they come and share their little moments with you, their sad moments and their happy moments.

School staff member

”

children”. One parent felt that “the staff are better at [knowing him] than me actually, in some ways.”

For parents of children with particularly complex educational and medical needs, knowledge of their children and consistent relationships with them were critical to their care: “They’re with her all the time and the doctors and staff get to know her really well. And they can have a lot of consistency in their approach. The consistency is across the house to the school, the therapeutic input, the educational inputs, let’s say the caring, homey sort of input, it’s all consistency and everyone understands her.”

Many teaching and care staff spoke of the need to build trusting relationships with their young people, emphasising the surrogate family life that they tried to provide: “We are like substitute parents really, because we’re there every day. When they see you they

recognise you, they know who you are. And then you are teaching them day-to-day things like washing up and what they need to do to tidy up.” Other staff noted that sometimes they feel like “proud parents” when their young people do things that are “breathtakingly unusual – like the first time we got a couple of kids cooking together” or when they “want you to be part of their life, when they come and share their little moments with you, their sad moments and their happy moments.”

Some staff felt their job far surpassed that of a teacher: “You’re not just a teacher. I think you’re everything.” They noted the importance of getting to know their young people as much as they can because “all of a sudden, we’re taking over the role, well the parental role.” Others, however, were hesitant to adopt family-oriented language to describe their relationships with the young people: “I wouldn’t say love, that’s too strong a word. But we do build up relationships with pupils in our class ... we treat them how we would want to be treated.” Others were also reticent to use words such as “parents” and “family”, although this was what their descriptions implied: “I suppose in a way you are replacing ... replacing’s the wrong word, but you’re substituting their parents for the time they’re here”; “Because some families unfortunately don’t visit them, that the staff become - not their family, because that’s not quite the right thing to say, but they become their ... they are their family really, I suppose.”

They also noted that developing stable relationships was sometimes difficult

because the large turnover of staff “makes it difficult for the kids to get to know them and trust them.” Other staff were cautious about children becoming too dependent on their care workers and support staff. In some schools, they actively sought to rotate staff among learners rather than have just one person with the same learner every day “because that’s real life and there’s a lot of staff changeover, people leaving, days off sick.” One parent from a different school noted the detrimental effect that “taking away” her autistic son’s support worker had on her son: “he’s gone downhill. He came home not speaking, more withdrawn, not the happy-go-lucky boy that I’d seen previously.”

Some staff also described a tension between developing relationships with young people and at the same time ensuring that they understood the boundaries of those relationships: “It’s quite hard to actually sit the young person down and tell them

that they’re not your friend. Because they class you as a friend. ‘We care for you, we care about you, but you know I’m not your friend.’ It’s very hard, very difficult.” Others also noted, particularly with young people with limited spoken language of needing to strike a balance between creating clear boundaries and supporting their emotional needs, especially in the absence of their parents: “It’s a nurturing process and they don’t receive that from their parents on a day-to-day basis, but how do we do it safely and how are we open about giving physical affection?” They were concerned about trying to keep the students “that we care about safe all the time.” Others still were adamant of maintaining such boundaries: “It’s about being very black and white from the beginning, making it very clear that you’re not there as a friend, you’re there to support them. You can be friendly with them and show empathy and sympathy and things like that at appropriate times, but it’s a professional relationship.”



The group of children who often face the greatest challenges in accessing a secure and fulfilling family life are those who are looked after. For some looked-after children the school community is their family. The survey completed by participating schools’ headteachers (see Appendix A) indicated that the majority of the looked-after children boarding in their schools had section 20 care orders and therefore still have access, albeit at a distance, to their family. A significant minority (15%) of those with section 31 care orders often experienced the most fragmented experience of ‘family life’,

for some of these children the school was often the one place where they experienced continuous and supportive relationships that are more typically provided by a family. School staff described how difficult it can be for these children, especially those who have a series of placements – “two days here, a day there ... I can remember spending most of the day with her waiting, to see where she was going. She was never settled before she left us.”

While many local authorities discharge the duties of the so-called corporate parent diligently, there often remain great inconsistencies in the quality and extent of outreach support provided by local authorities to children in residential special schools, despite their inherent vulnerability [25]. This inconsistency was highlighted in one interview with a senior member of care staff, who described a young person who had experienced significant discontinuity of care: “He was in a couple of different foster homes. Then he was placed in a supported living unit within his local authority when he was sixteen, which he went home to during the holidays.” However, due to constant changes of staff, “they’d change social workers, then he’d have a temporary one. It was constant ... we never knew who to talk to.” Ultimately, the placement could not provide a consistent or stable relationship with either peers or adults in this community context. This lack of consistency meant that school staff felt that there was “a complete lack of advocacy for him because the people making decisions didn’t know him.” Perhaps more importantly, the young person faced returning to a community in which

he had no existing relationships. By removing him from the community of the school, he effectively lost his ‘family’ for a second time.

These findings raise issues about the importance of having stable, consistent and often strong relationships with the adults who take care of them. The young people in these schools, often with very complex needs, are dependent on the physical and emotional availability of the key adults who support them – who clearly feel a much greater responsibility than their status of ‘carer’ allows. The enduring relationships that result from ‘being there’ is central to the child’s trust of other people, their understanding of the nature of relationships and their feelings about themselves as valued, important and competent human beings. Staff turnover, professional boundaries and the demands of running a residential setting meant that these relationships were not always cultivated consistently in those settings covered by the research. These issues are particularly poignant for looked-after children, especially those who experience high levels of discontinuity in their carers. In these cases, the sensitivity of care and school staff to the child’s need for trusting and supportive relationships is crucial to their healthy emotional development. One senior care manager, when discussing a care leaver returning to a local authority many miles from school with which he had no connections observed: “You don’t stop caring just because they leave. Not when you’ve been with somebody that long. You’ve built up a ... it’s almost like a parent relationship.”

Summary:

- Some young people report feeling homesick but others prefer living at school to living at home. Some children found lack of privacy and freedom a problem.
- Many young people, their parents and the staff who support them felt that residential should be – and often is – a ‘home away from home’.
- Adults reported that residential school placements help families of children with the highest levels of need to stay both together and (mentally and physically) healthy by supporting them to raise their child.
- Developing stable, trusting relationships with young people is integral to meeting their needs as human beings – which means that care staff often go beyond the ‘call of duty’ to ensure that these needs are met.
- Some staff, however, were concerned that there should be more established boundaries and there appeared to be little consistency of approach in this regard.
- Looked-after children, who do not have access to consistent carers in the local authority context, and children with extremely difficult family circumstances, may be extra dependent on care and school staff to provide the trusting and supportive relationships and advocacy that parents typically provide.

3. Being Part of My Local Community

Children have the right to enjoy and take part in their local community – developing friendships with other children in the neighbourhood, playing in the local park, going to the shops, riding their scooter to the local school [6]. Learning how to engage with people of differing backgrounds, ages and experiences who make up the world immediately around them can be crucial to their development. They need, too, to learn to help each other and to look out for each other [26].

Article 23 of the UNCRC [6] highlights in particular the rights of a “mentally or physically disabled child ... to ... enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” Children also have the right “to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts” [Article 31]. Furthermore, Article 24 of the UN Convention on the Rights of Persons with Disabilities [24] provides, inter alia, that governments should ensure that “persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.”¹

Many of the children and young people in our study lived quite a distance from their families and home communities – in one case, up to 150 miles away from the family home. Of the 83 young people who took part,

only 21 children lived less than 20 miles from their family home (average = 51.2 miles). As the accounts below attest, this distance makes it difficult to participate actively in their home community. In addition, however, some of the children we worked with spent most of the year (48 – 52 weeks) in residential care, which means that they see their family – and the place where their family lives – only very rarely.

The distance from their family and home communities caused considerable strain on many of the young people and their families. One young man with autism described the choice of going to a school other than his current one that would have meant becoming a fortnightly rather than a weekly boarder and he “really wasn’t going to stay for a fortnight because I’ve got like a club [at home] on Saturdays. I quite like doing that.” Another young person, whose previous placement had broken down due to several incidents regarding safeguarding, said that he could have gone to another school “that was good but it was too far away from mum.”

One 15-year-old boy with autism, who had had 7 previous school placements, explained the problems associated with not attending school in the local area: “The problem is, when you get too attached to your friends, you miss them when you leave. They’re not local.”

Parents were acutely aware of the lack of local provision for their child and were concerned that they were missing out on establishing and maintaining connections with their local

1. The UK has entered a reservation on this provision of the Convention since it believes that there may be circumstances in which a disabled child’s educational needs can best be met through specialist provision outside their local community.

community: “There are things at home that he does locally that he misses out on, like football. It’s quite difficult when he doesn’t go to school here” [mother of a young boy with SLCN]. One staff member commented that the distance from home had an impact on young people’s social relationships: “They obviously have difficulties with relationships and friendships so, really, all their friendships are here. If they can go out with a friend down to the shops here, that’s great because they wouldn’t do that so much at home.”

The lack of local community provision was a serious concern raised by many parents, who were worried not only that about not being close to their child but also that they were unable to build connections with the local community that would set them up for when they reach adulthood. While one mother noted that they “are quite fortunate that we do live quite close by, so we do see an awful lot of her” others spoke of the disappointment of the dearth of suitable, local schools. One father explained, “As parents, we were both reluctant for her to be a hundred-odd miles away. I particularly thought, no way is that going to happen. But when you looked around, there was nothing [in county] that could offer anything remotely safe, to be honest.” Another mother, who had gone through 7 tribunals to get her son into various placements said that “if the right interventions were in place in terms of after-school clubs, just the right interventions locally, he would not have had to go into residential school when he did.” Other parents noted constraints on visiting their children due to the costs of travel and accommodation.

Parents wanted to be more involved in their child’s education and care but repeatedly mentioned that the distance prohibited such involvement. Schools and staff were aware of the challenges raised by the distance some families were away from their children and sought to support them where possible: “Because for some of our parents, it’s not about coming round the corner to your child’s school, we have an open door policy. We say, ‘contact us, come and have dinner with us, come and join in’. But we also understand that there are real challenges with the distance for some parents.” Others try to facilitate communication with families, especially those that live some distance away: “I spend a huge amount of time emailing parents. And some of them spend a huge amount of time emailing me. Because we can’t see them in the playground



and most of them aren't local, I think they need that."

On the whole, however, many parents were dissatisfied with the amount of information they received from school about their child and wanted to hear more – not just about what they did during the day or any incidents that arose (which they felt the schools did well to convey) but particularly about the child's progress educationally, socially and emotionally. One father of a young man with BESD summed it up: "I think there's much broader recognition of the need for good communication with parents and the fact that, actually, parents have a constructive role to play in making sure that the kids are a success for the school."

Schools make active efforts to build links with the local community

School and care staff were aware of the need to ensure "that learning is functional, purposeful and effectively relevant to them". Many of the schools to whom we spoke had therefore developed excellent links with the local community as a way to facilitate such learning and to support young people to participate in community life. Staff members described taking young people to the local Sainsbury's to practise their shopping skills, to youth club to develop their social skills, and "if we're practising road safety and bus travel, we might be going charity shop shopping and go for a hot chocolate." Indeed, several of the researchers during school visits went on trips with the young people both during and after school, to the local supermarket, the local park and to the swimming pool.

While the trip to the supermarket offered a targeted learning experience for 8 largely nonverbal young people with autism, the trip to the park after school allowed them to play uninhibited. One staff member commented: "Our aim is to include as much community-based stuff as possible – it's a priority. Because the kids aren't learning to be in this environment, they're learning to be part of the community. So they're transferring what they've learned here out in the community." There was also evidence of bi-directional community contact with some schools welcoming members of the local community with appropriate DBS clearance into the school grounds to work on allotments located in a school's horticulture centre.

Schools also mentioned the opportunities available for work experience in their local communities – in the local charity shop or other small businesses. One 19-year-old young man with MLD spoke of how much he enjoyed his time working in the community: "On Tuesday mornings I'm at the garage and Fridays I'm at the garage, fixing broken-down cars."

Young people and staff also spoke of the many activities that they were able to take part in after school or on the weekends, including going to the local park, swimming pool or cinema to relax and enjoy themselves. One staff member said: "we get them out in the community probably almost every night. We don't want them to feel institutionalised or isolated. We want them to be doing really normal things. You or I might go down the gym or go swimming; that's what we do here." And communities were reported to be responsive to that

Table 2. Frequency of participation in a range of community and leisure activities.

Activity	Rating					
	% Never	% Very Occasionally	% Quarterly	% Monthly	% Weekly	% Daily
Swimming	0	7	7	21	57	7
Horse riding	21	21	0	14	36	7
Trampolining	0	7	14	0	57	21
Eating out	0	7	14	29	43	7
Cinema	7	7	14	50	21	0
Sailing	43	36	7	0	14	0
Holiday	7	79	14	0	0	0
Circus	36	36	29	0	0	0
Visits to parks/historic sites/ theme parks	0	7	0	21	64	7
Disco	14	14	21	7	36	7
Cooking	0	0	0	0	43	57
Craft	0	0	0	0	29	71
Listening to music	0	0	0	0	7	93
Playing music	0	0	0	0	7	93
Watching television	0	0	0	0	0	100
Watching films	0	0	0	0	29	71
Computer games	0	0	0	0	29	71
External clubs	0	21	7	0	50	21

participation: “They’re very supportive in the village, very supportive. Quite often work experience is the first time that our learners are out in the community unsupported by anybody. They’re out there by themselves.”

These reports were supported by the results of the survey completed by headteachers (see Appendix A), which

showed that there appear to be generally high rates of participation in community and leisure activities (see Table 2).

Given that communication for some young people can be particularly challenging, certain schools specifically sought to prepare young people to be confident enough to get involved in the community: “We show them

deaf role models and show them they can get out into the community and into the world.”

Some schools did note, however, that developing strong links with the school’s local community did not necessarily prepare them well for living and working in their home community, their likely place of residence when they leave school (see Box 4). Staff spoke of attempts to set up work experience in the family’s local community so that the transition to life after school would be smoother.

Sense of belonging: building their own community

Developing connections between children is an essential ingredient of a thriving community. With many young people spending so much time, and often growing up, in their schools, it was encouraging to hear many of them – and the adults supporting them – speak of the sense of belonging within the schools: “It’s quite nice to have friends that understand your needs and have the same needs as you” [young autistic woman]. As another young man with autism described, “it’s better to be around people that understand you, how you’re like because they’re the same. And they can’t bully you about it because they’re the same.” Another talked about how his autism initially made him “feel quite nervous” because he did not know what it was. But that “learning that there was more people at the school that had almost the same problem that I had” made him feel “more comfortable”. One pair of young women described what it has felt

like to have their first real friendship: “She’s like a sister.”

Parents also commented on the importance of having people around them with similar needs: “It unites them. It’s the first time she’s not felt isolated or singled out” (father of young woman with epilepsy). Many staff emphasised what they saw as the benefits of group living, particularly how it can both empower young people to be aware of their own and others’ differences and “normalize” them: “A lot of students come here and they’ve never seen another person have a seizure. So it is about building their self-esteem, their confidence, to understand that their epilepsy is not something to be ashamed of.”

