CHILDREN'S COMMISSIONER

Annex: research findings on children with disabilities

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Summary

Background

The Children's Commissioner's Office (CCo) was commissioned by the Cabinet Office Disability Unit to find out more about the lived experience of children with disabilities. This includes:

- How children with disabilities are experiencing transitioning into and out of different learning settings,
- What kind of access children with disabilities have to extra-curricular activities outside of school,
- How children with disabilities experience moving between health and social care services,
- The extent to which different services feel well coordinated for children with disabilities.

This annex reports in detail on the findings. A companion report, *'We all have a voice': Disabled children's vision for change* includes recommendations for changes to policy and practice.

Methods

This study is based on new research and analysis by the Children's Commissioner's office, supplemented by a literature review and secondary analysis of published data:

1. The CCo carried out a thematic review of Help at Hand cases involving children with disabilities. The service had not previously broken down cases in this way. Help at Hand is the Children's Commissioner's office's advice and representation service for children in care, children who have a social worker, children living away from home and care leavers[1]. As such, it does not hear from a representative cross-section of children, nor of children with disabilities. Children, young people, or their advocates can get in touch with Help at Hand for free by phone, website or email and receive help with any child rights issue. The analysis covers 743 Help at Hand cases (204 involving children and young people with disabilities, of all ages including some aged over 18) handled in the 2022-23 financial year.

2. The CCo analysed data from The Big Ask by Special Educational Need (SEN) status and other characteristics. The Big Ask was a national consultation exercise with children aged 9-17 in England launched in April 2021, which ran for approximately 6 weeks and gathered over 550,000 responses, including 51,007 from children defined as having SEN because they received support from a teaching assistant or SENCO, attended a special school, or completed the easy-read version of the questionnaire. The extent to which The Big Ask can be generalised is limited by the fact that it captured the views only of children who were willing and able to self-report, either directly or with support. Previous publications based on The Big Ask have broken down children's answers by SEN status, but not looked at other characteristics too. Findings were weighted to be representative of the national population of children based on age, gender and local authority.

3. The CCo carried out 11 focus groups and 5 interviews with a total of 101 people – 51 children, and 50 parents, carers and professionals. The interviews took place in March and April 2023 in a range of school and community settings, and virtually. Children and young people were aged between 11 and 24, and a range of disabilities were represented.

4. The CCo commissioned Opinium to conduct a nationally representative survey of 3,593 children aged between 8 and 17 years old and their parents in March 2023. This total sample size includes additional boost samples of single parent households, ethnic minority households and households with children receiving free school meals.

Findings

Definitions and concepts of disability in childhood

In the Equality Act 2010, disability is a physical or mental impairment that has a substantial or long-term negative effect on someone's ability to do normal daily activities. Children for whom this is the case may or may not identify as 'disabled'. In the 2021 census of England, 6% of children aged 0 to 14 (590,908) were limited a little or a lot in their day-to-day activities by long-term physical or mental health conditions or illnesses.[2] One survey of children, the Next Steps cohort study, used a version of this definition adapted for children: a long-standing illness, condition or impairment affecting school attendance and/or the ability to complete homework, and/or a special educational need of any kind.[3]

Higher proportions are assessed as having mental health problems when using a standardised measure, rather than when asking young people to self identify: as of 2022 in England, the NHS estimated that 18% of children aged 7 to 16 years and 26% of those aged 17 to 19 had a probable mental health disorder.[4]

A larger number had a plan or support provided in their school or nursery for their special educational needs or disabilities (SEND). In academic year 2021/22, 1,485,409 children and young people had either an EHCP or SEN support: 16.6%.[5] The minority, 355,566, had a Education, Health and Care Plan (ECHP) due to their special educational needs or disabilities (4.0%),[6] a larger number were receiving SEN support without having a EHCP (1,129,843 or 12.6%).[7]

Having a EHCP does not mean you are disabled: outside the school context, a child may experience no impairment and could be surprised or unhappy to hear themselves described as disabled. Government guidance for organisations supporting children with special educational needs or disabilities explains that, though children with disabilities under the Equality Act definition do not necessarily have SEN, there is a 'significant overlap' between disabled children and children with SEN.[8]

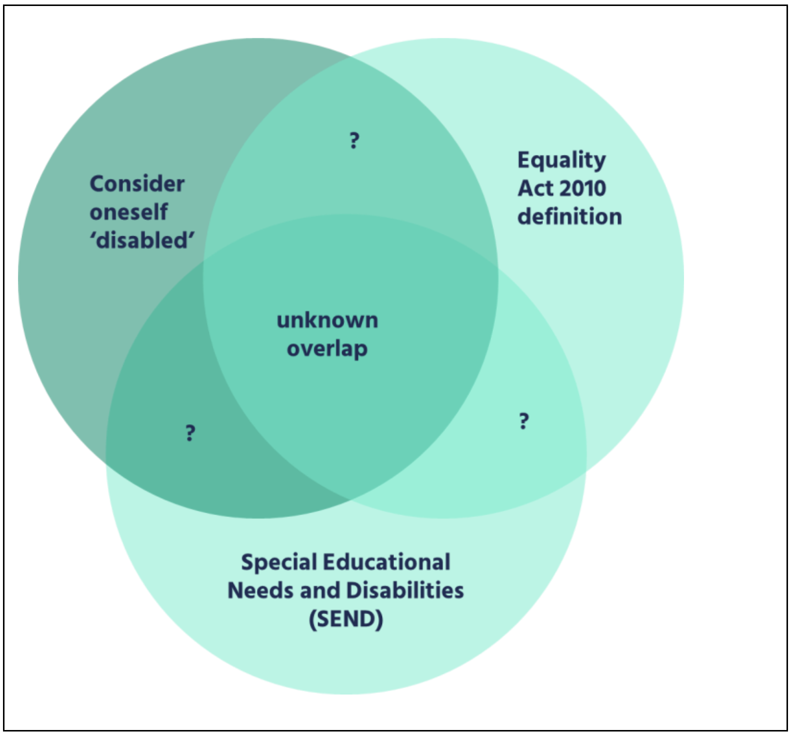
Under the World Health Organisation's biopsychosocial model, disability is created when a person interacts with their environment, rather than being a characteristic of a person.[9] Following this logic, children are disabled by their environment rather than being children 'with' or who 'have' particular impairments or diagnoses. Some of the disadvantage experienced by disabled people may be indirect, stemming from other factors like their (more likely than average to be disadvantaged) family backgrounds.[10] One boy we spoke to did not like the expression and said he thinks of himself as having a special need, not a disability. Children who do consider themselves disabled may consider other identities, such as being care experienced, as equally or more significant. Their care experience, rather than their experience of disability, stood out in the accounts we heard from care-experienced young people with disabilities. A disability, learning difficulty or health condition is only one feature in a child's complex life. Our analysis of The Big Ask found SEN status did not stand out as making more difference to children's answers than other demographic characteristics. It is important to hear children's views on their identities and preferred language and avoid adult labels. Not enough research includes the voices of disabled children themselves, a gap in the evidence that this report helps to address.[11]

In contrast to many adults and disabled adults, children generally experience good health. In the 2021 census, 97% of children in England aged 0 to 14 were in good or very good health.[12] Compared to adults, fewer children receive help for the extra costs of disability in the form of benefits, but the latest Department for Work and Pensions statistics for Great Britain show 66,000 children aged 16 and 17 were claiming Personal Independent Payment.[13] Limiting long-term health conditions and disabilities manifest differently for children and have different implications for care, education and other public services.

Definitions are difficult and may partly explain the lack of data on children with disabilities, who are not flagged as such in many public service data systems, including children's social care national data returns. Some systems use SEN status as a proxy. Different sectors use different jargon. For example, the umbrella term 'learning difficulties' may be used in education to include all children with additional learning needs, whereas health and social care services may use the term 'learning disabilities'. The number of children in England who consider themselves disabled is unknown, though will be smaller at a point in time than when considered over a period, as conditions and impairments come and go over time. One analysis of the school census found that 39% of the 2016 GCSE cohort were recorded with SEND at some point since Reception, compared to a maximum of 23% in any one year.[14] One 2020 survey by the Children's Commissioner for Wales found 5% of children replied 'yes' to 'Do you have a disability?'[15] The degree of overlap is unknown between these children and children who fit the Equality Act definition or who have SEND (Figure 1).

Definitions have implications for policy and practice. Specialist services need to think about referral routes, how they refer to themselves, and any potential for stigma. Universal services may struggle to understand and adapt, as every disabled child is different. The challenge for services is to deliver support which meets children's varying needs while not defining children as different or stigmatising them - children with disabilities, like all children, want to be accepted and included.[16]

Figure 1: definitions overlap to an unknown extent



Differences and similarities between children with and without disabilities

Every child with a disability is different, and yet this report seeks to generalise about common and shared aspects of life for a group of children with, but not defined by, their disabilities, special educational needs, and health conditions. There are limits to the extent to which this report can do so, as the findings do not represent all disabled children and young people. But some common threads can be identified in children with disabilities' experiences – themes and patterns of responses to questions.

Children recognise that sometimes children with disabilities face specific barriers. Children complain about specific problems related to their disabilities, like inaccessible toilets, toilets marked as accessible which are not, and broken lifts. In some areas and in some surveys, children with disabilities report more negative experiences and greater pessimism. Children with SEN in The Big Ask analysis were 2 percentage points more unhappy with their personal safety than other children. They were also a little more likely to select education among their areas of future worry, and slightly more pessimistic about the likelihood that 'you will have a better life than your parents'.

These patterns are comparable in scale to the differences between groups of children seen when responses are broken down in other ways, such as by gender, ethnic group, and whether children have a social worker. Disability does not stand out among other child characteristics as more powerfully determining their views and experiences.

There is more similarity than difference. Children with disabilities are children first and foremost.[17] Both groups, children with and without disabilities, express similar or identical views on a range of topics. Across most aspects of their lives, children with SEN were just as happy as children overall, The Big Ask found. They mostly feel supported by their families, enjoy school, and have hopes for the future. When things go wrong, and they seek help from the Children's Commissioner's Help at Hand information and advice service, they do so for broadly the same range of issues.

Transitions

There are life transitions unique to children, like starting school, moving from primary to secondary school, and entering adulthood. For some children with health conditions and disabilities, transitions may be delayed, different from or take longer than the mainstream experience of most children.[18] There are also transitions, such as the onset of a disability, or moving between mainstream and special education, that are unique to children with disabilities. Permanent school exclusions represent a transition which is more common for children with SEND, especially social, emotional and mental health needs.[19] Transition support exists for some sub-groups of children with disabilities, such as Transition Assessments for young carers with disabilities. Children would value more practical help to prepare them for the transition to adult life. One special school we visited had put in place a range of support to make transitions as easy as possible for children, including a dedicated coordinator, transition meetings, and involving young people in a recent move between buildings.

It was clear that transitions and big life changes mean different things to different young people. For children in care, their experiences of moving between foster carers can be the overwhelming change in their lives, that influences everything else; for others moving between primary and secondary school, or secondary school to college. College can feel overwhelming, adapting to new environments and understanding the different support that is available in different settings.

Some children and young people had good experiences with their transitions. They had dedicated teachers who supported them, found their families supportive or were lucky to have the opportunity to learn skills at the local community café. But children, families and professionals also mentioned many things that were not going well for them. For example, it became clear that experiences of transitions and the services that are available for the same transitions, such as transition assessments for young carers, vary hugely between settings and different areas of the country, and local authorities can struggle to put the right accommodation for young people in place. Some young people felt they missed out on early diagnosis which would have made a huge difference to them looking back, for example during their time at school. There are advantages of the early diagnosis or identification of some disabilities. For example, children can be added to their general practice learning disability register, which gives access to annual learning disability health checks and annual flu vaccinations from the age of 14.

Wanting to be understood

Most importantly, children with disabilities we spoke to wanted to feel understood. They wanted to be part of the community and be treated as an equal. It was refreshing to hear from young people, such as the young people who attended college at the residential special school or the young people who we met at the community café, who felt valued through the work they did. But it became clear that children felt society as a whole had not reached a point where their transitions between different life situations would be as supported and smooth as possible. Children and young people with a disability are not always offered the same opportunities - such as being able to go to university, or earning money through part-time jobs - as children and young people without a disability, reasonable adjustments are not always put in place, and there is a lack of provision to suit their needs.