For a number of deaf children, the residential placement had provided their first contact with other deaf children, and the opportunity to develop British Sign Language (BSL) or other means to facilitate their ability to communicate with others. One deaf young woman aged 16 explained: “I like school because I have a lot of friends. I get excited about seeing them. I love BSL so much because it makes me understand more than speaking.” The care staff stressed that being with others with the same needs made them feel at home: “I just feel here they’re stable, they’re Monday to Friday in a deaf family environment with consistency and support around them.”

The experiences were not so positive for all young people, however, especially young people with autism: being with others with similar needs did have its drawbacks. One young woman observed

that “it’s nice to have friends that understand you ... but then, if they’re, like, autistic like me, like them, then you all get on pretty perfect, but at the same time, there’s no-one to help.” Staff also acknowledged, “sometimes being with 12 or 14 autistic people together doesn’t always work. It would be nice sometimes for them to perhaps have some peers and some input from people who aren’t autistic.” Sometimes these difficulties were due to the noise

levels in dining rooms and classrooms (“They all like to make a lot of noise but they don’t like each others’ noises at all”) while other staff noted that sometimes it was just having other young people around – autistic or not – that was particularly challenging for them: “Most of our young people would prefer adult interaction – it’s predictable. It’s not necessarily that they don’t ever want other young people around them. It’s just a little bit scary.”

Summary:

- Many young people live very far away from their families. This distance, combined with how much time some spend in school, makes it very difficult for them to build connections with their home communities.
- Schools reported many efforts to ensure that young people participate in communities and leisure activities, especially because such activities offer opportunities to generalise the learning achieved in school.
- Many young people emphasised the sense of belonging they felt in their schools, developing connections with other young people with similar needs, although this also presented some challenges.
- When young people leave their schools and return to their home community they can lose contact with those who mean a lot to them at school – their friends, their carers –, which can make the transition even more challenging for them. This is especially the case for looked-after children who have no ‘home’ to go to.

Box 4. Peter's story

Peter is a happy and friendly young man aged 19, who has learning difficulties and autism. He has attended his residential special school for ten years. When he joined the school he was in foster care, with extremely limited and regulated contact with his birth family. While Peter has resided at school he has experienced a number of changes of foster carers and, at 16, he was moved into a supported living unit, where he spent the school holidays. When asked about what he would like to happen in the future he was clear: "Staying here, staying here forever and in my work experience." He described being "scared of leaving" and "worried" about what was going to happen next.

Peter has no established relationships in his home local authority. He has experienced numerous changes of social workers and carers, as his school care manager explained: "they'd change social workers, then he'd have a temporary one. It was constant change. We never knew who to talk to." There has also been a considerable turnover of the staff in the supported living unit. Peter could not name his social worker or any staff at the unit. He explained that, during the school holidays, "It is boring. I sit in my room and watch TV."

The local authority that cares for Peter is in a large urban context – which is in direct contrast to his school placement, in a rural setting

with long-established links with the local community. This enables the school to offer a range of interesting work experiences. Over a number of years, Peter has had a very positive work experience placement, developing skills in a trade that he is passionate about. When asked what subjects he likes at school, he immediately replied: "Work placement. I go twice a week. It is great working there." Peter was adamant that he wanted to remain in the school's local area and to work there. The trade person he had been placed with had developed a supportive relationship with him. His care manager described how: "the man came to his presentation at the end of term and would have happily offered him some sort of employment, had he [Peter] been able to stay here in the area."

Throughout Peter's final summer term the school struggled to engage his local authority in planning for his transition. As the staff explained: "As a team we were emailing social workers on a weekly basis saying, what's happening? But nothing happened ... to be brutally honest the social workers did nothing. We had a meeting eight weeks before they [Peter and a peer] left, and that was the first meeting we had to discuss their pathway into adult services. At the end of the day the social worker said, 'it's all right, we've got a year to sort this one out'. And we said, 'hold on a minute; they're leaving

in eight weeks.’ That’s how little they understood of the situation.” Another staff member continued: “The other lad had the same sort of issues, at least he had a father who was speaking up for him. He got what he wanted. And that’s all Peter wanted. If Peter could have stayed around here and lived in the supported unit, he could have been quite independent. Someone like Peter had nobody to keep fighting his corner other than his team at the school.”

During Peter’s last month at the school the knowledge that he was not able to remain at school and the uncertainties about what would happen next for him took a toll on his emotional state: “Obviously, as time went on, because he knew he was leaving to go to nothing, to leave what was his family, his anxieties and distress about leaving grew; he was unsure where he was going, what he was going to do. So he was becoming more and more anxious.” Another staff member said: “For me, it was dreadful to see a lad in that level of distress. And for the sake of a little bit of communication, he could have had a life that would have been what he wanted.”

In the ten years Peter has spent living at school, he has built strong relationships with the care staff, teaching staff and the local community. The school context has provided his only stable and authentic relationships as his care



Obviously, as time went on, because he knew he was leaving to go to nothing, to leave what was his family, his anxieties and distress about leaving grew; he was unsure where he was going, what he was going to. So he was becoming more and more anxious.

School staff member



manager explains: “You know, we’ve been his family. I’ve been with him for basically six years.” He concludes: “Making decisions based on finance – it is not ultimately going to save any money, but it will do him a lot of harm.”

Peter had articulated very reasonable desires but these have not been listened to. On the basis of belonging regulations, Peter has been forced to return to a locality where he has no existing relationships and has therefore been denied his right to the only ‘family’ life he might have.

“He had nothing planned. And now he’s gone.”

4. Having My Say



Learning how to make choices about their own lives and developing a sense of independence is crucial to the development of a child's autonomy. It has been increasingly recognised therefore that children should have a say in where they go to school and how the most important decisions within that schooling shape their lives [5]. Understanding children's views, wishes and feelings is therefore a vital component in understanding their best interests in decisions that affect them. These decisions include day-to-day matters that are important to children, as well as decisions about children's schooling which have profound consequences for their lives.

Article 12 of the UNCRC [6] requires States Parties to "assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." Implementation of Article 12 of the UNCRC "requires recognition of, and respect for, non-verbal forms of communication including play, body

language, facial expressions, and drawing and painting ... Children with disabilities should be equipped with, and enabled to use, any mode of communication necessary to facilitate the expression of their views" [27].

This right applies to all children. Schools must actively seek the views of those children who cannot use speech and help them to develop functional communication skills. Even where children cannot fully articulate their concerns, it does not mean that those concerns do not matter to them. All children have needs, wishes and views. Adults have a responsibility to ensure that they understand these perspectives, especially when children struggle to communicate them.

Current policy frameworks recognise these rights. Recent legislative changes, for example, emphasise the importance of involving young people with SEN in the educational decisions that ultimately affect their lives [20], including where they will go to school. Children with a statement of SEN should have the opportunity to contribute to their annual review.

Those in residential special schools who are looked after are also entitled to participate in regular case reviews and to have access to a social worker, an Independent Reviewing Officer, or an independent advocate if they need one to make complaints or representations.

Participation in such decisions can of course take many forms – ranging from false types of participation (including tokenism) to genuine control in the decision-making process. We were therefore interested in examining the extent of children’s participation – whether they are listened to, how they are supported to express their views, how their views are taken into account, whether they are involved in decision-making processes and whether they share power and responsibility for decision making [28-29].

Few children who took part in our study, however, were actively involved in choosing their current school. Some young people visited schools with their parents and were involved in making the final decision: “Mum and dad chose the three schools that they thought were good. And then we went and looked at them and I chose which one I wanted to go to” [young man with BESD]. One mother described why it was so essential to include her autistic son in this decision: “Because he’d had such a rough time at his previous schools, I felt he should also have a say in which school he should go to. [Child] was actually very sensible and gave me reasons of why he was hit on [current school] from the start.”

Yet other young people described how their parents had made the decision

on their behalf. One primary-aged boy with SLCN told us how his mum had chosen his school and that he would prefer to go to a “different school” instead “cos it’s not much fun here.” One young woman with autism told us that she had “none, no choice at all. They just said, go to this school, so I got in a taxi one morning and they brought me to school ... I was scared.”

Some parents of young people with complex needs and limited communication explained how their child “doesn’t speak” and so “couldn’t make a decision”. Another mother remarked how her child “wouldn’t understand the concept” and another still said that her child “hasn’t got a clue at all. He doesn’t have much understanding of his environment. So those decisions just have to be made for him.”

One school acknowledged the importance of involving the child in decisions about school placement. One staff member described how “it’s not a ‘you will do it’ thing; it’s an agreement with the child and the parents. It’s not that they have to come here. So the vast majority of the young people that come into boarding are quite happy to do that and the transition isn’t really a problem.”

Not being listened to

Many of the parents were extremely concerned about the adversarial nature of the system, that there was too much bureaucratic ‘red tape’ involved in getting their child into the school that they felt best fit his/her needs. They repeatedly described how they felt that their voice – and their child’s

voice – was simply not being heard. One mother, who reported going through 7 tribunals, said “the [local authority] don’t listen to you. You have to go to tribunal to get them to even look at the first part of the statement – they wouldn’t change it. So it was just literally fighting and fighting and fighting.” One parent noted that if her son’s first school were better equipped and had listened to her “he wouldn’t have ended up in such a dire position and needed a residential place at a cost of £80,000 per annum to the tax payer.”

Many parents gave heart-wrenching accounts of their child’s developmental and educational histories and recounted how difficult the journeys had been – financially, physically and emotionally – for them and their families, and some young people did too (see Box 5). More than half of the parents interviewed (n=18) went to SENDIST to secure the child’s placement in their current residential school. Five additional parents were due for tribunal but the case was settled the day before or a few days before. One father described the constant struggle they had with the local authority to ensure that his daughter was provided with the most appropriate provision: “We felt every time we needed something or [child] needed something, it was a battle. We’d read all the information that the school should have done and what she was entitled to and again, that was difficult to deal with.”

Several parents spoke angrily about how their child is unable to have a voice because the “people making decisions about my child have never seen him.” They described feeling



We get the students to agree, have their choice, have their say - what they think’s fair, what they think’s not fair. It’s about empowering them to make all these choices for themselves and make these decisions within a safe environment.

Staff member



effectively ‘cut off’ by the lack of direct contact with people in the local authority: “We haven’t had anything at all from them [since the tribunal]. They’re not in contact with [the school]. They don’t bother turning up to the annual review, they don’t get in touch with us practically at all.” School staff were also concerned that the lack of contact from social services, particularly with regards to their role with looked-after children, often meant that “they don’t know the children or their needs, and they’re therefore not really able to act as their advocates. ... I don’t know whether it’s their caseload, they’ve got so much on. But I don’t think they’re always listening, I don’t think they take on board what we’re saying.” One senior care manager described how in some local authorities the constant changes

of social workers means that “there’s a real sense that the people making decisions didn’t know [the young people].” It was clear to him that in some cases, even when a young person clearly expressed preferences, financial considerations often took precedence: “They wouldn’t fund [what the young person wanted], because who was going to pay for it?” The absence of Independent Reviewing Officers or other advocates in these meetings, together with discontinuity in the support from local authorities, meant that young people’s voices were at risk of being ignored.

Several parents also reported education and social services were often fighting over who should pay for the placement, which made them feel as if all the authorities were concerned about was money.

These discussions raise issues about the degree of choice parents – and their children – have in the decision-making process. In so doing, it also questions whether involving young people in placement decisions that are in dispute is necessarily the best option since it might lead to disappointment and (further) distrust in the system. In these cases, the adversarial process may make it very difficult to involve the child. Indeed, only one young person, a 15-year-old boy with autism, explicitly referred to this process: “It just took a long time, but they just went to panel and that, didn’t they.”

These reflections and discussions further highlight the place of residential special schools in society and in the education

system. Several parents and school staff noted the stigma associated with sending children to residential special schools. One mother said, “It’s often perceived in society as the worst thing in the world. And although there are some aspects which are hard, I think it’s a really positive thing for certain children.” Several parents further commented, “it’s often seen as a last resort”, put in place often after years of “no support”. One staff member explained how “it’s often seen as such a negative move. Parents feel they’ve failed and they’re guilty and all that, whereas it shouldn’t be like that.” Several staff members suggested that residential placements “should be an option right from the start. Every year the Statement is reviewed, and in theory their placement should be reviewed.”

Schools promote independence and autonomy by actively teaching children how to make choices

Article 24 (3) of the UN Convention on the Rights of Persons with Disabilities [24] mandates states parties to “enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community.”

For all of the schools we spoke to, promoting young people’s independence and autonomy was a key feature of the curriculum. Many schools emphasised the importance of their “24-hour curriculum”, which targets not only education but also young people’s life skills and social skills consistently across the day. For schools serving young people

with particularly complex needs and limited communication, they described how “choice is so fundamental to everything that we do ... just making a choice is a huge learning curve. Our young people can’t cope with choices, so we have to help them learn how to make choices. For those who can’t articulate their preference, they do it by their behaviour.” Another staff member raised the importance of making mistakes and learning from them: “Allowing them to get to make the wrong choice as well, following through on that, and knowing that’s not what they want.” Box 6 describes the results from our observations with young people. These built a picture of the ways in which children with limited communication systems could contribute to shaping their lives, given appropriate support.

Young people also clearly valued the emphasis on the “independence stuff ... I never had much of that” [young woman with SLCN]. Another deaf young man described how he had “learnt about my emotions. My education was limited before. And I really do like the residential because I can relax and then I can cook with my friends.” One young man with BESD also reflected on what he had learned at school and why it was so important to him: “The whole school is work experience. The things you do in the school day is just like work experience. I’m currently doing a project in school to provide a coffee service to the staff. We’re going to be doing a bit of role-play in it as well because I have trouble, like, taking the word ‘no’ for an answer and stuff. So it would help me with my social skills quite a lot.” Schools also sought to develop young

Box 5. Damian’s story

Damian is a thoughtful 15-year-old young man with autism and additional behavioural difficulties. He began as a day pupil at his current school but almost immediately began living on site, which he had been doing for the past 4 months. Prior to that, he attended three mainstream secondary schools, all of which he “hated” because he “didn’t get on really well ... with everyone”, often lashing out at other students and teachers: “They didn’t understand what I was trying to get across when I was trying to get it across and what was happening.” He further noted how the process “took a long time” as his parents had to go to tribunal to secure a place at his current school and,

“

It’s easier to get along with people (at this school). I have somebody to support me all the time. They just know they way that I like to do things and know that I have to find things out for myself. And the way that things have to be structured.

Damian

”

although he did not have a choice about the school itself, he “wanted to come here”. Damian described how difficult it was living at home because his family “just do my head in” but also how he now misses them and enjoys getting to see them on weekends, when his mum or dad come to visit.

When asked about his current placement, Damian said: “It’s easier to get along with people. I have somebody to support me all the time. They just know the way that I like to do things and know that I have to find things out for myself. And the way that things have to be structured. That was at my old school, nothing was structured. One minute you’d go in there, the next minute you’d be going somewhere else and you didn’t even know.”

His time at the school so far has not been without its challenges, however. Damian reported difficulties with the other boys he has been living with: “It feels like I’ve been here a long time because of the guys I’m living with.” There have been several incidents: “I think I’ve only hit him once to be honest with you, because he’s annoying. It’s not bad in four months.”