Sub-groups of children with disabilities

The most common disability recognised in Education, Health and Care plans, listed as a primary need in almost 1 in 3 plans, is autistic spectrum disorder.[20] The most common type of need among the larger group of pupils receiving SEN support is speech, language and communication needs, for example children with dyslexia. Next most common are social, emotional and mental health needs, and moderate learning difficulties. Smaller numbers have EHCPs or SEN support primarily due to their physical disabilities, hearing impairment, vision impairment, multi-sensory impairment, or other difficulty or disability. Children may also receive special educational support because they speak English as another language, or because they have been identified as 'gifted and talented', but these groups are not usually included among children with SEN in analysis.[21] The preponderance of behavioural, emotional and mental health needs among children with SEN implies a need for services to, as well as overcoming obvious physical barriers, address the other kinds of social and policy barriers that impact on children's access, experiences and outcomes.

Data for younger children is not available, but the 2023 GP Patient Survey for England shows that among young people aged 16 to 24, 6% have a learning disability, 2% have a neurological condition such as epilepsy, 6% have autism, 1% live with blindness or partial sight, 10% report living with another long-term condition or disability, 8% have a breathing condition, such as asthma or chronic obstructive pulmonary disease (COPD), 3% have arthritis or ongoing problems with their back and joints, and a smaller proportion are living with conditions like diabetes (1%), a heart condition (1%) and/or high blood pressure (1%).[22]

The current limitations in data are one barrier to a proper understanding of children with disabilities: capturing only 'primary need' means the data are limited and do not accurately describe the complexity of needs of many children with disabilities, for example a child who is deaf, autistic, has a learning disability, and has emotional and behavioural needs.

Certain special educational needs, mental health conditions and disabilities are more commonly identified in boys, as shown by Department for Education data, and reflected among The Big Ask respondents with SEN, and the children helped by Help at Hand. In 2021/22, 73% of all pupils on EHCPs and 64% of pupils with SEN support were boys.

In The Big Ask, children with SEN were more likely to be in a White ethnic group (74%) than children without SEN (70%). Children with SEN were slightly more likely than children without SEN to be attending a school in the most deprived fifth of neighbourhoods (18% vs 15%). They were more likely to have certain vulnerabilities: to have a social worker, be in foster care, or be a young carer.

The link between disability and poverty is strong: Department for Education statistics show that in 2022/23, 41.1% of pupils with an EHCP and 37.5% of pupils with SEN support were eligible for free school meals, compared to 23.8% of all pupils in schools.[23]

Differences and similarities between sub-groups of children with disabilities

We explored differences and similarities between groups of children with disabilities. The uniquely large sample size of respondents to The Big Ask allows for analysis of relatively rare characteristics, like being a young carer, by SEN status. The analysis looked for any extra effects of SEN and another characteristic (like being a boy, or attending a school in a deprived area) when these two factors were examined together. A few of these statistical interaction effects were found, but the overall pattern was one of similarity between groups of children with SEN and other characteristics. This reflects qualitative research finding that the needs, preferences, priorities and aspirations of children with disabilities are in many ways the same as those of other children, albeit many need additional support to achieve their goals.[24]

Research by the University of Oxford highlights that Asian pupils (Indian, Pakistani, Bangladeshi and Other Asian) are half as likely to be identified with Autistic Spectrum Condition (ASC) as White British pupils, and Black Caribbean and Mixed White & Black Caribbean pupils are twice as likely to be identified with Social, Emotional and Mental Health (SEMH) needs as White British pupils. The researchers argue this inequality cannot be accounted for by factors such as socio-economic background and early attainment / development on entry to school.[25] Other research also points to gendered biases in the identification of conditions which may be disabling without early support, such as the late diagnosis of ASC in girls.[26]

Where rare characteristics intersect, services can struggle to accommodate all needs. Professionals spoke of the challenge of providing a break for young carers in a service reaching young carers both with and without additional needs.

Education, jobs and skills

Children have a right to education, and disabilities have particular implications for children's schooling. Children and young people in focus groups and interviews had positive things to say about their teachers, schools and hopes for the future. However, they also spoke about pressure at school. Previous analysis of the survey Understanding Society has found children in the UK aged 10-15 with a long-term health problem or disability to be statistically significantly less happy with school than their peers.[27]

Children also spoke of unfairness in employers not considering reasonable adjustments, and limitations in the range of extra-curricular activities available. When support was in place, or parents willing to help, activities can offer children with disabilities a range of opportunities to have fun and potentially gain useful skills for later life. Many children with disabilities are being successfully supported to take part: Sport England finds that levels of physical activity among 5- to 16-year-olds with a disability or long-term health condition in 2021/22 were the same as for those without one.[28] However, young people noted room for improvement, like only some shops and galleries offering quiet times, and there being room in some public places for only one wheelchair space.

A growing proportion of children have EHCPs.[29] Generally, most young people we asked knew whether or not they had an EHCP. But children do not always feel involved in their development or know what is in them. Children with special needs and disabilities contacted Help at Hand for many reasons. But the most common issues relate to education (28%), such as being out of school, or needing advice on Education, Health and Care (EHC) plans. Many children with disabilities in contact with Help at Hand had difficulties attending school, often due to a lack of infrastructure for mobility challenged pupils, lack of support for SEND, and problems with their EHCP plans not being followed.

It is clear from this and from focus groups and interviews that there is variation in service provision for children with disabilities, with some schools and colleagues more understanding or able to meet needs than others. Children and parents spoke of differences between the support offered by mainstream and special schools, and between primary and secondary.

About 9 in 10 children with SEND are educated in mainstream settings, and 1 in 10 in specialist (special) schools.[30] In academic year 2021/22, 146,000 children attended special schools (either state-funded, or non-maintained).[31] There are pros and cons to mainstream education and specialist education for children with disabilities. Children at mainstream schools can feel misunderstood and some talked about the need for more teacher training. But while special schools can provide quality specialist education, they are often far from the child's home, which can be difficult. It is challenging for mainstream schools to understand all of the wide range of disabilities children have, but specialist provision may bring stigma, or only be available after a wait.

Children who wrote comments about disability in The Big Ask wanted teachers to have more training to equip them with learning materials and teaching approaches that would work for them. They also wanted easier routes to diagnosis within school, easier access to treatment, and more awareness within school of different types of SEND.

A question in The Big Ask asked about the barriers to success. For children who were home educated or were not in any education, the most consistently mentioned barrier was the lack of support for SEND. This included access to timely diagnoses, support from the school and teachers and lack of suitable adjustments or provisions to meet their needs, resulting in them not being able to participate in mainstream education.

Overall, answers by 27,000 children with SEN and 224,000 children without SEN to The Big Ask were very similar. Both groups most often discussed education, peer relationships, and self-belief. Children with SEN more often brought up the pandemic (13% vs 9%) and were less likely to bring up mental health (14% vs 18%). Over a thousand children, both with and without SEN, mentioned disability as a potential barrier to achieving success in adulthood. Specifically, these children raised concerns around preparing for the future, accessibility of public spaces, discrimination and bullying and challenges in education. Children with disabilities talked about wanting to be treated equally and not be judged on the basis of their disability.

The answers to The Big Ask by children with SEN show that they worried a little more about education and prioritised education a little more highly than other children. Interestingly, there was a statistically significant interaction effect between having SEN and having a social worker. Children with SEN who did not have a social worker were more likely to worry about and prioritise education than children with SEN alone, or children without a social worker alone.

Children's social care

In social care, the issue is not usually safeguarding children with disabilities from their parents. The Department for Education defines children in need as a group supported by children's social care, who have safeguarding and welfare needs, including disabled children.[32] Analysis for the Department's 2019 children in need review found that 9% of children with SEN were children in need.[33]

In 2022, concerns about the child's disability or illness were a factor in 23,850 child in need assessments carried out by local authority children's services departments, a small minority of the 645,070 completed assessments.[34] A further 54,670 noted a child's learning disability as a factor, and 87,750 noted concerns about children's mental health (more than one factor can be noted). These children with disabilities in need may receive a range of support and services from local services to promote and safeguard their welfare.

Many children with disabilities who have a social worker live at home. The new analysis of Help at Hand cases in this report illustrates this. Children with disabilities helped by the service were almost twice as likely to live with a parent (29% compared to 15% of children without disabilities). This is likely because social services were involved because of their disability (rather than due to concerns about abuse, for example) and the involvement of social services makes a child eligible for the service. The issues can be different. For example, there are cases where not enough support (like short breaks and adaptations) is available for children to stay at home with parents.

Advocacy

When things go wrong, children with disabilities can be vocal in speaking up. In the context of the Help at Hand service, many of their problems are easily solved, though children may need help from parents, carers, advocates and others. Children with a social worker, or who live away from home, can contact the Help at Hand service about their problems. Where the team get involved in a case involving a disabled child (rather than just providing information), 81% of cases get fully or partly resolved.

Young people who are known to social services because of their disabilities but who are not in care do not have the same entitlements to statutory advocacy as children with disabilities in care.[35] So families are often at a loss for assistance and contact Help at Hand, one of the few services available to such children. This, combined with the fact that many young people with disabilities are unable to seek assistance for themselves, means most contacts made to Help at Hand were from family and friends (42%) and professionals (38%) rather than children and young people themselves (12%).

Ultimately, children with disabilities face many challenges in life that often seem invisible to those without. This report shows that, in the context of the Help at Hand service, these problems are mostly resolvable. Too often children are not at the centre of decision making about their lives. This is perhaps particularly acute for children with disabilities who cannot articulate their needs and wants easily. For these children Help at Hand and effective advocacy help to make sure their voices are heard and that professionals are challenged when necessary.

Safe, suitable homes

Housing is important for all children, but some children with disabilities struggle to find suitable housing. Some children are placed in residential educational settings by their families who decide they like the school and feel their children living there is the best solution for the whole family. In 2022-23, 9% of all Help at Hand cases relating to a disabled young person were about housing, such as difficulty finding a placement or forced or unwanted placement changes. Case notes reveal an insufficient supply of homes for children in care who have very challenging behaviour and high needs, especially when this overlaps with learning difficulties and mental health conditions. In cases where the child lived at home, there were cases indicating a lack of support for helping families better manage disability, such as short breaks and other adaptations, such as home infrastructure and schedules. In our March 2023 survey, 22% of parents of a child with SEND agreed that ‘my home negatively affects my child’s health’ compared to 12% of other parents.

Across all aspects of life asked about in The Big Ask, the largest relative difference between children with SEN and children without SEN was in the share of children unhappy with their personal safety. Children with SEN in Black and Mixed ethnic groups were more unhappy than when looking at White and Other children with SEN alone, and Black and Mixed children without SEN alone. Positively, where children with SEN reported receiving help from a social worker, they more often reported being happier with their personal safety than children with SEN but no social worker.

Bringing it all together

Children with disabilities have lives that can be complicated, but can also be full and happy. This report cannot conclude that the experiences of children with disabilities are either positive or negative, because they are both. Children can feel happy in some aspects of their life while seeing room for improvement in others. They may see themselves as disabled at some times or in some contexts, but not others.[36] Children are part of families who usually support and care for them, to which is added a complex picture of universal, targeted and specialist support and services.

Children with disabilities are not, for example, just pupils, patients or foster children. They should be seen as rounded individuals who may access a range of services for their varied needs. Continuity of care between different services is important, but is sometimes lacking. Professionals cited funding shortages and waiting lists among the reasons for this. Parents and carers sometimes fill the gaps and services sometimes rely on this goodwill.

Methodology

This study used four main methods, supplemented by literature review, secondary analysis of published data. In particular, we draw on a previous CCo publication, *Findings from The Big Ask on Special Educational Needs and Disabilities,* published as an Annex to *Beyond the Labels: A SEND system which works for every child, every time.*

1. Thematic review of Help at Hand cases involving children with disabilities
2. Analysis of The Big Ask by SEN status and other characteristics
3. Focus groups and interviews with disabled young people
4. Analysis of a nationally representative survey of children and parents in England

Thematic review of Help at Hand cases involving children with disabilities

To gain insight into the lived experience of children with disabilities and the challenges they experience, this report is based on analysis of 743 cases of children and families received by the Help at Hand team from April 1st 2022 to March 31st 2023. Where recorded, the young people and care leavers involved in these cases were aged between 0 and 39.