Damian described his keen interest in baking and cooking, which the school has been fostering. He cooks for his housemates and for staff and is keen to be a pastry chef

when he leaves school. Damian also spoke of various trips that he has been on with his housemates and noted that he has a say on whether he wants to take part in these activities. In fact, he reported feeling that what he has to say makes a difference: “Definitely, because they all listen, and they all take action really.” He also felt that he and his peers are treated “really good” in residential: “If you’re acting dangerously, like throwing things around, hitting people, and if you continue, then you get restrained, which is obviously fair. You don’t want to hurt someone.”

Damian also showed a great deal of insight into his own often challenging behaviours, as well as of potential ways to overcome them. For example, before his Annual Review, he described how helpful it had been to write things down because “sometimes I can be a bit non-verbal; not very often, but sometimes. Sometimes I can’t say things whenever I need to.” He also talked about how he would go for walks to “just calm down a bit. That seems to work. The staff follow me usually, but just to make sure I don’t do anything dangerous.”

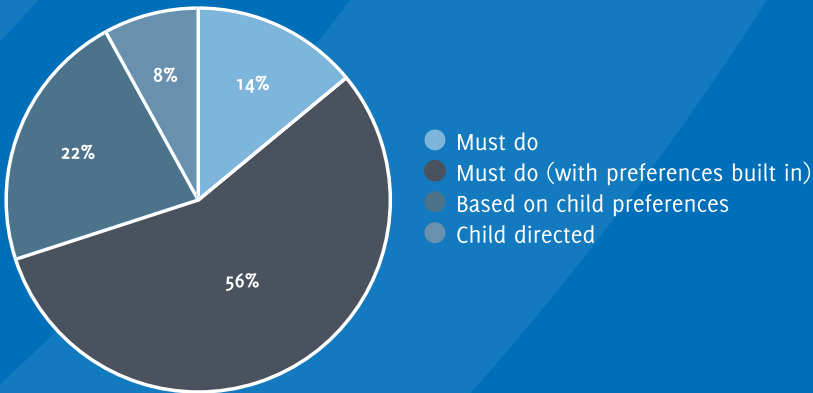
Damian clearly felt comforted about being in a school where they “understand what I like and what I don’t like, when I’m stressed what I do. Hopefully I’m staying here, so I’ll be all right.”

Box 6. To what extent did young people direct their activities?

During the structured observations, researchers recorded the nature of the activities in which children took part to determine the extent to which a child's views had been taken into account when offering the learning experience (see Appendix A). Specifically, we coded whether the activities were 'must do', 'must do (with the child's preference built-in)', 'based on the child's preferences' or 'child directed'. When children and young people are at an early developmental level, good practice states that, in order to ensure the child's engagement, adults should aim to 'follow their lead', so as to provide

them with frequent opportunities to participate in activities embedded in their own interests.

As shown in the pie chart below, a variety of activities were offered to the 10 children and young people observed. Yet more than two thirds of their activities fell into the 'must do (with preferences built-in)' and 'must-do' categories – that is, the adult largely directed the activities. While there will certainly be activities that children 'must do' throughout the day, building activities around the child's preferences may well enhance their level of engagement and thus their learning.



people's ability to reflect on their own behaviour and regulate it appropriately. Many of the young people we spoke to were remarkably self-reflective, that is, they were aware of their challenges and had developed ways of dealing with those challenges, particularly those that related to their behaviour and emotions: "I've got my feeler

meter and what to do when I'm angry, I look at. It's good for me to have one so I know what I can do if I'm angry" [young woman with autism]. Another 15-year-old with autism described how "sometimes you just need somewhere you can just calm down, do what you need to do, get on with it really." In this way, the schools aimed to equip

them with both the confidence to understand their own feelings and behaviour and the tools to make choices about their actions – to stop and think before they act. As noted in Chapter 5, however, not all children had access to appropriate mental health or other expertise in order to assess and address underlying issues.

Formal mechanisms for young people to have their say

Many young people talked about their school councils, which provided opportunities to discuss “what kind of changes we can make in the school” [young person with SLCN]. Young people described how they could go to their student council representative, “like, if we have any ideas for what we want in the school and sometimes it happens ... if it’s something reasonable, then it might.” One young man with autism was chair of the student council in his school, which “comes up with new things for the school. We’re still working on raising money for soft play.”

Few young people talked about being involved in the annual reviews of their SEN statement, and when they did speak about it, they noted the challenges during such reviews. One young woman with MLD described how she gets upset because her mum and dad, who she sees rarely, are at the school: “It makes me frustrated ... I get very agitated inside.” Another boy described how “well sometimes, yeah sometimes, you can choose your own thing, what you want to do and what ... but sometimes I get a little bit shy in there.” On a more positive note, one 16-year-old girl with autism explained

how she enjoys preparing for her annual review. She described how she has made films or presentations for the meeting so that, if she feels shy, her views can still be shared – which she thinks is important: “I get to go. I get to go. I’ve been to every one so far. Yeah, I stay for the whole meeting.”

School staff and parents confirmed that young people did often attend at least part of their annual reviews, where possible: “obviously the majority of our young people in the home are non-verbal so [getting them involved in decisions] is something that we definitely struggle with. Their views are just put forward by their key workers and we just interpret what we think their views are, which obviously isn’t ideal.” Indeed, some parents of young people with autism and very limited communication explained how they were not involved in their annual reviews because “he wouldn’t understand what’s going on.” One parent of a 15-year-old young man with no speech said that he “has no voice – I’m his voice. And that’s where that scares you – if I’m not here, who would take on that role?”



Box 7. What is most important?

Sarah, a 15-year-old girl with autism, and Tom, a 14-year-old boy with ADHD were shown 9 cards showing statements (in words and symbols) about taking part in decision making and asked to work

together to rank them in order of importance. During the activity, the young people spoke in depth with the researcher about their experiences and explained the order of the statements.

Most important



To be helped



To be listened to



For adults to make good choices



For adults not to put pressure on me



To have time to think about things



To let me have my say



To know what is going on



To be given choices



To get what I want

Least important

Schools described other formal mechanisms by which young people could “air their views”. One young man with Prader-Willi Syndrome described how he is the activity organiser in the residential part of school: “I organise where we go on the internet and see what activities people like and then plan to go. There are treats once a month.” One young man with autism explained how he and others at school had helped set the rules, which were

all helpful “because we came up with them and we all agreed with them.” One school also mentioned how the young people in residential were involved in “re-writing the behaviour policy; just looking again at what rewards they want and what systems they want in place.”

Some of the members of staff that we spoke to were both uncertain and concerned about whether young people

Sarah and Tom's rank order is shown in the picture to the left.

They both felt that *To be helped* was the most important statement. They explained how they were helped by the residential staff and teachers and also considered what it would be like if no-one was there to help: "because I think without having help, stuff could get even worse." They rated *For adults not to put pressure on me* to be of relatively high importance. Sarah believed that adults put pressure on her during her learning ("Like you should not make a mistake") and felt that it was important for teachers to speak to her "nicely" when she does make a mistake.

When discussing the placement of *To let me have my say*, they talked about the importance of showing respect and taking turns when someone is speaking. Sarah demonstrated this by showing that someone can only speak when they are holding the teddy bear, and it is the rule to listen to that person.

Sarah and Tom rated *For adults to make good choices* to be more important than *To be given choices*. They both recognised that, at school, there were times when they were not given a choice, such as bedtime, whereas they could go to bed at "any time" when they were at home. Their decision to rate *For adults to make good choices* seemed to be centred around valuing and depending on adults' help: "Say if like there's a robber, if the adult wasn't there, like, to help you, you couldn't like call 999."

Tom also expressed the importance of treating everyone fairly when placing *To get what I want* at the least importance: "if you like wanted a 3DS and then they just let you have it ... then it's not fair for like other people." These findings show that these two young people were more concerned with being supported and listened to than getting their own way (a view commonly held by adults; 31).

attended their Looked-After Child (LAC) review and, if they did, how much their views were taken into account: "The child isn't actually heard at the LAC meeting, are they?" ... "The social worker is heard but the social worker's agenda is not the child's agenda." ... "Yeah, but that's where it is our role to put the [child's] agenda forward, to be their advocate. Because they don't have a parent who's going to be ringing the local authority every day for

6 weeks until they know where they're going" (see also Peter's story; Box 4). There was evidence of considerable inconsistencies in the way that local authorities discharged their duties to looked-after children. Responses to the headteachers' survey indicated that while some local authority representatives were attending two LAC reviews per year, Personal Education Plan (PEP) meetings and annual reviews, others attended meetings



Informal mechanisms for young people to have their say

Young people reported often feeling able to choose what they could do after school and during the weekends “because it’s, like, very open – the school are very open to ideas of what to do” [young man with BESD]. Another young man described how they are sometimes given a choice of activities: “It depends. Sometimes you choose, and then other times we all go.” He further explained how the staff “would like you to take part in the activities ... but if you really didn’t want to, then they wouldn’t make you.” Staff in many schools repeatedly emphasised that although they would prefer for children to take part in structured activities, that they could always opt out or do something else if they preferred.

only once a year, and others still were very inconsistent attenders despite regular invitations. Headteachers felt that this lack of consistent support had potentially negative implications for young people transitioning between child and adult services.

There was also evidence of inconsistent involvement of Independent Reviewing Officers (IROs) in children and young peoples’ reviews, despite their statutory obligations, and there was only one mention of an independent advocate attending formal review meetings. Local authorities must ensure that they discharge their duties to looked-after children living outside the local authority with the same diligence as for those living in the local area [25].

Other young people felt they sometimes were unable to have a say, particularly around bedtimes: “Sometimes it’s just too early ... sometimes I want to stay up till later” [young person with SLCN]. Others also wanted more independence: “I get forced to do stuff I don’t want to do. [At home] I go to the shops by myself. I get milk, packs of sweets, chocolate. And my mum trusts me. The only one who can do it [at school] is [another child].”

When staff members asked about how they elicited children’s preferences, their views and perspectives, they described using choice boards with Picture Exchange Communication Symbols (PECS) during dinnertime, using Voice Output Communication Aids (VOCA) on their iPads and other forms of alternative and augmentative

communication (AAC). They did acknowledge, however, that this was easier with the young people who can communicate using language: “But it’s about knowing your kids, knowing the kids you work with. With some you can just tell by their facial expressions. With one girl, you know exactly when she wants to do something. And you definitely know when she doesn’t want to do something.”

Indeed, during one observation, one young man with autism and no spoken communication used an intricate and well-rehearsed method of communication to inform the adult working with him of his choices. On entry to the breakfast room, this young man chose a table to sit at and his carer opened a specially-designed choosing book consisting of numerous photographs taken of objects or places around the school. The staff member identified all of the photographs relating to breakfast and placed them near him so that all of his options were visible. He chose one and handed it to his carer, who went to collect what had been requested and held it in front of the young man alongside the photograph. The item was given to him only when he tapped the photograph, indicating his preference. In this way, he was able to choose what to eat for breakfast.

Several staff members stressed the importance of not just making assumptions about children’s preferences: “It’s also down to staff education, isn’t it, not to influence what you want through the students. We’re careful to make sure it’s something the students can make a choice over, not the staff member.”

They also cautioned that “you can offer the choice but you’ve also got to make sure that you’re keeping them safe and that they’re choosing appropriate things to do for the level they are and the support they need.”

For children with very complex needs, one staff member described how “a lot of our kids will let you know if they don’t want to join in an activity – they’ll cry and they’ll moan or they’ll just shut their eyes and go to sleep.” They further explained how they can tell when some young people are enjoying their learning: “How do I know? He engages more. He opens his eyes more, he holds his head up more, he’s more awake and alert when standing. And therefore he likes to learn ... well, we feel he likes to learn more [when he’s in his standing frame]. In his chair, he’s quite often hunched up with his head down and not engaged.” For another young woman who had limited speech, the school uses a piece of technology called iGaze to help her choose her snack every morning: “It works through infra-red cameras and it can track her eye moments because she can’t say yes or no. The iGaze will measure how long she’s looking at certain pictures for and it will tell you which one she’s chosen.”

For children with epilepsy, particularly those who have recurrent seizures, teachers explained that they needed to be cautious in demanding too much of them: “I have a student who pretty much one week in three will have continual seizures so he’s not really himself. It wouldn’t be fair for him to make quite an important decision in that week because it might not be the same thing the following week.”

Care staff also explained that because of their life-threatening condition, each young person's bedroom is equipped with audio monitoring to monitor seizure activity while they sleep: "There are some young people who opt out, or have it conditional, where 'only when I've properly fallen asleep are you allowed to switch it on'. Some youngsters who do have night-time seizures have the capacity to say, 'no, I don't want to be checked that often. I want to just rest and sleep. I don't want you walking into my room every half an hour'."

You can't always get what you want

Parents and teachers often suggested that their young people might have too many choices and opportunities at residential school: "That's where we're most unrealistic, because at weekends we have this big thing – we've got to do things, we've got to take them out, every day, twice a day, we're going out. In the real world, when I was a kid you were lucky if you got one outing once a month. It's not a realistic view of how life is."

They also acknowledged that opting in to activities was an important part of their socio-emotional development. One parent commented that the school where his child with BESD attends "use both a combination of teacher and peer pressure to say you're here to participate and not to sit on your own in a room. Because it's about building their confidence in social situations. You can give kids like that the option, and often their option would be to opt out. So I think you have to force them not to opt

out." Similarly, a teacher noted that the choice of opting out of activities is discouraged because "actually that's the whole point of them being here. Most teenagers want to spend a lot of time in their rooms. But ours will spend an awful lot of time in their rooms; so we have to encourage them to come out. It might be actually very helpful to them to learn to cope with or manage those sorts of situations and build their confidence."

Staff also described the challenges in making sure that they have opportunities to choose things they might not otherwise choose. One teacher described how for her children with autism, it was important to "check that they're not getting, whatever it is, say a Twix bar, every day just because they always get a Twix bar. Because they might choose a Twix bar only because they've never been exposed to a Mars bar. So we need to create the opportunities where they can try as many things as they want so that they can make informed decisions."

One staff member was concerned about whether young people, particularly those with limited communication, were given enough choice: "It's difficult. I personally don't see why they couldn't have Coco Pops every day because I think that is what a normal child would have in the real world at home. But we're so fixated on it being a treat and not it being just what they have. Often we don't think to give it to the kids because they can't ask for it."

Summary:

- Residential school placement decisions are most often made for young people with SEN and disabilities rather than *with* them.
- Parents described feeling cut-off from, and supported by, local authorities, who, they felt, fail to listen to their concerns and the needs of their children.
- The adversarial nature of the process that leads to many residential special school placements often precludes the participation of the young person.
- Schools described how they aimed to promote young people's independence and autonomy by actively teaching children how to make choices and by teaching them to be more self-reflective, leading to greater self-regulation. Some schools were using innovative ways of accessing the thoughts and feelings of children with limited speech and complex needs.
- Young people often take part in their annual reviews but it is unclear what impact that has on the child's development and on educational decision-making.
- There is concern about how much the voice of a looked-after child is heard, when their views and wishes are not those of the social worker or local authority.
- Not all local authorities are delivering the statutory requirements in respect of care reviews and attendance at annual reviews for looked-after children.
- Schools provide many ways to ensure that young people's voices are heard, although parents and staff noted the importance of encouraging young people to actively participate in activities even when they would rather opt out.

5. Feeling and Keeping Safe

Keeping children and young people safe includes making sure that children are protected from harm, are brought up with safe and good care and are given good chances for their future life [6]. All the other rights that children have are, in a large degree, dependent on this right to be safe and secure being maintained.

Under Article 19 of the UNCRC [6], all children have the right to protection from all forms of violence to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse. Article 34 focuses particularly on the protection of children from sexual abuse and exploitation. Article 37 protects every child from torture or other cruel, inhuman or degrading treatment or punishment. Under Article 2 of the UNCRC, every child is entitled to the realisation of all rights, without discrimination. Yet a recent research review [32] drew on international evidence to conclude that disability is disproportionately associated with all forms of child abuse, especially neglect.

Many of the young people we worked with came from school placements that had broken down in some way – largely because of their own often challenging behaviour or others’ behaviour (usually bullying), or because the schools simply could not meet their needs. One 17-year-old girl with autism described how her old school “was horrible ... because it was four hours away and this guy that I’m not friends with on Facebook attempted to strangle me. And there were lots of bullies. I weren’t happy there. I wanted to kill myself.

I even tried to.” Another girl also described persistent bullying in her previous mainstream school: “I hated it. I got bullied by teachers ... all the years in the school. Everyone bullied me, everyone. So you know when you go to a point when you’ve had enough? I had enough of everything.”

One 15-year-old boy also described what it felt like to go to four different high schools, several of which he had been excluded from for aggressive behaviour: “Makes me feel like a traveller. Hopefully I’m staying here, so I’ll be all right. It’s somewhere I actually enjoy. It’s easier to get along with people here. I have somebody to support me all the time.” Some parents also gave often-harrowing accounts of neglect in their child’s previous schools. One mother recounted how she “got the phone call that a member of staff was caught dragging [her child] and pulling him across the gravel. So I pulled him out immediately.”

Young people also explained how their individual needs were not being met in their previous schools, particularly with regards to the need for structured and predictable environments. One young man with autism described how at his “old school, nothing was structured. One minute you’d go in there, the next minute you’d be going somewhere else and you didn’t even know.” Another 16-year-old boy with BESD described his dislike for change in his current school: “When the school make changes the kids here get really, like, really stressed; it’s not good.”

Young people generally reported feeling like their current school treats

them well and keeps them safe, including ensuring that they had the privacy that they needed: “Also like all the bathroom doors all lock, so it’s good” [young man with SLCN]. One young woman with autism described how she gets shadowed when she goes out in the community: “I get shadowed. That means I walk ahead of somebody. [The staff] also help me stay safe when the fire alarm goes off. Because I don’t like loud noises. ... I do feel safe in boarding.” Young people also identified various members of staff who they could go and speak to if something was wrong.

Many of the parents agreed. One parent of an autistic boy said, “I know he feels safe because he would tell me. He would say, ‘I don’t feel safe

here’, which is what he used to do.” Another mother of a girl with complex needs described how the open-door policy of the school was reassuring: “The school is really welcoming. You’re welcome to go into the classroom or the house. It’s very, very open door and I think that’s a real strength of the school.”

For children with complex medical needs, including epilepsy, safety was a key feature of conversations with young people, their parents and staff. One mother of a young woman with complex medical needs described how “[The school] manages all her needs, particularly her medical needs. She can’t begin or hope to have any education until you manage her medical problems because she’s not



“

If we did go into crisis then they would call for help on the radio and they'll get more to help us. So there's always staff around, which is good.

16-year-old with autism and mental health needs

”

capable of taking anything on board until you've got those under control and that's very difficult to do.” One staff member described how the young people “all feel safe here. They know we've got facilities to treat them medically. They know that there are people around that can help them during their seizures, or they don't have to worry about someone not being there, or them hurting themselves.” One father of an 18-year-old young woman with uncontrollable epilepsy agreed: “She often comes home and talks about her monitor, in a positive way. It gives her reassurance.”

Some staff also emphasised how the structure and routine provides a sense of security for their young people – something that often cannot be offered at home: “I think they all feel safe here. We put that structure in. Whereas at home, it's hard to put

the same intense structure for a young person with autism as we can do here. Young people being here and having somewhere very safe and familiar, that can be very reassuring.” One mother also stressed the importance of structure for her 15-year-old with autism: “[Child] only comes home once a month. And it's only one night because you let him go out of his routine for any longer than that and any work that they have done at school is just out of the window.”

A number of young people described situations where the staff needed to act to ensure their safety and that of others. Their words demonstrate that they often considered these actions appropriate and supportive – to prevent someone from hurting themselves, other people, or from badly damaging things – rather than restrictive. A 16-year-old girl with autism and mental health needs explained, “If we did go into crisis then they would call for help on the radio and they'll get more to help us. So there's always staff around, which is good.” Another young person described a situation in which physical restraint might be used, “You know, like [young person], he gets really upset and he hits himself, so you need three to hold him to stop him from hurting himself. You know, to protect him and keep him safe and everyone else. So that's what it is.” Similarly, a 16-year-old with autism explained: “It's just, like, they try to stop you from slapping people because it's not very nice for the person being slapped. It's not a right thing to do, so they try and stop you from doing that.”

There were some instances, however, where safety was a concern. One 18-year-old girl with autism described how she needed to be followed around by staff “to protect me from flirty guys around here.” She talked about one of her peers, who was “all over me; stroking me, trying to kiss me. And I didn’t want that. I just felt pressured.” She reported finding it difficult to get the staff to believe her because when the boy was asked about it, he would say it wasn’t true, which made her feel “not trusted”. Her statement was followed up with the school, who reported dealing with the issue when it arose and are currently attempting to regain the young woman’s trust. Despite being extremely troubling, it is important to highlight here that this was the only incident of its kind raised by the students we worked with during this project.

Schools also reported making efforts to keep young people safe as they reach sexual maturity and to protect



other children from exposure to sexualised behaviours and actions. In one case, a school had helped a young man with autism to use a symbol to indicate when he needed privacy to self stimulate. Before the school day began, the young man would point to an individualised picture, indicating that his teacher should leave him alone in his room. Prior to this, the staff’s lack of understanding regarding his communicative intentions had led to much challenging behaviour. A better understanding of and respect for this young person’s needs and the provision of ways to communicate his wishes has led to him being more able to regulate his behaviour.

Another young person aged 19 with SLCN described how she had begun a relationship with a young person at school, and complained: “they don’t like relationships ... just like they go, no holding hands during class”. Care staff explained how they had worked with the young people at the school to agree some rules around relationships to help keep everyone safe and ensure a consistent approach: “We went to the student council and they came up with their own rules. Some of them didn’t think they were fair. But sitting holding hands in a classroom – it’s kind of like, do you think you should be doing that or not? In the common room times, that is not a problem.” It was clear that the sensitive management of relationship and sexuality issues is an important part of the social and life skills curriculum and a number of the schools visited reported having open discussions with young people around these issues and were developing practise that supports safety at school,

while at the same time acknowledging the rights for young people to enter into relationship with other young people.

One staff member from a different school noted the importance of treating the children and young people with respect and dignity, and building young people's trust: "We have more safeguarding situations than would arise in a standard school. But we're better at what we're doing in some ways now. And so the girls trust us, they're a bit more relaxed. And they feel safe. And so therefore they feel able to talk a bit more."

In another interview, one mother explained how "one time I turned up at school and no-one was capable of dealing with a seizure if he had one. No duty officer was available in the house." One mother of a 17-year-old with autism and complex needs described how there was no specific incident but a general worry "in the back of her mind", which was driven partly by the fact that her son lives so far away and she sees him so rarely: "I think they treat him ok. How can you know a hundred percent for sure if you're not there? And the media doesn't help. It makes you think things that you wouldn't think before."

Our observations also revealed that in the majority of cases, the adults supporting the young people observed treated them with respect and dignity. There were two rare exceptions to this, however, which gave cause for concern. In one case, a support worker was observed bullying the young person with whom he worked. He had snatched a ball from the young

person's hands, which had caused him to become upset and lash out at others. In another case, one young person was left alone for long periods of time during the 'school' part of the day and thus given no learning opportunities and no possibility for engaging with others. These issues were reported by researchers to the relevant safeguarding authorities within each school and were reassured that appropriate action was taken.

Feeling safe from other children

Young people with SEN and disabilities are at greater risk of peer group difficulties – even in both mainstream and special education settings. Previous reports have identified bullying as a significant concern in residential special schools [13]. Bullying was mentioned during several of the interviews but was rarely a major focus. One young man described how "that one I just can't cope with. Like people bully me sometimes, call me 'midget' because of how small I am." Another young man with SLCN describes bullying of another child in his class: "Well, one student was bully to [young person]. It upsets me." One staff member noted the importance of 'catching' cases of bullying early: "Bullying isn't a major problem but we do have issues that we have to deal with. If you've got your finger on the pulse it's less likely to be an issue. I think it's when you take your eye off the ball, it's going to be a problem."

Rather than focusing on bullying, young people reported feeling less safe around other young people as a result of their

Table 3. Frequency of access to a range of health and social care providers.

Service provider	Rating					
	% Never	% Very Occasionally	% Quarterly	% Monthly	% Weekly	% Daily
Doctor	0	36	14	7	21	21
Nurse	0	21	7	0	7	64
Dentist	7	29	57	0	0	7
Optician	14	43	43	0	0	0
Clinical Psychologist	0	64	7	7	7	14
Educational Psychologist	0	79	0	7	7	7
Orthopaedics	21	50	7	21	0	0
Dietician	36	43	7	7	7	0
Physiotherapist	0	29	14	0	36	21
Speech therapist	14	7	0	0	14	64
Music therapist	21	0	7	21	43	7
Social worker	0	36	29	21	7	7
Occupational therapist	0	21	7	0	29	43

challenging behaviour. Indeed, as one staff member put it: “We have some children with quite extreme forms of challenging behaviour and whether it’s bullying – or just collateral damage – children, including the ones with the extremely challenging behaviour, are vulnerable.” Some schools have dedicated rooms for children to go to when they lose control or want to calm down; they also provide places for others to go to when peers are having a “behavioural episode”.

One 10-year-old boy with SLCN described how sometimes other

children “get cross and then they start hurting people, hitting someone.” Another young person with autism explained how sometimes young people have more than one-to-one support because “you know, like [child], he gets really upset and he hits his self, so you need three to hold him to stop him from hurting himself to ... you know, to protect him and keep him safe and everyone else.” Another 15-year-old with autism described how he “gets scared” of other children “making noises, shouting”, while another young man said that he felt safe at school but recounted a story about being hit by

“

All services have refused to come out. The police have refused to come out, the ambulance have refused to come ... you can't even get the emergency services sometimes. Or if you're out they'll bring them back here and that's it. They'll escort you back to a place of safety. Everybody else's obligation finishes at that point. We've even been banned from the hospital before.

School staff member

”

another student, albeit not maliciously, which clearly had an effect on him. Another young woman was reflective on her own often challenging behaviour: “Sometimes when I’m not safe, I hit people and I get very angry and stressed. Sometimes we shout at each other. Sometimes we hit each other. Sometimes we swear or kick. Because I kick things, which is not a good thing to do.”

Some young people also emphasised the need to strike a balance between

safety and independence. One young person with autism described how it was difficult to go somewhere on your own because “there’s always staff, like, around, following us or checking on us to see if we’re all right. Like normally, I just want to sit on my own my room on my iPad and just chill ... and then they’re just like always coming in and just like annoying me.” A parent of a young woman with epilepsy also reported that at his child’s old school, “they had teaching assistants follow her around all the time and so she felt she had no independence, she felt different to everybody else. She couldn’t even walk to the dinner canteen.”

Several schools stressed the need to support young people’s mental and emotional wellbeing: “It’s about understanding that mental health is an integral part of somebody’s ability to learn. If their head is full of worry, you can’t put anything else in there” (care staff member). They felt that “actually our job is ultimately to keep them out of adult mental health services so that they can self-regulate and take charge of it and learn strategies.” Some schools provided a therapy team, including psychologists, play therapists, speech and language and occupational therapists, to provide input for how to manage young people’s behaviour and socio-emotional wellbeing. But other schools noted that accessing mental health services for children “is very, very difficult.” One staff member said: “We’ve had some quite severe cases that nobody will take an interest in because as far as they’re concerned we’re ‘holding the baby’. And we’re not. We don’t have that provision. We

are not mental health experts. We have no mental health staff.”

The potential lack of access to mental health services is deeply concerning not least because it is well-established that children and young people with learning difficulties are at significantly greater risk of mental health problems than those without a learning disability [33-34]. It is particularly worrying also because the potential risk of exclusion from mental health services has previously been reported and clear recommendations have been outlined to prevent such exclusion [35-36].

Another school described how this feeling of ‘nobody wants to know’ included, but also extended beyond, mental health services and therefore the challenges of keeping their young people safe: “All services

have refused to come out. The police have refused to come out, the ambulance have refused to come ... you can’t even get the emergency services sometimes. Or if you’re out they’ll bring them back here and that’s it. They’ll escort you back to a place of safety. Everybody else’s obligation finishes at that point. We’ve even been banned from the hospital before.” These latter comments highlight the nature of staff’s responsibilities, which seem to fall outside the standard remit of ‘carer’.

Our headteachers’ survey (see Table 3) also shows variable access to different health and social care providers. The reported frequency of access to educational and clinical psychology services is particularly limited in the participating schools.

Summary:

- Many young people reported feeling concerned about other children’s often challenging behaviours, although they felt that school staff protected them from harm.
- Ensuring that young people are listened to is critical for maintaining their trust and keeping them safe.
- Schools were aware of the need to promote young people’s self-awareness and attend to their often complex mental-health needs but wanted more expert support in this area.
- Some schools reported being poorly supported by local child and adolescent mental health services.

6. My Life After School

Leaving school can be difficult for all children, with the move from a relatively stable and secure environment to the broader social community presenting a range of challenges. Those challenges can be particularly onerous for those who have attended residential special schools. Such young people stand, therefore, in particular need of effective support and planning at this potentially difficult time of life if their wellbeing is to be maintained and their rights promoted.

Under the UNCRC [6], education should be directed towards the development of the child's personality, talents and mental and physical abilities to their fullest potential. The Children and Families Act 2014 [5] includes provisions to help young people with SEN and disabilities prepare for adulthood and life outside the education system.

The children and young people in this study generally reported positive education and learning experiences, which might be expected to contribute to their preparations for life after school. Children often attributed these experiences to the individualised support and help they received in their current schools. One 12-year-old boy with BESD described how he has “help with writing and typing because I’m not that good at handwriting.” One 16-year-old deaf young man said, “Using BSL has really helped my learning, I’m doing much better here. In my last school all the lip reading was exhausting me and really slowed my learning.” Other young people also felt reassured by the teachers and teaching assistants who support them: “At least you’re somewhere where there’s lots of people to help you with your work, so you don’t get so frustrated” [16-year-old

girl with autism]. Another 13-year-old boy with autism described how “we do get a bit of help if we don’t understand ... but you don’t have a person standing over you all the time they’re teaching. Do you need help? Do you need help? Do you need help? Because I don’t like that.”

Some young people also described how their current placement had also helped to promote their learning beyond standard academic work. One deaf student explained how much she valued the social curriculum and the focus on her needs: “I love learning about emotions and wellbeing, I never had that before”.