Using a series of search terms designed to identify cases involving a young person with a disability, we estimate the number of children who directly or indirectly contacted Help at Hand. This report uses the Equality Act 2010 definition of disability: a person has a disability if they have a physical or mental impairment that has a substantial and long-term negative effect on their ability to do normal daily activities.

Help at Hand emails and case notes were subject to textual analysis and filtering. This filtering by disability-related terms means we only estimate the child's disability status. Case notes were not systematically reviewed in detail so we may have wrongly included or excluded children with disabilities from the analysis. The search terms used to identify cases relating to disabled young people were:

- Autism/autistic
- Education, health and care plan/EHCP[37]
- Disability/disabled/disabilities
- Special schools
- Special needs
- Social, emotional and mental health (SEMH)
- Non-verbal
- Non-instructed
- Global delay

The unit of analysis was the case, not the child, in line with the format of Help at Hand records. This means there are some gaps in the data: for example, gender is not recorded for cases concerning more than one child. It may bias our sample, for example, towards only children, rather than children with siblings.

Case studies of children with disabilities in contact with Help at Hand are used in this report to provide examples of the challenges they face and the kind of support Help at Hand offered. These case studies are from the 2021 and 2022 calendar years.

For simplicity, in this report, we refer to children 'contacting' and being 'in contact with' the service. However, some children and young people contacted Help at Hand directly, and others indirectly, when others raised issues on their behalf.

Analysis of The Big Ask by SEN status and other characteristics

Survey background

In April 2021, the Children's Commissioner for England, Dame Rachel de Souza, launched The Big Ask: a national consultation exercise with children in England to ask them about their lives and their priorities, aspirations and worries for the future. The purpose was not only to provide a large-scale 'state of the nation' assessment of the views of children on these issues, but also to help inform the Commissioner's priorities and longer-term strategy for her term in office, and to help ensure that children's needs and interests could be placed at the forefront of policy measures to recover from the impacts of the pandemic.

The Big Ask ran for approximately 6 weeks and gathered more than 550,000 responses, making it the largest ever survey of children anywhere in the world, to our knowledge.

All four of the substantive closed questions included in The Big Ask were analysed for this report. These asked children about their happiness with different areas of life, priorities, future worries, and whether or not they thought they would have a better life than their parents.

The surveys also included one free-text question, previously analysed with respect to special educational need and disability themes, and published as *Findings from The Big Ask on Special Educational Needs and Disabilities,* which was an annex to *Beyond the Labels: A SEND system which works for every child, every time*[38] and reproduced here. The survey asked: *'What do you think stops children/young people in England achieving the things they want to achieve when they grow up?'*[39]

Defining characteristics from The Big Ask data

The Big Ask included demographic questions and questions on the type of support received by children which allows for analysis in this report by gender, aggregated ethnic group, income quintile of their school neighbourhood[40], whether the child had a social worker, whether the child was in foster care, whether the child was a young carer and whether the child had Special Educational Needs (SEN).

For all findings from The Big Ask, 'children with SEN' are defined as:

- those who reported that they received support from a teaching assistant or Special Educational Needs Co-ordinator (SENCO),
- those enrolled in a special school, or
- those completing the easy read version of the questionnaires.

Therefore, they may not consider themselves to have SEN or be representative of the population of all children with SEN. For example, children with SEN who receive help from a teaching assistant but do not find this help supportive may not have been picked up. It is unlikely that The Big Ask captured the views of all groups of children with disabilities, such as children with the most severe and profound learning and multiple disabilities.

In The Big Ask, 51,007 children aged 9-17 were identified as having SEN. Of these children the majority (69%) went to a mainstream school and completed the regular version of The Big Ask questionnaire but were identified as having SEN because they received support from a teaching assistant or SENCO (as shown in Table 1). 19% of these children didn't go to a special school or receive support from a SENCO but were identified as having SEN because they completed the easy-read version of the questionnaire.

Table 1 – Reasons for being identified as having SEN in The Big Ask

Reason for being identified as having SEN	Number of children	Percentage of children who were identified as having SEN
SENCO or Teaching Assistant only	35,346	69%
Easy read version of questionnaire only	9,411	19%
Special school only	2,112	4%
SENCO or TA and easy read version of questionnaire	1,466	3%
SENCO or TA and special school	1,187	2%
SENCO or TA, special school and easy read version of questionnaire	844	2%
Easy read and special school	641	1%
Any of the above	*51,007*	*100%*

Children with a social worker are identified as children who said they received support from a social worker, children in foster care are identified as children who said they currently lived with their foster parents, and young carers are identified as children who said they received support from a young carers project. The IDACI quintile refers to whether a child's school is in a postcode in the bottom 20%, second to bottom 20%, middle 20%, second to top 20%, or top 20% of the Income Deprivation Affecting Children Index.

Findings from The Big Ask are weighted based on age, gender and local authority to ensure findings are as representative of the national population of children in England as possible.

Any differences referred to in this report are statistically significant, however, the large size of The Big Ask sample brings a risk that differences between groups that are not substantial or meaningful gain unwarranted importance due to being statistically significant. Therefore, interactions between two variables are only discussed if the interaction term in a two-way analysis of variance (ANOVA) is statistically significant at the conservative 0.01 level. This is a more robust threshold for reporting results than the 0.05 level typically adopted.

Focus groups and interviews with disabled young people

CCo conducted 11 focus groups and five 1-to-1 interviews with a total of 101 people, made up of 51 children, and 50 parents, carers and professionals in March and April 2023. The young people were aged 11 to 24. A range of disabilities were represented.

The young people were not asked about their specific disabilities, or whether they were diagnosed. In some places, details of a young person's disability have been withheld to reduce identifiability. Participants were selected based on a mixture of self-definition and presence in certain settings such as students at special schools.

The focus groups took place at different settings: virtually with a young carers group and professionals working with young carers who are also disabled, in person at an independent special school in London, in person at a community café in the Midlands, in person at a conference for professionals working with children with vision impairment, in person at a residential special school in North West England. One youth group for disabled young people in the West Midlands talked about our questions during their session and submitted their answers in writing. This was agreed with their youth worker who felt that speaking among themselves, rather than having visitors in the room, would work better for the young people. The focus groups were conducted by two CCo members of staff. For two of the focus groups, a member of staff from the Cabinet Office Disability Unit observed. CCo also conducted five interviews with children. These were 1-to-1 conversations either with young people who could not take part in the groups, or who are members of CCo's care experienced advisory board. All five interviews took place virtually (Table 2).