When asked about their lives after school, young people described a range of ambitions and aspirations (see Box 8). Some were reflective on the challenges in meeting their own ambitions. One young woman with autism described how she wants to be a veterinary nurse with the RSPCA but that her “anger might get in the way because when ... I try to push myself to work, but sometimes I don’t want to work. But I do want to work because I want to get somewhere in life.” Another young man with BESD explained how he wants to become a barrister because he’s “quite interested in law and order and stuff like that. The barrister who help me come here, I’d like to talk to him a bit more and ask what it’s like and what qualifications you need.”

School staff were aware of the need for young people “to get the most out of life that they can get” but that they needed to ensure that young people were “realistic in their aspirations.” One staff member described the need to present

Music college, Professional
barista, Lawyer, To visit France,
To live with my Dad, Chef,
Veterinary nurse, Chef, Work
in a restaurant, Hairdresser,
Teaching assistant, Professional
football manager, IT job,
Film editor, Photographer,
Professional footballer, Drive
a car, Mechanic, Work with
the RSPCA, Work with kids with
autism/learning disability, Work
in a pet shop, Hair stylist, Cook,
Policeman, Hairdresser, Chef,
Designer, Singer, Paralympic
swimmer, Chef, PE teacher,
Post woman, Baby sitter, Pop
singer, Looking after children,
Work with animals, Work with
children with other disabilities,
Gardener, Chef, Artist, Something
in technology

Box 8: Aspirations

options for young people in the form of “small, positive steps. So you break everything down so each step is more achievable for the young people ... and then they get a kick out of ‘yeah, well I can do that, so I should be able to do this.’” Other staff noted the challenges in managing young people’s expectations: “You have to give them a sense of reality. If we said to one of sixteen and a half year-olds, yes you can get a license and learn to drive, that wouldn’t be helpful for them. You have to explain that if the epilepsy gets managed and you go for 2 years without a seizure, then there is a possibility to drive.”

Another staff member also emphasised the importance of striving for high aspirations for their young people: “Sometimes it’s about breaking down the boundaries. Letting them think outside the box and getting them to start to take ownership of things and challenging themselves to do something different. Also to encourage staff not to worry about those kind of things, to take risks and do things a bit differently.”

For many parents and school staff, they wanted their young people to be happy, healthy, safe, and lead as “fulfilled a life as possible, whatever that looks like for them.” The primary aim for all schools was to “give them the life skills they need to be as independent as they possibly can.” Such skills included practical skills, like being able to feed, toilet and bath themselves: “They’re set individual targets that we work with them towards ... whether it be washing their body and their personal hygiene, all the basics that they need for life.” One staff member explained that it’s about being as independent as possible, and

less reliant on other people as much as possible. And that goes right down to, can they pull their own trousers up after they have been changed? If that’s the level of independence that they’re ever going to get to, then let’s try and get them to that. Because that is just that little bit more dignified than someone else doing it.”

Staff in schools were also aware that many of the students when they arrive at their schools – often following a series of failed placements – are lacking in confidence and self esteem. Staff need to “build that up over time”, often “by focusing on what the young people can do. We know that this area’s always going to be a difficulty, so how can we get round that? Who can you get to help you? How can you ask for help? Even when you’re out and about?” Staff also emphasised the need to celebrate



young people's achievements, however small: "For some of our students, some of the smallest things are such a big achievement. They're like landing on the moon moments for them, aren't they?"

School staff described how one young deaf person had described an ambition to become a chef, quickly adding that this would not be possible because of her disability and the need for an interpreter. To directly challenge this young person's view, the school care team responded by inviting a deaf chef to visit the school. The head of care explained: "We aim to develop confident and happy members of the deaf community, we help them develop their confidence and achieve their aspirations."

Promoting self-awareness in young people, particularly around their own disability, was a key area of concern for school staff: "We have been working with them quite a lot on understanding their own special needs. Because quite a lot of them don't have an awareness of how it affects them, what it means to them or what information or support they'll need as they move forward." One staff member described this as the biggest challenge for their school for young people with BESD: "Getting the boys to manage their own condition. Because a lot of them don't understand it and some of them can understand it better than others." Such awareness is critical for fostering young people's ability to regulate their own behaviour: "One of the biggest things we can teach these kids is behaviour management. There's not much point in teaching them to wash, clean their teeth and cut up their food if they can't keep themselves regulated."

Transitioning to life after school

Some of the young people in the study had well developed plans for their transition to adulthood. Several young people were transitioning to adult services on the same site. One 18-year-old with autism took considerable pleasure in showing the researchers images of the flat that was being refurbished for him. In other schools, young people were encouraged to think about their future studies and potential careers. One 16-year-old deaf student had already started a course in beauty therapy and hairdressing at a FE college and had plans to "do the next level" when she leaves school. Another student at the same school with a passion for IT was planning to study ICT at college or university in the future: "I love IT and I want to do it for my job". A number of schools were organising work experiences that reflected pupils' interests: "Well I really, really want to be a gardener when I'm older, because at home I do a lot of gardening and I had to go and do some today. Because gardening's my thing" [16-year-old girl with autism].

Several of the older young people we spoke to, however, were concerned about leaving their current school. One young man with looked-after status (see Box 4) was extremely anxious about what was to happen to him in the future, although he had clearly explained his desire to remain in the area of the school and continue his work experience, he knew that this had not been agreed, and that he was to return to his 'home' local authority with no immediate plans in place. He explained, "I'm scared. I don't want to leave. I want to stay

here.” Another young man with autism expressed similar views, “I want to stay here.” The young people often reported feeling safe, settled, and accepted within the community surrounding the school.

Some staff acknowledged that the security provided by their schools was not necessarily setting them up for the challenges of everyday life and that “the real world can be quite a shock to the system.” One staff member commented that when you ask young people, “What do you want to do when you leave school? And they’re like whoa! Leave [current school]? You know, it’s very scary for them. They’re in a bubble here.” Another staff member observed that “they’re so safe here and they’re so risk assessed and controlled. I don’t know if sometimes we’re a bit institutionalised.” Staff also observed how these challenges caused anxiety in the young people themselves: “It depends on the kid. But there have been a few of them where they’ve been quite stressed the last month or so because they were leaving. They’re panicking. Because to a lot of them, because they’ve been here for so long, it’s all they know. The routine and everything.”

Some schools were making active efforts to ensure that young people were more prepared for the uncertainty of life after school: “We used to find that the feedback from colleges was that our children had been very cosseted and were finding it difficult to move on into different environments where they are having to take more responsibility for themselves. The school has done a huge amount of work there, working and liaising with the colleges to try and make the children more independent.”

Another school described that they “decrease their nights in boarding during the transition period. It’s not the case that you’re here for 5 years and you’re here all the time, and then suddenly you’re gone. We also want them to have that integration back into their home life so that they can start accessing things in their own area. Because that’s just as important as the experience they have here. They’ve got to be able to transfer that into home life skills.”

While school staff made efforts to ensure that the transition to post-school placements was as smooth and successful as possible, they repeatedly noted that failures of the system, particularly delays in decision making, were preventing such success: “The funding now is taking longer and longer to put in place. Our guys really need preparing.” One staff member described a case “where we’ve got young people now who are coming to the end of their time with children’s services and we’ve got three weeks before we finish for the summer, and they don’t know where they’re going to be in September. So for the young people and for their families, it’s very distressing. And there isn’t a huge amount that we’re able to do to support them in that.” A staff member from a different school described how this situation had become all too familiar: “So we’ve got a guy and he’s going to be leaving in the next week and the placement has just broken down. It was identified before Christmas but wasn’t agreed and it still hadn’t been agreed by the local authority after 7 months. And now it’s not happening. The parents are distraught.” One staff member believed the root of the problem was that “transitioning into

adult services is budget controlled and not always needs led.” Another school described the challenges they encountered trying to facilitate the transition of a looked-after young man with no family or carers back to his ‘home’ authority. The school reported feeling frustrated when their request for phased integration into the ‘home’

community was denied on fiscal grounds: “We tried to say from the start of the last year, can’t he go home every other weekend, to try and build up a network of friends within the local community, at his supported living? But no, they wouldn’t fund that, because who was going to pay for it?”

Summary:

- Residential schools offered security for young people with SEN and disabilities in terms of stable, predictable environments, but setting them up for their often-uncertain future life is a huge challenge.
- Schools helped to promote young people’s aspirations and challenged their sense that their disability might prevent particular career choices but at the same time tried to manage their expectations.
- Successful transitions from school to adult provision can be affected by delays in local authority decision making. For many young people their wishes are undermined by short-term local authority financial priorities.
- Some local authorities are not delivering their statutory duties for children in care. Children who are looked after and attend a school in a community some way from their local authority face being made to return to a context where they have no connections or existing relationships.

Conclusions

More than 6,000 children and young people with SEN and disabilities attend residential special schools in England. Many require round-the-clock support for their education and learning, their social and life skills and their physical and mental health. And many live some distance away from their family and home community. They therefore represent some of the most vulnerable young people in society.

Very little is known, however, about what these young people's lives are like – including what they feel about living away from their families, whether they feel part of their local community, whether they get to have a say in decisions that affect them and feel listened to, whether they feel safe in school and in the 'home' part of school and whether they receive the necessary support for the transition to adulthood [6]. This study sought

to understand their perspectives and experiences on precisely these issues. We interviewed more than 70 young people with a range of SEN and disabilities from 17 schools and conducted intense and fine-grained observations of another 11 young people with very complex needs and limited communications skills. We also elicited the views of their parents and the adults who work with the young people in school to gain a fuller picture of the realities of their lives.

Overall, our findings suggest that, although many miss their families, the children participating in our research are happy in their current schools, they feel part of the community engendered by the schools and they feel looked after and treated well.

There were, however, four key messages that emerge from careful collective examination of each of the five main rights that were examined.

These key messages were common to children and young people with different SEN and disabilities, of different genders and of different ages. We believe that attention to these themes should assist the protection and promotion of each of the rights examined, both during school years and in the transition to adulthood.

Promoting stable, trusting, nurturing relationships

Many of the children live some distance from their families and do not get to see them as often as they or their parents would like [1, 8-10]. Residential special schools necessarily pose a threat to young people's right to a family life. In



They stimulate her, they care for her, they're there as a safety net, and she does feel safe about that. And she doesn't feel different to everybody else because they're all in the same boat.

Father of an 18-year-old with epilepsy





response to that threat, many of the young people and parents interviewed recognised the important role that the staff and other young people in the school play in providing a ‘home away from home’ – an environment in which children and young people feel safe and secure and where they are surrounded by people with whom they can form deep relationships. These relationships are critical in ensuring children’s social, emotional and physical health and wellbeing, just like they are for any child.

The importance of these nurturing relationships was, however, inconsistently recognised by staff at schools. While some staff reported feeling as if they were young people’s “surrogate parents”, fulfilling the responsibilities and relationships required in the absence of their caregivers, others were adamant that the role of parent fell outside their remit as ‘carer’ or ‘support worker’ or ‘teacher’. They felt that the boundaries of their roles needed to be clearly understood by all, including the young people themselves. In some cases, issues of staff turnover

and the unpredictability of continuing relationships exacerbated these concerns.

The variety of responses from staff as to the nature of their relationships with children is troubling even if the ongoing practice in schools is not. It remains unclear where the actual boundaries lie regarding staff-young person relationships, which means that the types of relationships afforded to young people in these schools is contingent on the attitudes and sentiments of individual members of staff and staffing arrangements and practices. Where staff showed reticence to foster relationships with the young people they support, this appeared to be caused by understandable anxieties about the need for boundaries and for appropriate relationships. Yet failing to provide these stable, nurturing relationships could cause developmental difficulties, placing young people at an even greater risk of socio-emotional problems in the immediate and longer term [37]. This is especially the case for looked-after



children who do not necessarily have a family to go home to and may be additionally vulnerable at transition due to the geographical distance from their local authority [10; see also 38].

These findings call for greater public discussion of the social, political and ethical issues raised by ‘providing’ for children and young people with SEN and disabilities in residential special schools – and the challenges and potential risks of not providing to the fullest. Standards and inspection should reflect the importance of nurturing stable relationships, and sustaining relationships with home and family, particularly where children are looked after, or where families may

find it difficult to sustain relationships with children living far away.

Fostering connections with the community – at school and at home

Placing a child or a young person in a residential special school is no easy or straightforward decision. Many parents described their children’s turbulent school histories and, despite their general satisfaction with their child’s current placement, some felt that placing their child in residential school could have been prevented if the right support were available earlier on in their home communities. The very distance and length of time that children and young people are away from their families

challenges their rights to access their local community. Some parents and children also talked about the many painful “fights” with local education and social services authorities required to secure placement in residential schools [see also 1,9,12]. These concerns also impact on the ability of children to transition effectively to adulthood, as relationships within the broad community can be particularly important to maintaining young people’s wellbeing as they leave school.

Young people did tell us about the varied ways that they participate in activities in their schools’ local communities – whether it was going to the park, doing work experience in local shops and businesses, or going shopping. Some schools invited their local community members to come to them in order to build a sense of community for their young people. Yet there was a striking tension expressed by young people, their parents and school staff around the safe, structured and insulated environment provided by residential special schools and the realities of growing up, and eventually living, “in the real world”, especially in their home communities. Indeed, many young people spoke of the fear and anxiety of life after school and losing contact with those who mean a lot to them at school – their friends and their carers. Again, this is all the more striking for looked-after children, who often have no existing relationships or support networks in their ‘home’ local authority.

These findings raise important issues about the place and purpose of

residential special schools and their relationship with services nearer to where parents live. Parents largely wanted their children closer to home and many children expressed a desire to be connected to the communities their families were from [12]. But children and parents also recognised the unique support offered by the residential schools. More needs to be done, especially across different local authorities, to ensure that health, education and care services for children are coordinated far more effectively, particularly at key moments of transition, both before and after placement, with joint planning for transition to adult and post-16 services occurring as early as possible [10,39]. Local authorities should aim to provide innovative, flexible support packages for children and young people with SEN and disabilities that meet their distinctive needs in their home communities [see 9, 40].

Placing the child at the centre of decision making

Children and young people should have a say in the decisions that affect their lives. Young people with SEN and disabilities are no exception. Children’s rights to expression are underpinned by Articles 12 and 13 of the UN Convention on the Rights of the Child [6], which concern the child’s right to make his/her views known and to have these views given due weight and his/her right to share information in any medium that they choose. This latter emphasis on varying means of communication is especially important for children and young people with SEN and disabilities, who often have difficulties communicating via



I just want him to be able to live as independently as possible, and to be safe, and to have people who will look out for him and love him. And that's my biggest worry, what will happen when we've gone. It's the thing that worries me more than anything.

Parent of a child with SLCN



traditional (spoken) means [41-42]. Overall, children and young people felt that they did have a say in issues at school that meant something to them – how their bedrooms are decorated, what kind of activities they do after school and on weekends, what they ate at dinnertime, for example. All of the schools we spoke to emphasised the importance of promoting young people's independence and autonomy by actively encouraging them to make choices, sometimes on a moment-by-moment basis. We also heard about several different formal mechanisms by which children could take part and have more control over decision making. Some young

people felt empowered by their roles in school councils, for example. Others, however, found annual review meetings “scary” and confusing.

While the work schools are doing to involve young people in decision making is commendable, it was not always clear how much impact this participation had on their lives – at school, in the ‘home’ part of school, or especially in their life after school. Did the ability to exert control over the decisions that affect them improve their self-confidence, their self-belief, and ultimately, their life chances and opportunities? In some cases, it would seem that it did. However, for several young people, we know that having a say in their future lives appeared inconsequential; they reported that they were simply not listened to. Indeed, there seemed to be little consistent use of Person Centred Planning by local authorities supporting transitions back to the ‘home’ local authority and adult services.

Much more work needs to be done to ensure that our involvement of young people in decision making extends beyond tokenism, that their voices are heard and acted upon and, critically, that we understand more fully the short- and long-term impact of such involvement for young people with SEN and disabilities [39,41-43].

Furthermore, it was rarely the case that young people's current school placement decisions were made with them¹. More often than most, young people failed to have a say in where they went to school. Indeed, parents repeatedly emphasised that

the adversarial nature of the system, which placed unnecessary stress and anxiety on families, often meant that their children were simply unable to have a voice. Current legislation for children with SEN and disabilities [20] has sought to address these concerns by requiring that local authorities provide greater transparency and share information with parents and that parents and young people have greater choice and control in educational decision-making. Whether such legislation allays these concerns remains to be seen.

Ongoing attention to keeping children and young people safe

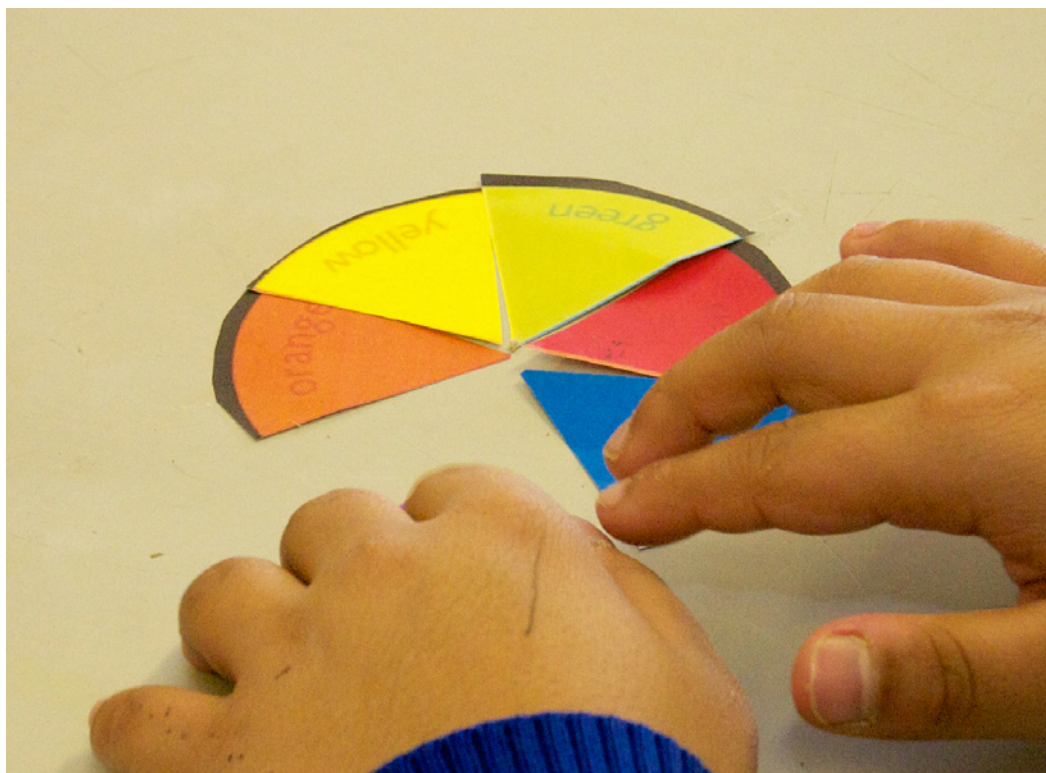
All children have a right to be protected from harm and to feel safe and secure [6]. This is especially important for children and young people with SEN and disabilities living in residential special schools, who are often the most vulnerable young people in society – by virtue of their disabilities and/or of their invisibility. Residential special schools must therefore pay extra care and attention to keep their young people safe – from the environment, from adults, including those working with them, from other children, and in some cases, from themselves.

Young people, parents and schools reported having to deal with a great number of safeguarding issues, often on a day-to-day basis. Reassuringly, we found that issues of safety and security were taken extremely seriously by participating schools. Children reported feeling safe and secure in the vast majority of interviews and parents

displayed a high degree of satisfaction in this regard too. Of course, this should not be seen as a cause for complacency, however. The issues raised by the young people, especially with regards to not feeling safe around other children, are clearly complex issues that need constant attention and consistent support for staff to fulfill their roles and responsibilities in that process [39].

Feeling and keeping safe goes far beyond simply protecting young people from harm. Staff also have a responsibility to promote the general welfare of the young people who reside in their schools, not least to help prepare them for adult life. In doing so, they must foster resilience in young people – promoting communicative competence, self-awareness, tolerance and high aspirations – qualities that many of the schools prioritised. A balance must be struck therefore



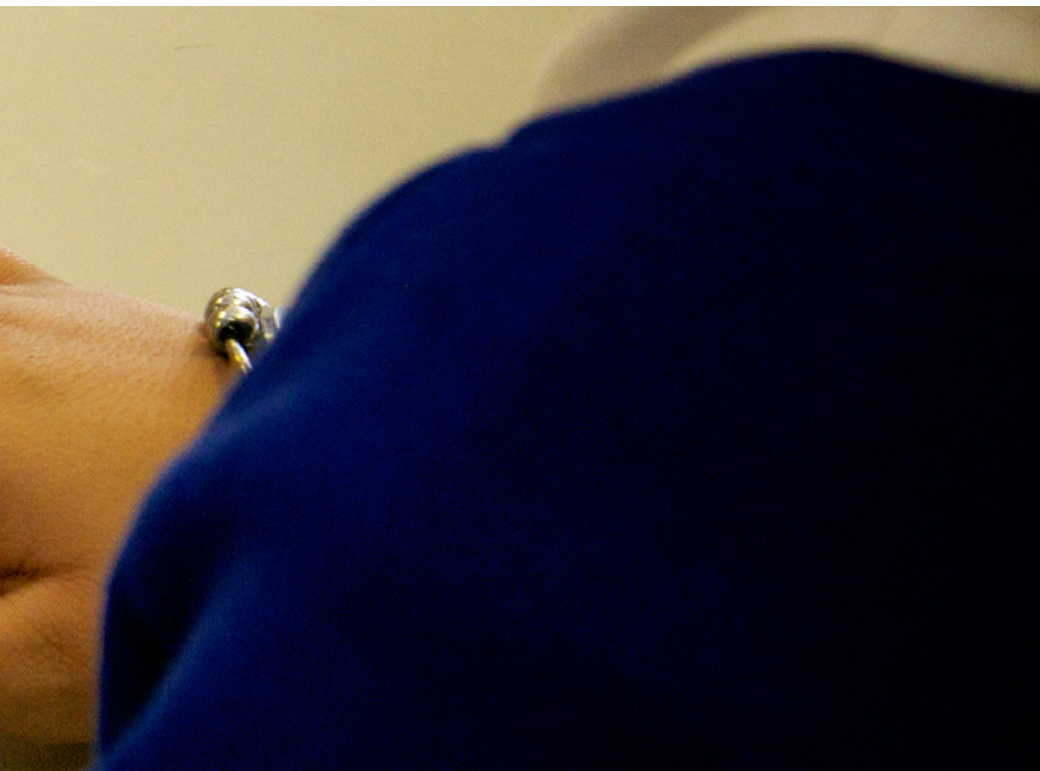


between providing a consistent, structured environment (to help optimise life and learning at school) and encouraging young people's ability to adapt flexibly in new situations (to help optimise their chances for life after school).

One area of concern was notable in this regard. The importance of promoting good mental wellbeing was clearly reflected in many of the interviews and observations, with young people, their parents/carers, and school and care staff. But schools often reported feeling ill-equipped to address their young people's many and often complex mental-health needs and they also reported that they felt poorly supported by outside specialist services (such as CAMHS). Given that mental health plays a

critical role in lifelong and overall societal functioning and that children with special educational needs are at greater risk of mental health problems, preventative action must be taken [36-37]. This requires a coordinated approach between education, social care, and especially health, who are best placed to ensure that the young people in residential special schools have access to in-house or community-based assessment, planning and action using evidence-based approaches.

Our findings show that children and young people's rights to family life, to participate in the community, to have a say in the direction of their own lives, to be safe and secure and to be suitably prepared for their adult lives are often being impressively protected and promoted in some very



testing circumstances. But much work needs to be done further to ensure that children and young people enjoy stable, trusting, nurturing relationships, are connected to, and receive support from, their home communities, are placed at the heart of decision making, with its intended consequences, and feel safe and secure, especially with regard to their mental and emotional wellbeing. Young people and parents generally reported positive experiences with their current residential school placements. This is a notable achievement on the part of the schools, their teaching and school staff. It is also, however, a reflection of the difficulties these families have previously faced and is often a direct result of families' relief at securing a place in a school that will attend to their or their child's

needs after many years of struggle. We could – and should – always be striving to enhance these young people's life chances and opportunities at every stage of their lives. As we do so, we should also continue to pay close attention to the views and opinions of young people themselves.

Our experience suggests that it is possible to elicit the views and experiences of children and young people with SEN and disabilities living in residential special schools – even for children with limited communication who face barriers to such participation. The future lives of these children and young people will be shaped in part by society's effort to listen. ■

Appendix A: Methods

Sample Characteristics

Schools

To ensure that our sampling would be as representative as possible, two emails (an initial email and a follow-up email two weeks later) were sent to all residential special schools in England (n=287; data from DfE publication 'Schools, pupils and their characteristics', accessed April 2014) inviting them to take part in the project.

Seventeen residential schools across England (6% of sample) agreed to participate (see Table 1). These schools varied in location and type of school and catered for children with a range of SEN and disabilities, including those who are blind and partially sighted, are deaf and hearing impaired, are on the autism spectrum (including Asperger's syndrome), have a diagnosis of speech, language and communication need (SLCN) and/or specific learning difficulties (dyslexia, dyscalculia, dyspraxia), have behavioural, emotional, and social difficulties (BESD), have moderate, severe or profound and multiple learning difficulties (including autism) or other physical and learning disabilities.

The schools also varied in terms of the ratings provided by Ofsted. Of the 17 schools, 10 of the school provisions and 8 of the care provisions were rated as 'Outstanding'. This imbalance reflects the pattern of ratings in residential special schools more broadly: A higher percentage of such schools are rated 'outstanding' than other categories of schools in England [44]. Schools whose performance was judged 'satisfactory'/'adequate' did not come forward in representative numbers in our survey and no schools with an 'inadequate' rating chose to participate.

Headteachers of all 17 schools were asked to complete an online survey to gather details on their provision. This survey was based largely on a questionnaire designed by Pilling et al. [45] and elicited information about the characteristics of their boarders, including their backgrounds and primary SEN, their participation in a range of community and leisure activities (see Table 3) and their frequency of access to a range of health and social care services (see Table 4). Headteachers from 14 participating schools responded.

Headteachers reported that, on average, 79% of young people boarding were boys (range: 51 – 100%) and 20% were from black, Asian and other ethnic minorities. On average, 24% of their young people were on part-time placements (range: 0 – 92%), 32% on 38-week placements (range: 0 – 67%), 8% on 48-week placements (range: 0 – 33%) and 36% on 52-week placements (range: 0 – 100%). An average of 36% of young people have looked-after status (range: 0 – 67%). The costs of these placements ranged from £51,000 (38-week) to £222,000 (52-week). [Note that many schools chose not to provide this information.] Some of their young people had been there for a very short time (2 days) while others had been in residential care for long durations (11 years).

Headteachers also indicated that 39% of their current boarders were looked-after children. The majority of these children and young people (85%) had section 20 care orders, with more than two thirds (68%) of them residing 52 weeks per year. The remaining 15% had section 31 care orders, the majority of whom either boarded part-time (40%) or for 38 weeks per year (30%).

Children and young people

Within each of these schools, information letters were sent home (via post and/or email) to all children boarding part-time or full-time inviting them to take part in the project. Eighty-three children and young

people (33 girls), ranging in age from 8 years 3 months to 19 years 8 months, were seen by researchers in schools. An additional 30 families provided consent for young people to take part but were unable to be seen either because they were absent on the day of the school visit(s) (n=10) or due to insufficient time (n=20).

All 83 children were in receipt of a Statement of SEN, a legal document that details the child's needs and services that the local authority has a duty to provide, which specified each child's primary need, including ADHD (n=2), autism (n=44), BESD (n=3), dyslexia (n=1), epilepsy (n=3), hearing impairment (n=11), MLD (n=3), PMLD (n=2), SLCN (n=13), and visual impairment (n=1). The predominance of young people with a diagnosis of autism in our sample echoes previous work on children in residential special schools [e.g., 9, 12]. Indeed, it also reflects data from 2014, which shows that the top three primary needs listed on a statement for SEN for boarders in residential special schools were behaviour, emotional and social difficulties, autism spectrum disorder and hearing impairment (see OCC's Overview Report).

Thirteen of the children in this study had looked-after status. Of these thirteen, seven were looked after under a section 20 care order. The remaining 6 children had section 31 care orders, with 5 of these young people living in foster homes and one young person attending a supported living unit during school holidays.

Staff

School and care staff from each of the individual schools were also invited to take part in focus groups with researchers. One hundred and fourteen members of staff (86 female) took part in 29 focus groups (mean length = 36.30 mins; range = 17.10 – 58.36 mins) across 17 schools. These staff members included headteachers, deputy headteachers, classroom teachers, 6th-

form teachers, learning support assistants, occupational therapists, therapy assistants, clinical psychologists, heads of care, care workers and care/house managers. Staff differed in the amount of experience that had working in each of the schools, ranging from 1 week to 20 years. Focus groups were generally conducted separately for teaching staff and care staff, with the exception of those schools (n=5) whose staff worked across school and care.

Parents

We also sought the views and perspectives of the young person's parent or carer by inviting them to take part in a 30-minute semi-structured interview. Thirty-two parents and carers, including 4 fathers, 2 grandmothers (primary carers) and 1 (female) carer, agreed to take part and were interviewed over the telephone (n=29), over Skype (n=2) or in person (n=1) (mean length = 38.71 mins; range = 10.50 – 98.33 mins). Seventeen of their children had either a primary special educational need of an autism spectrum condition (12 boys), BESD (n=3; 3 boys), dyslexia (n=1; 1 girl), epilepsy (n=2; 1 girl), hearing impairment (n=1; 1 girl), PMLD (n=2; 2 girls), Rett Syndrome (n=1; 1 girl), SLCN (n=4; 4 boys), and visual impairment (n=1; 1 boy). Many, however, had multiple needs and disabilities.

Children were, on average, 14 years 7 months (range: 9 years 2 months – 18 years 9 months) and had been attending their current school for an average of 3.5 years (range: 1 year – 7 years). Overall, 65% of the children were white, 5% Asian, 5% Black, and 24% mixed ethnic background. Eleven were reported to be on medication for a variety of reasons (e.g., epilepsy, anxiety, asthma, sleep, mental health issues).