This report is informed by an additional four children the CCo spoke with, in a focus group carried out for a separate piece of work, in February 2023. Their views aided our understanding and have informed the findings outlined in this document.

The research was carried out in line with the CCo's policy on engagement with children, meaning for example that children consented to take part and did not have to answer all the questions if they did not want to. The topic guide was agreed on with the Disability Unit (see Annex A), and was adapted based on the needs, interests and age of the young people in each session. For example, we found with some groups it worked well to give the young people some thinking time to first write down their ideas before the discussion. With some groups we focussed more on education, with others more on employment.

Eight of the focus groups and interviews were voice recorded and transcribed. The other focus groups were not voice recorded as one or more of the participants did not want this, or because the set-up of the group made recording not feasible, e.g., when visiting young people in the residential special school. In these instances, CCo took written notes of the conversation instead.

Two of the conversations at the residential special school required sign language interpretation. This was provided by members of staff from the school. One group of children was visited during one of their lessons and no direct interaction with the children took place due to the needs of the children. Staff explained to CCo the activities the children were engaging in.

Table 2 - Research participants

	Number of young people	Number of parents or professionals	Ages of young people	Group of participants
Group 1	3	1	13-7	Disabled young carers
Group 2		6		Professionals working with disabled young carers
Group 3	8		14-16	Pupils at an Independent Special school
Group 4	11		16-19	Pupils at an Independent Special school
Group 5	8		15	Pupils at an Independent Special school
Group 6	3	2	18-24	Community Café
Group 7		31		Professionals working with children with vision impairment
Group 8	5	2	11-12	Residential special school
Group 9	3	4	22-23	Residential special school
Group 10	3	4	13-18	Residential special school
Group 11	2		13-14	Support youth group for disabled young people
Interview 1	1		22	Community Café
Interview 2	1		21	Care experienced young person who identified as disabled
Interview 3	1		22	Care experienced young person who identified as disabled
Interview 4	1		24	Care experienced young person who identified as disabled
Interview 5	1		23	Care experienced young person who identified as disabled
TOTAL	51	50	11-24	

Analysis of focus groups and interviews

Recordings from the focus groups or interviews were either transcribed in full by a transcription company, or written up by researchers from CCo, depending on the timing of the focus groups.

One CCo researcher conducted thematic analysis of the notes, which included familiarisation with the qualitative data, noting down ‘codes’ (i.e. labels assigned to pieces of text to identify and summarise important concepts), and generating themes. The first section of findings, ‘Talking about transitions’, is structured along the themes CCo identified.

The Disability Unit was also interested specifically in the experiences of disabled young people who are also young carers or care experienced. We draw on the focus groups and interviews with these groups throughout the report, but their specific experiences are documented in the second and third sections of findings.

Analysis of a nationally representative survey of children and parents in England

The CCo commissioned Opinium to conduct a nationally representative survey of 3,593 children aged between 8 and 17 years old and their parents in March 2023. The total sample size includes additional boost samples of single parent households, ethnic minority households and households with children receiving free school meals. Parents reported that 18% of children had SEND, 80% did not, and 2% did not know.

The survey used a custom accessible theme and was designed to take respondents less than 15 minutes to complete. The survey was in two parts; the first section was completed by a parent or carer, the parent was then asked to hand the survey over to their child aged between 8 and 17 years old, though some questions were only shown to older children. We asked parents to pick one child, if they had more than one. The survey findings have been weighted to be nationally representative by the child’s age and gender, and the geographic region of the household.

Table 3. Overview of sample demographics, including age, gender and ethnic group and household region at the time of the survey.

Demographic variable	Unweighted count	Weighted count	Weighted % of sample	National population*
Age group				
8-11	1,507	1,471	41%	41%
12-15	1,096	1,084	30%	40%
16-17	990	1,038	29%	19%
Gender				
Female	1,761	1,789	50%	51%
Male	1,821	1,789	50%	49%
Region				
East Midlands	334	305	8%	9%
East of England	315	405	11%	11%
London	510	562	16%	16%
North East	168	162	5%	5%
North West	498	477	13%	13%
South East	621	597	17%	16%
South West	332	337	9%	10%
West Midlands	416	396	11%	11%
Yorkshire & The Humber	399	351	10%	10%
Ethnic group				
Asian background	285	286	8%	9%
Black background	161	164	5%	4%
Mixed/multiple ethnic	128	131	4%	3%
White	2,989	2,980	83%	82%
Other ethnicities	22	23	1%	2%
I don’t know/ Prefer not to say	8	8	<1%	-
Total sample	**3,593**	**3,593**	**-**	**-**

*National population estimates for age, gender and region are calculated using the Overview of the UK population – Office for National Statistics (ons.gov.uk) and ethnicity is calculated using the 2021 UK Census.

Thematic review of Help at Hand cases involving children with disabilities

Demographic breakdowns

Gender

For young people without disabilities, a similar proportion of boys and girls contacted Help at Hand in 2022-23 (Table 4). For those with disabilities, boys were more likely to contact the service than girls (46% compared to 28%). This is likely due to how certain special educational needs, mental health conditions and disabilities are more commonly identified in boys. According to Department for Education (DfE) statistics, 73% of all pupils on EHCPs and 64% of pupils with SEN support were boys in 2021/22.[41]

Table 4 - Gender breakdown of contacts to Help at Hand by disability status, 2022-23

Gender	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
Male	93	46%	166	31%
Female	58	28%	172	32%
Unspecified/multiple	53	26%	201	37%
Total	**204**	**100%**	**539**	**100%**

Age

In the minority of cases where the ages of the young people in contact with Help at Hand were recorded, over half were aged 12 to 17 (60% of children with disabilities) and 17% were care leavers above age 18.