Although we made every effort to reduce bias in the sample (e.g., by inviting all residential special schools, and all children residing in those schools, to take part), the

resulting sample, including the minority of schools who expressed their interest, the young people who took part, their parents and teaching and care staff, was necessarily self-selecting. The results therefore cannot be treated as representative of the population of these schools as a whole. Nevertheless, the consistency both across the viewpoints of different informants and with previous work [1,12-14] warrants confidence in our results.

Our focus on the school setting and the limited timeframe meant that local authority staff, including those responsible for commissioning, disabled children and their families, looked-after children, and safeguarding, were not interviewed for this study.

Young Researchers' Group

At the outset of the project, we formed a Young Researchers' Group to ensure that children and young people with relevant current experience of residential special schools were involved in the research design, including in the identification of priority research questions, the development of the project methodology and reviewing findings. The group consisted of 17 young people in 2 different participating residential special schools. They met 3 times over the course of the project – the initial two meetings were held within the first 6 weeks of the project and the final meeting, which concentrated on interpretation of the findings and their dissemination was held towards the end of the project.

The first meeting, facilitated by two researchers, introduced the young people to the project, the goals of the Young Researchers' Group and the ways that we might work best together during the project.

The second meeting provided an opportunity for the young people to comment and critique our then-proposed methods, including the questions for the interviews and focus groups and the nature of the various activities. On the basis of the young people's expert comments, we subsequently adjusted our methods to ensure that they reflected the needs and experiences of children and young people in residential special schools. Specifically, we (1) simplified and reduced the number of questions for the focus groups, (2) used widget symbols and images to make the interview questions more accessible, (3) tried to keep the size of focus groups small enough to ensure everyone had a chance to have a voice, (4) began focus group discussions with a *post-it!* activity to help generate ideas and to make sure that everyone had their say, even those who found it hard to speak for a variety of reasons, including shyness, expressive language difficulties, or anxiety, and (5) simplified the consent form so that the young person's signature was the only written requirement and that they were supported to process the information contained in the information letter. This process also highlighted the need to ensure that discussions were attentive to the concentration skills and abilities of different pupil populations.

The third meeting with our young researchers took place once the data had been analysed and the first draft of the report had been written. The findings were shared with the young people and they were asked to help summarise the main findings for a report that would be suitable for other young people. There was a lively discussion and an illustrator joined the group to help capture the process in comic-book form.

Ethical Issues

Before the project began, ethical approval was obtained from the Institute of

2 Given the short timescale for this project, we were unable to pursue ethical approval from the relevant National Health Service Research Ethics Committee in order to include young people aged 16 and above, who fall under the Mental Capacity Act 2005.

Education Research Ethics Committee (FCL 612). Young people (aged 16+ years) who may have a restricted capacity for consent and therefore fall under the remit of the Mental Capacity Act 2005 were not seen for this study². Where possible, we spoke to either their parents or school staff to understand their histories and current progress but their lack of direct participation means that the experiences of young people 16+ years with the most complex needs are potentially under-represented in this study. Clearly, this is a limitation and the exclusion of these young people raises complex ethical issues, which urgently need to be addressed in future work if we are truly to access the experiences of the potentially most vulnerable children.

All adults (parents and school staff) provided informed written consent to participate in this project. Young people also provided their consent, where possible given their needs. Our information letters to parents, staff and young people emphasised that they were under no obligation to take part, that they could stop taking part at any time, without having to provide a reason and without affecting their education or access to services in any way, that whatever they told us would remain confidential and that our final report would contain no data that would identify them.

Every effort was made to ensure confidentiality and anonymity of all participants. Participants were assigned anonymous ID numbers and these numbers were

used on all paper forms and computer records. There were two exceptions to this rule. First, if we had reason to believe that a young person was at risk of harm, we would have had a duty to inform the relevant authorities. Indeed, we were aware that 'children in need', disabled children and looked-after children each present a distinct and enhanced risk. There is strong overlap between: 'children in need', disabled children and looked-after children and that each population presents a distinct and enhanced risk of exposure to abuse in the past and of subsequent abuse, which meant that these issues could emerge during our work with children and young people and would require sensitive and well informed management. This situation, however, did not arise. Although several young people reported serious safeguarding incidents at their previous placements, none spoke of any on-going issues. Second, while extra care was taken to ensure that nothing written in this report would enable any individual participant to be identified, this research included one component, the short film, in which children and young people would be identifiable. In this instance, all young people and their parents/carers provided permission for their inclusion in the film.





Activities with Children and Young People

Interviews and focus groups

Individual interviews and focus groups were used to elicit the views and perspectives of those children who could communicate themselves effectively. The groups in particular allowed us to gain some consensus from children and young people around issues relating to living and being schooled away from home and participation in decision-making. Thirty individual interviews (mean length = 32.68 mins; range = 15.02 – 49.24 mins) and 9 focus groups including 41 children (mean length = 32.87 mins; range = 19.02 – 44.45 mins) were conducted with children and young people in their respective schools.

The topics focused on five main themes:

(1) living at school, (2) how things are run, (3) having your say, (4) staying safe and (5) life after school. Widget symbols were used to support access to the verbally presented questions where necessary and British Sign Language interpreters supported access for deaf children. In addition, illustrations depicting each of these themes (see figure above) were shown face-up to children on laminated cards at the beginning of the interview to allow them to choose the order of the topics. Cards were turned face-down once discussion of the topic had finished. The cards were beneficial in two ways. First, they allowed the children to have a certain amount of control over the process, directing the order of the questions according to their preferences. Second, the cards provided young people with a structure of the interview, that is, they knew

that the interview would end when they had completed all five cards.

Within these topics, we also asked explicitly about young people's participation in decision-making – from what they get to do in their free time to being involved in key decisions (e.g., about school placement, transition to 'adulthood', etc.) – and how much they feel that they have a choice (and how much they would like to have a choice) in these decisions. Importantly, children and young people were assured that, unlike many activities at school, there are no right or wrong answers – we just wanted to know what they thought about their life at school.

We also used other activities to facilitate discussion during the interviews and focus groups, depending on the children's preferences and ability level [see 19]. For several focus groups, we used a *post-it!* activity, where children were given a number of *post-its!* in two different colours and asked to write down all the things they liked about school on one colour and the things that they didn't like about school on the other. Children and young people who needed support for writing were facilitated by either the researcher or a learning support assistant. This warm-up activity served to help stimulate ideas and discussion with groups with very different needs and abilities.

For another group, we used O'Kane's [31] 'What is most important?' activity, where children were given a set of laminated cards showing 9 statements (using pictures and words) about taking part in decision-making. Children were asked to work together to

rank the statements from 'most important' to 'least' important', and explained the reasons underpinning their rank order to the researcher. This activity provided insight into young people's views on issues that were most important in taking part in decision making (see Box 7).

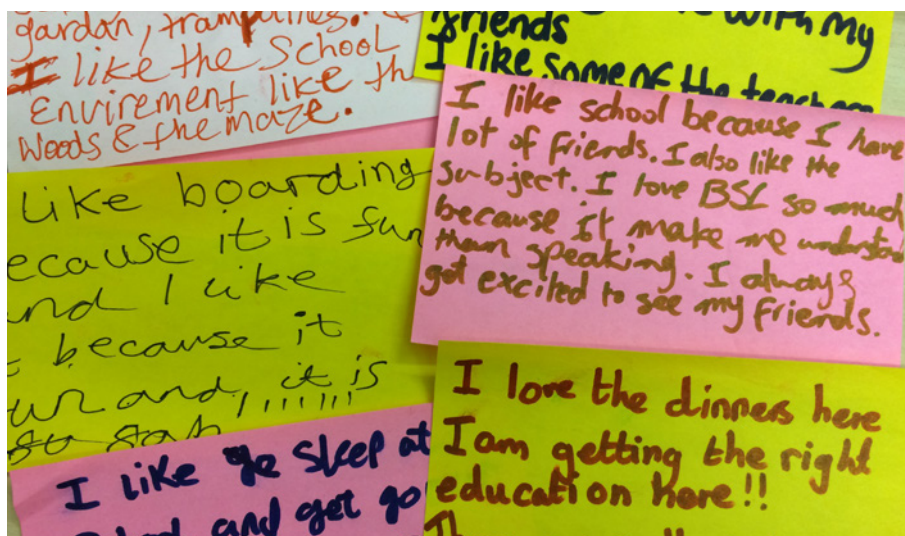
In some interviews children produced drawings and in one interview with a young person with limited communication, we used *Playmobil* to facilitate discussion.

All focus groups and interviews were audio recorded, with the exception of an interview with one child, who opted out of recording. Where appropriate, children were asked at the outset whether they would like their teachers/support workers to sit in on the interview. As a result, members of school staff (teachers/teaching assistants) and/or an interpreter were present for the majority of interviews/focus groups with young people. Although their presence raises issues about the nature and role of such a supporter, we felt that it was important to give the young person the choice of having someone familiar (and potentially supportive) in the room. Researchers were attentive to the needs of children and young people during activities, especially regarding consent to take part.

We were aware that a young person might change his/her mind although they may not say so explicitly and that sometimes children begin an activity quite happily but later become restless or disturbed. We therefore used a 'traffic light' system, where pupils were able to give the researcher a yellow card if s/he did not want to answer a question or a red one if s/he wanted to end the session altogether. No interview was abandoned because children decided no longer to take part.

School preferences activity

We used a card-sorting activity to access children and young people's views regarding aspects of their life at school. It is a visual communication tool, which has been used successfully to investigate the sensory preferences of adults on the autism spectrum with additional intellectual disabilities and minimal spoken communication [46]. We adapted the task to reflect the themes of the current project and the living and working environment of the target school. Initially, a researcher visited the school to take photographs to represent the places, procedures and choices encountered by the child. For example, one photograph showed a classroom visual display of





Observations

A combination of ethnography and structured observations was used to gain an understanding of the experiences of young people with SEN and disabilities, who cannot communicate themselves effectively using speech, signs or symbols. The 11 young

rules, another showed tables set for lunch, and another displayed the range of games offered in residential. The photographs were made into photocard and labelled in simple language to focus on the intended topic (e.g., one photocard showing the staircase accessing the residential area was labelled 'arriving in residential').

During the activity itself, young people were introduced to the photocards and a further three cards representing the sorting categories: 'like'/thumbs up, 'ok' and 'dislike'/thumbs down'. They were asked to select a photocard and place it on the appropriate category card to reflect their preference (see figure to the right). In this way, the activity acted as a visual questionnaire tapping children and young people's school/living preferences.

Next, the researcher noted which photocards received particularly positive or negative responses (i.e., the child's most salient preferences) and asked the child to match the photocard with a particular emotion (e.g., happy, bored, cold) using a range of expressive symbols. This enabled children to explain their choice of category by attaching a feeling or cause to it. For children with greater verbal ability, we probed further to understand the reasoning underpinning their likes and dislikes.

people that we observed broadly presented at an estimated developmental level of under 2 years. Consequently, this was by far the most challenging group of young people for the research team to build a genuine picture of their experiences of school.

Researchers spent time with the child or young person from the beginning of the school day and/or at the 'home' part of school to gain information about their experiences. Sometimes this involved closely observing the young person's activities, interests and relationships with others. Other times it involved joining in an activity, including accompanying young people on a trip or having dinner with them. Some observations took place over the entire day – from the moment the child woke up to when they went to bed. In this way, we were able to capture a 'day in the life' of the young person living in residential school. In other schools, observing young people for a whole day was not feasible so some observations occurred for less time (between 1 and 4 hours).

To understand young people's interactions and experiences, we developed an observation schedule [following the SCERTS model; 30] to record the child's interactions and activities during a specified period of time. The schedule captured information regarding the activity in which the young person was involved and the extent to which s/he took part in choosing the activity, as

well as the communicative behaviour (e.g., sounds, symbols, or gestures) indicative of a young person's level of participation and wellbeing (e.g., expressing happiness/positive emotions) within these activities. We used an interval sampling technique to measure the frequency and duration of target behaviours occurring within a specific time interval.

There were two primary target behaviours in this study:

1. *Child-initiated interaction* for which researchers coded the modality, its intent, whether it elicited a response from the adult, whether there were supports (e.g., communication aids) in place, and whether the bid for interaction led to reciprocal communication.
2. *Adult-initiated interaction* for which researchers coded what adults communicated, whether there were supports in place, whether the bid for interaction elicited a response from the child and whether it led to reciprocal communication.

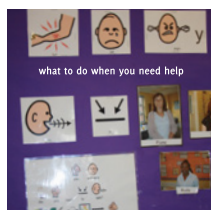
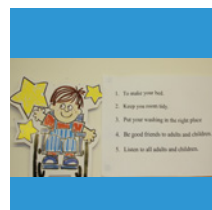
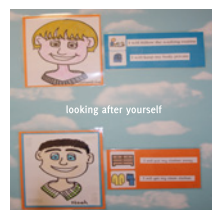
The total observation time (in this case, at least 1 hour) was divided into smaller (60-second) intervals. Researchers recorded whether either of these target behaviours occurred within that interval.

We also recorded information about the adult supporting the young person, including the nature of the support offered by the adult. These supports were divided into two types:

1. *Interpersonal supports*, which describe the strategies that adults use to adapt their communication style to suit a young person's needs. These supports consist of the adult being responsive to the child, fostering initiation, respecting a child's independence, setting the stage for engagement, providing developmental support, adjusting their language input and modelling appropriate behaviours.

2. *Learning supports*, which describe the way the environment is organised to foster young people's communicative competence. These supports comprise the way that activities are structured for active participation, the use of Alternative and Augmentative Communication to foster development, the use of visual and organisational support, and the adjustment of goals, activities and the environment, as necessary.

Recording young people's activities in this way allowed us to examine the degree to which young people created, and were given, opportunities for choice-making during their day-to-day activities and how the supports offered to a child by the adults working with them impacted on their degree of engagement. The observation schedule also provided space for field notes, to detail the nature of any activities, resources and to note informal discussions with staff throughout the day. Photographs were also taken every 10 minutes during the observation to document information about the child's activities, the environment and the adult during the observation.



Participatory film

With the support and guidance of the research team and staff from Wac Arts, members of the Young Researchers' Group contributed to making their own film about their lives at residential school, providing a powerful description of these children's experiences of living away from home. This meant that the young people were able to decide on the material they wished to include and to help capture the images and information they wanted to share.

In capturing the essence of their life at school, the young researchers interviewed one another, spoke directly to camera or interviewed members of staff to help explain what being at a special residential school means to them. They filmed and photographed the resources and facilities in their school, with an accompanying narrative about their daily lives and what they liked or disliked about school. They also told us about developing life skills, learning to understand and manage their disability and needs, learning, making friends, feeling understood and safe, work experience, community links and plans and aspirations for the future. The film also includes images of the research project in action, capturing *post-it!*, *Playmobil* activities and focus group discussions.

Interviews with Parents and Carers

Parents and carers took part in a semi-structured interview (approx. 30 minutes). We asked them to reflect on the specific abilities and needs of their child, their experiences of the decision-making process that led to the child's placement in a residential school placement, their child's involvement in that decision (if any), their perceptions of their child's wellbeing, hopes and aspirations, their satisfaction with the school, the amount of contact with their child and the nature of that contact and the degree of communication with school

staff. These interviews provided important context for the young people's views and perspectives about their placement.

Interviews and Focus Groups with School and Care Staff

Interviews and focus groups were conducted face-to-face in school. We asked questions about the children they support (and their perceived needs), the services and strategies that they use to support them and the challenges in doing so, their perceptions of children's wellbeing, mental health and relationships with others (peers, parents and school staff) and relationships between staff and parents.

We also sought to understand formal procedures and processes regarding safety and involvement in decision-making processes (e.g., school councils, annual reviews) as well as less formal processes, including the amount and type of support given to the young people to express their views and perspectives – about school, home, or any other aspect of their life. We also wanted to know school staff's views on the perceived benefits and challenges of pupil participation and whether such participation influences their everyday experiences.

Finally, we also asked for specific details regarding the experiences of looked-after children and the quality of contact and support and advocacy that they received from their local authority, and whether they received support (for example, independent advocacy) to support them to make their wishes and feelings known. We were keen to understand how their views were taken into account when planning for their future and how transitions to adulthood were planned and managed.

Appendix B: Glossary of Terms

AAC: Augmentative and alternative communication (AAC) describes the communication methods used to supplement or replace speech or writing for individuals who have difficulties producing spoken or written language.

Autism: Autism is a lifelong neurodevelopmental condition that affects the way that a person interacts with others and experiences the world around them. One in every 100 UK children lie on the autism spectrum.

BESD: Behavioural, emotional and social difficulties refers to a range of complex and chronic difficulties experienced by many children and young people, which manifest themselves in many ways, including becoming withdrawn or isolated, as well as displaying challenging, disruptive or disturbing behaviour.

CAMHS: Children and Adolescent Mental Health Services are specialist services within the National Health Service that offer assessment and treatment when children and young people have emotional, behavioural or mental health difficulties

Children Act 1989: The Children Act 1989 allocated duties to local authorities, courts, parents and other agencies in the United Kingdom, to ensure children's welfare and developmental needs are met, including the need to be protected from harm.

Community school: A community school in England and Wales is a state-funded school controlled by the local council and not influenced by outside groups and organisations.

Department for Education (DfE): The Department for Education is responsible for education and children's services in England.

EHC plan: Education, Health and Care Plans have replaced the Statement of SEN. It details the education, health and social care support that must be provided to a child or young person who has SEN or a disability, following a detailed assessment by the local authority, and after consultation with relevant partner agencies.

Hearing impairment: Hearing impairment can range from mild hearing loss to profound deafness. Deafness alone is not defined as a special educational need but there may be an associated disabilities or learning difficulties.

Independent special school: Independent or 'private' schools are financed through tuition charges, gifts, and perhaps the investment yield of an endowment instead of being dependent upon national or local government finances. Also known as a 'maintained special school'

Learning difficulty: A learning difficulty affects the way a person understands new and complex information, how they learn new skills, and how they cope independently. A learning difficulty can be mild, moderate (MLD) or severe (SLD). Individuals can also have profound learning disabilities, which often coincide with multiple disabilities (PMLD), including of vision, hearing and motor skills as well as epilepsy and autism.

Local authority: Local education authorities (LEAs) are the local councils in England and Wales that have the strategic lead for education of children and young people. They are responsible for distribution and monitoring of funding for the schools and they have a legal duty to ensure that every child fulfils his or her educational potential.

Looked after child: The term ‘looked-after children’ is defined in law under the Children Act 1989. It is generally used to mean those looked after by the state. Children can be ‘looked after’ for a variety of circumstances, including those who are accommodated under voluntary agreement with their parents (section 20), those who are the subject of a care order (section 31) or emergency orders for their protection (sections 44 and 46) and those who are compulsorily accommodated (section 21). Those young people who are looked after under section 20 may include some children who are primarily cared for by their parents but who receive planned, regular short breaks in fostering or residential settings which exceed 75 days in any 12 month period.

Non-maintained special schools:

A non-maintained special school is a non-profit making school, that operate to a level at least equivalent to state maintained special schools, and whose day-to-day running is controlled by a governing body.

Children’s Commissioner: The Children’s Commissioner for England promotes and protects children’s rights in England. She does this by listening to what children and young people say about what matters to them and making sure adults in charge take their views and interests into account. The Commissioner is supported by the Office of the Children’s Commissioner (OCC).

PECS: The Picture Exchange Communication System is a picture-based communication aid and form of AAC.

SCERTS: SCERTS is an educational model that directly addresses the core challenges faced by children and young people with autism and related disabilities and their families. SCERTS focuses on building competence in Social Communication, Emotional Regulation and Transactional Support [30].

SEN: The revised SEN Code of Practice states that children and young people of school age have special educational needs if they “have a significantly greater difficulty in learning than the majority of children of the same age; or have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local authority”.

SENDIST: The Special Educational Needs and Disability Tribunal (SENDIST) was set up by the Education Act 1993. Parents whose children have an SEN can appeal to an independent committee, SENDIST, against decisions made by local authorities in England about their children’s special educational needs, particularly with regard to school placement.

Speech, Language and Communication Needs (SLCN):

Children and young people with SLCN have difficulties in communication. These difficulties could manifest as problems with expressing oneself effectively or with understanding what is being said to them.

Statement: A Statement of Special Educational Need is a legal document that details the child’s needs and services that the local authority has a duty to provide. It has since been superseded by the Education, Health and Care (EHC) plan (see p. X).

United Nations Convention on the Rights of the Child (UNCRC): This is an international human rights treaty that grants all children a comprehensive set of rights. It requires that states act in the best interests of the child. The UK ratified the convention on 16 December 1991. It came into force on 15 January 1992. All UK government policies and practices must comply with the UNCRC.



United Nations Convention on the Rights of Persons with Disabilities

(UNCRPD): This is an international human rights treaty designed to protect the rights and dignity of persons with disabilities. The UK ratified the Convention in July 2009.

VI: Visual impairment is when a person has sight loss that cannot be fully corrected using glasses or contact lenses.

Appendix C: Notes

1. Abbott, D., Morris, J., & Ward, L. (2001). *The best place to be? Policy, practice and the experiences of residential placements for disabled children*. York, UK: Joseph Rowntree Foundation.
2. House of Commons Education and Skills Committee (2006) *Special Educational Needs*. Available online at (accessed 21st September 2014): <http://www.publications.parliament.uk/pa/cm200506/cmselect/cmmeduski/478/478i.pdf>.
3. Children Act 1989. Available online at (accessed 21st September 2014): <http://www.legislation.gov.uk/ukpga/1989/41/contents>
4. Children Act 2004. Available online at (accessed 21st September 2014): <http://www.legislation.gov.uk/ukpga/2004/31/contents>
5. Children and Families Act 2014. Available online at (accessed 21st September 2014): <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
6. United Nations Convention on the Rights of the Child 1989. United Nations Treaty Collection. Available online at (accessed 21st September 2014): https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-11&chapter=4&lang=en
7. Paul, A., Cawson, P., & Paton, J. (2004). *Safeguarding disabled children in residential special schools*. London, UK: National Society for the Prevention of Cruelty to Children (NSPCC)/Council for Disabled Children.
8. Abbott, D., Morris, J., & Ward, L. (2000). *Disabled children and residential schools: A study of local authority policy and practice*. Bristol, UK: Norah Fry Research Centre.
9. Audit Commission. (2007). *Out of authority placements for special educational needs*. London, UK: Audit Commission.
10. Beresford, B., & Cavet, J. (2009). *Transitions to adult services by disabled young people leaving out of authority residential schools*. York, UK: Social Policy Research Unit.
11. Gordon, D., Parker, R., Loughran, F., & Heslop, P. (2000). *Disabled children in Britain: A re-analysis of the OPCS disability surveys*. London, UK: The Stationery Office.
12. McGill, P., Tennyson, A., & Cooper, V. (2006). *Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: their perceptions of the services received and expectations of the future*. *British Journal of Social Work*, 35, 1 – 20.
13. Morgan, R. (2014). *Children’s care monitor 2013/14: Children on the state of social care in England*. London, UK: Ofsted.
14. Morgan, R. (2009). *Life in residential special schools: A report of children’s experience by the Children’s Rights Director for England*. London, UK: Ofsted.
15. Morris, J. (1995). *Gone missing? A research and policy review of disabled children living away from their families*. London, UK: Who Cares? Trust.
16. Pinney, A. (2005). *Disabled children in residential placements*. London, UK: Department for Education and Skills.
17. Read, J., & Harrison, C. (2002). *Disabled children living away from home in the UK: Recognising hazards and promoting good practice*. *Journal of Social Work*, 2, 211-231.
18. Roberston, J., Emerson, E., Fowler, S., Letchford, S., Mason, H., Mason, L., & Jones, M. (1996). *Residential special education for children with severely challenging behaviours: the views of parents*. *British Journal of Special Education*, 23, 80 – 88.
19. Jay, A. (2014). *Independent inquiry into child sexual exploitation in Rotherham. 2007 – 2013*. Rotherham, UK: Rotherham Metropolitan Borough Council.

20. Department for Education. (2014) Special educational needs and disability code of practice: 0 to 25 years. London, UK: Her Majesty's Stationery Office. Available online at (accessed 21st September 2014): <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>.
21. Lewis, A. L., Roberston, C. M. L., & Parsons, S. (2005). Experiences of disabled students and their families. Research report to Disability Rights Commission. Birmingham, UK: University of Birmingham.
22. Sen, A. (2005). Human rights and capabilities. *Journal of Human Development*, 6, 151 – 166.
23. Hopgood, S. (2013). The endtimes of human rights. Ithaca, NY: Cornell University Press.
24. United Nations Convention on the Rights of Persons with Disabilities 2006. Available online (accessed 21 September 2014): <http://www.un.org/disabilities/convention/conventionfull.shtml>
25. Department for Education. (2014). Promoting the educational achievement of looked-after children. London, UK: Her Majesty's Stationery Office.
26. Fisher, D., & Gruescu, S. (2011). Children and the Big Society: Backing communities to keep the next generation safe and happy. London, UK: ResPublica.
27. United Nations Committee on the Rights of the Child, General Comment No. 12 (2009): The right of the child to be heard, 20 July 2009, CRC/C/GC/12. Available online (accessed 16 November 2014): <http://www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC-C-GC-12.pdf>
28. Office of the Children's Commissioner. (2014). Participation strategy: June 2014 – May 2015. London, UK: OCC.
29. Shier, H. (2001). Pathways to participation: openings, opportunities and obligations. *Children and Society*, 15, 107 – 117.
30. Prizant, B. M., Wetherby, A. M., Rubin, E., Laurent, A. C., & Rydell, P. J. (2006). The SCERTS® Model: Volume I Assessment; Volume II Program planning and intervention. Baltimore, MD: Brookes Publishing.
31. O'Kane, C. (2008). The development of participatory techniques. Facilitating children's views about decisions which affect them. In P. Christensen, and A. James (Eds), *Research with children: Perspectives and practice*, 2nd Edition. Routledge Press: London and New York.
32. Stalker, K., & McArthur, K. (2012). Child abuse, child protection and disabled children: A review of recent research. *Child Abuse Review*, 21, 21-40.
33. Office of National Statistics (2004). Mental health of children and young people in Great Britain. Basingstoke, UK: Palgrave MacMillan.
34. Green, H., McGinnity, A., Meltzer, H., & Goodman, R. (2005). Mental health of children and young people in Great Britain. Basingstoke, UK: Palgrave MacMillan.
35. National Health Service (2006). Mental health services for children with learning disabilities: a national care pathway. London, UK: Her Majesty's Stationery Office.
36. Murphy, M., & Fonagy, P. (2013). Mental health problems in children and young people, Chapter 10. 2012 Annual Report of the Chief Medical Officer: Our children deserve better: Prevention pays. London, UK: Her Majesty's Stationery Office.
37. Society for Research in Child Development (SRCD). (2009). Healthy development: A summit on young children's mental health. Partnering with communication scientists, collaborating across disciplines and leveraging impact to promote children's mental health. Washington, DC: Society for Research in Child Development.

38. Luke, N., Sinclair, I., Woolgar, M., & Sebba, J. (2014). What works in preventing and treating poor mental health in looked-after children? London, UK: NSPCC.
39. Munro, E. (2011). The Munro Review of child protection: A child-centred system. London, UK: Her Majesty's Stationery Office.
40. McKonkey, R., Gent, C., & Scowcroft, E. (2013). Perceptions of effective support services to families with disabled children whose behaviour is severely challenging: A multi-informant study. *Journal of Applied Research in Intellectual Disabilities*, 26, 271 – 283.
41. Cavet, J., & Sloper, P. (2004). Participation of disabled children in individual decisions about their lives and in public decisions about service development. *Children and Society*, 18, 278 – 290.
42. Franklin, A. (2013). A literature review on the participation of disabled children and young people in decision making. London, UK: VIPER/Council for Disabled Children.
43. Beresford, B., Rabiee, P., & Sloper, P. (2007). Priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services. York, UK: University of York, Social Policy Research Unit.
44. Office for Standards in Education, Children's Services and Skills (Ofsted). (2011). The annual report for Her Majesty's Chief Inspector of education, children's services and skills 2010/2011. London, UK: Ofsted.
45. Pilling, N., McGill, P., & Cooper, V. (2007). Characteristics and experiences of children and young people with severe intellectual disabilities and challenging behaviour attending 52-week residential special schools. *Journal of Intellectual Disability Research*, 51, 184 – 196.
46. Gaudion, K., & Brand, A. (2011). Sensory preferences: Housing design for adults with autism. London, UK: Royal College of Art, Helen Hamlyn Centre for Design.



About Us

The UCL Institute of Education, University College London, is both the largest and the leading research and teaching institution into education theory and practice in the UK. It houses the Centre for Research in Autism and Education (CRAE), a unique centre focused on helping to enhance the lives of autistic people and their families (crae.ioe.ac.uk). Dr Liz Pellicano is Director of CRAE. The IOE also houses the Doctorate in Professional Educational Child and Adolescent Psychology (DEdPsy), a three-year training programme for those wishing to pursue a career in educational psychology, approved by the Health and Care Professions Council and accredited by the British Psychological Society. Vivian Hill is Director of the DEdPsy programme.

Wac Arts is a dynamic, multi-functional charity (reg: charity no. 267043) that works in fresh and imaginative ways to support gifted young people facing exceptional challenges and hardship to discover their talents and fulfil their potential through arts and media programmes devised and created at the charity's vibrant community hub based at the Old Town Hall in London's Belsize Park. Their participatory work with young people with disabilities is both compelling and inspiring.

Citation

Pellicano, E., Hill, V., Croydon, A., Greathead, S., Kenny, L., & Yates, R. with Wac Arts. (2014). *My life at school: Understanding the experiences of children and young people with special educational needs in residential special schools*. London, UK: Office of the Children's Commissioner.

My Life at School

Understanding the experiences
of children and young people
with special educational needs
in residential special schools

PRODUCED BY:
Centre for Research in Autism and Education (CRAE)
UCL Institute of Education
University College London
55-59 Gordon Square
London WC1H 0NU
+44(0)20 7331 5140
crae@ioe.ac.uk
crae.ioe.ac.uk