Table 5 - Age breakdown of contacts to Help at Hand by disability status, 2022-23

Age group	Number of young people with a disability	% of young people with a disability*	Number of young people with no disabilities	% of young people with no disabilities
0 to 5	10	7%	18	6%
6 to 11	22	16%	27	9%
12 to 15	53	39%	86	30%
16 to 17	29	21%	77	27%
18 and above	23	17%	77	27%
Total	**204**	**100%**	**539**	**100%**

**Percentage calculation excludes cases where age was left unspecified or unknown.*

Setting

Most children with disabilities in contact with Help at Hand (if residential setting was recorded) resided with a parent (29%), in a children's home (18%) or in foster care (14%) – the same top 3 settings as those without disabilities (excluding "other" and "unspecified").

Children with disabilities were twice as likely to live with a parent (29% compared to 15%). This is likely because social services were involved because of their disability (rather than due to concerns about abuse, for example) and the involvement of social services makes a child eligible for the service.

Table 6 - Breakdown of contacts to Help at Hand by children with disabilities by residential setting, 2022-23

Setting	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
With a parent	60	29%	80	15%
Children's home	36	18%	64	12%
Foster care	28	14%	74	14%
Hospital	8	4%	14	3%
Supported accommodation	7	3%	14	3%
Independent living	5	2%	28	5%
Other	21	10%	87	16%
Unspecified	39	19%	159	29%
Total	**204**	**100%**	**539**	**100%**

Legal status

Where recorded, the most common legal statuses that children with disabilities in contact with Help at Hand had were: Care Order; Child in Need; no status; care leaver – former relevant; and have an order under Section 20 of the Children Act.

Children and young people with disabilities who contact Help at Hand were more likely than those without to have a care order (25% vs. 22% of those without disabilities) and to be a child in need (13% vs. 7% without disabilities)

Table 7 - Most common legal statuses of children with disabilities in contact with Help at Hand, 2022-23

Legal status	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
Care Order	52	25%	121	22%
Child in Need (CIN)	27	13%	36	7%
No status	28	14%	79	15%
Care Leaver: Former Relevant	16	8%	81	15%
Section 20 (S20)	14	7%	21	4%
Looked after child (LAC) unspecified	14	7%	53	10%
Child Protection (CP)	7	3%	10	2%
Other	14	7%	26	5%
Unspecified	31	15%	93	17%
Total	**204**	**100%**	**539**	**100%**

**Legal status with fewer than 5 children have not been report for statistical disclosure control purposes.*

Main issues raised

Children with special needs and disabilities contact Help at Hand for many reasons. In 2022-23, Help at Hand received contacts regarding nineteen different topics, plus one ‘other’ category, from children, both with disabilities and without. The most common issues (28%) relate to education such as being out of school or needing advice on Education, Health and Care (EHC) plans. This is followed by child in care support (14%), complaints (8%) and disability support issues (7%) (Table 8).

A qualitative review of case notes shows that children with disabilities often struggle with accessing education, finding suitable placements, and support for staying at home. Many children with disabilities in contact with Help at Hand have difficulties attending school, often due to lack of infrastructure and support services for SEND pupils (e.g. wheelchair ramps, lifts, sensory rooms, hydro/physiotherapy sessions, fidget toys, weighted blankets) and problems with their EHCP plans not being followed.

Some cases reveal that there is an insufficient supply of homes for children in care who have very challenging behaviour and high needs, especially when this overlaps with learning difficulties and mental health conditions. In cases where the child lives at home, there is a lack of support for helping families better manage disability, such as short breaks and other adaptations including home infrastructure and hiring carers to help with household duties and/or take the children out (to school, play or otherwise).

Most issues were raised by family and friends (42%), and professionals (38%). Only in 12% of cases was the issue raised by the young person with disabilities, compared to 25% of children without disabilities. This may be due to how disability affects children and young people's ability to seek support for themselves.

Furthermore, young people open to social services but who are not in care do not have the same entitlements to statutory advocacy that children in care do. As a result, they may not be able seek the assistance of advocates, causing family members to contact Help at Hand, a service that is open to children who have a social worker but are not in care.

Table 8 - Top 10 issues raised with Help at Hand by children with disabilities, 2022-23

Presenting issue	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
Child in care support	29	14%	66	12%
Education - out of school	29	14%	17	3%
Complaints	16	8%	62	12%
Education – EHCP	16	8%	*	*
Disability support issues	14	7%	5	1%
Education- other	13	6%	17	3%
Housing/accommodation	12	6%	50	9%
Local authority support	12	6%	20	4%
Care leaver support	10	5%	46	9%
Safeguarding	10	5%	53	10%
Other	34	13%	182	34%
Unspecified	9	4%	10	2%
Total	**204**	**100%**	**539**	**100%**

Note: In some cases, a child may have more than one issue. For example, a child who has an issue with a EHCP and is also out of school. Only the primary presenting issue is included above.

The case study below illustrates an example of a case involving ‘support for a child in care’.

‘Maddie’ is 6 years old and has autism. She has been in care for several years and had been in her current foster placement for a year when she accessed advocacy. Maddie’s foster carer asked for an uplift in her fee on the basis of Maddie’s disability. The social work team then said they wished to move Maddie to a different placement. This placement was with a single carer who worked full time, was out of area, would necessitate a school move and there were real concerns it would not meet her needs. A referral was made for an advocate. The advocate was from the charity commissioned by Maddie’s local authority. Maddie is verbal but due to her disability and age she worked with an advocate on a semi non instructed basis. The advocate met with Maddie who was clear she wanted to stay where she was. The advocate also obtained the views of those close to her, including her birth family and current carers. The advocate challenged the move. The advocate also escalated concerns to the Children’s Commissioner’s Office and instructed a solicitor on Maddie’s behalf. As a result, the local authority employed a clinical psychologist to review the care plan. The decision to move Maddie was reversed and she remained at home.

Actions taken and outcomes

Actions and representations made

It is a requirement that all children in need, whether in care or not, have a clear plan of how a local authority will best look after them and outline the individuals responsible for the welfare of the young person. However, this does not happen every time, as recent CCo reports on school attendance[42] and SEND[43] have highlighted. In some cases, children with disabilities are not provided with accessible accommodation and/or schooling. In other cases, young people have issues with local authorities and schools failing to ensure that their Education, Health and Care Plans (EHCP) are followed.

Help at Hand can assist children, with or without disabilities, in situations where they are not receiving the support they are entitled to. In such situations, advice and advocacy services such as Help at Hand can intervene and make representations to relevant organisations to support those in care or in need. Besides local authorities, other organisations that Help at Hand has contacted on behalf of children with disabilities include the NHS, other advocacy services, Ofsted, accommodation providers and support services (e.g. care agencies and therapists) if needed.

The following case study illustrates an example of Help at Hand contacting local authorities directly to support a child with severe disabilities and mobility issues:

'Henry' is a care leaver with profound disabilities, meaning he is blind, non- verbal and uses a wheelchair. However, he is able to communicate with specialist support from his school, independent advocate, and a computer aid. He lived with long-term foster carers for many years and was very happy. As he approached 18, the plan was for him to remain with them, either via a Staying Put arrangement (funded by Children's Services) or a Shared Lives agreement (funded by the Adult Social Care team). However, a lack of communication between services, confusion about the best arrangement, and disagreements over funding meant that nothing was in place by the time he reached 18. The plan was then changed to propose that Henry moved into a residential care home, away from his foster family. His advocate contacted Help at Hand for support and the team wrote to the Leaving Care Service and the Adult Social Care team, asking them to work together to do what was in Henry's best interests. His wishes and feelings were presented by his specialist school teachers, foster carers and advocate at the subsequent planning meetings, and the services were ultimately able to work together and agree funding for him to stay with his foster family in the long-term

In some cases, representations were not needed or not recorded. Where the Help at Hand team did make representations, the vast majority (85%) made in cases involving children with disabilities were to local authorities.

Help at Hand log data splits local authority contacts into relevant teams, including senior management, multi-agency safeguarding hubs, SEN management, and social workers.

Where representations were needed, Local authority social work teams were the most commonly contacted (45% of cases involving children with disabilities compared to 41% of cases involving the non-disabled).

A slightly higher proportion of cases involving children with disabilities involved making representations to local authority senior management (10% compared to 5% cases relating to children without disabilities) and SEND teams (6% compared to no cases relating to children without disabilities).

Outcomes

For both children with disabilities and those without, a substantial percentage (29%-39%) of Help at Hand cases were simple information requests where someone contacted the helpline with a question or request for available or online resources. These are not considered cases that need to be resolved.

Focusing on cases where the Help at Hand team had to get involved, make representations and/or advocate for children, the majority of cases (81%) were resolved or partly resolved. Over half were wholly resolved (52%), and 29% partly. Only 19% of cases relating to children with disabilities were unresolved.

Among the 19%, in cases where a reason why was noted, lack of engagement from other relevant parties was the most common reason (44% of cases) – the same as in cases representing children without disabilities. In these cases, "lack of engagement" usually refers to when the child or young person stops communicating with Help at Hand.

Other reasons why a case might be unresolved include representations made had no impact (24% of cases of children with disabilities and 10% of case of children without disabilities), the child's case was out of remit (18% cases for children with disabilities and 25% of cases for those who are not) and having insufficient information to proceed (15% cases for children with disabilities and 17% of cases for children without disabilities).

Table 9 - Breakdown of contacts to Help at Hand relating to children with disabilities by outcome, 2022-23

Outcome	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
Information only	59	29%	209	39%
Partially resolved	37	18%	87	16%
Resolved	67	33%	156	29%
Unresolved	24	12%	80	15%
Unspecified	17	8%	7	1%
Total	**204**	**100%**	**539**	**100%**

Risk ratings

Most cases (71%) received by Help at Hand from children with disabilities were categorised as low to medium risk. These include cases in which only advice was shared and/or a non-urgent representation was made to an organisation. A further 8% were unassigned a risk rating, often because they were considered low risk by the Help at Hand team. Only 10% of cases were considered complex or urgent. These cases often involved children with severe disabilities, safeguarding concerns, violent outbursts, mental health deterioration and unwanted changes to foster care placement, among other topics.

Table 10 - Breakdown of contacts to Help at Hand relating to children with disabilities by risk rating, 2022-23

Risk rating	Number of cases with a disability	% of cases with a disability	Number of cases with no disabilities	% of cases with no disabilities
Complex/Urgent	21	10%	61	11%
Low	100	49%	340	63%
Medium	66	32%	123	23%
Unspecified	17	8%	15	3%
Total	**204**	**100%**	**539**	**100%**

** Note: Percentage totals may not add up to 100% due to rounding.*

Findings from The Big Ask by SEN status and other characteristics

Quantitative findings

Interaction of different characteristics

In The Big Ask, children with SEN were more likely to be boys (48%) compared to children without SEN (43%) and more likely to be in a White ethnic group (74%) than children without SEN (70%). Gender was not reported or other for 6% of children with SEN and 5% of children without SEN. Children with SEN were slightly more likely than children without SEN to be attending a school in the most deprived fifth of neighbourhoods (18% vs 15%).

Children with SEN were more likely to have certain vulnerabilities than children without SEN:

- Children with SEN were more likely to have a social worker than children without SEN (8% vs 2%).
- Children with SEN were more likely to be in foster care than children without SEN (1.5% vs 0.6%).
- Children with SEN were more likely to be a young carer than children without SEN (3% vs 1%).

We analysed children's answers to four questions, according to six characteristics in addition to having SEN: gender, ethnic group, deprivation score of school, and whether the child had a social worker, was in foster care, or was a young carer. Some of these made no difference when examined alongside SEN status. That is, they did not add to or subtract from the overall impact of SEN status and the other characteristic when analysed separately. For some characteristics and questions, however, there was an interaction (table 11).

Table 11: Interactions between SEN and other characteristics

	Unhappy with personal safety (SEN children more unhappy)	**Education as a future priority** (more prioritised by SEN children)	**Education as a future worry** (SEN children more worried)	**Whether life will be better than parents** (SEN children more pessimistic)
Gender male	Not statistically significant at 0.01 level	Girls prioritise more if they have SEN, but a smaller gap for boys	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level
Ethnic group	Black and Mixed SEN children more unhappy	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level
Most deprived 20% of areas	Not statistically significant at 0.01 level	Smaller SEN/non SEN gap than if comparing SEN/non SEN in less deprived areas	Not statistically significant at 0.01 level	Most and least deprived children with SEN more pessimistic
Social worker	SEN children with a social worker less unhappy	SEN children without a social worker more likely to prioritise	SEN children without a social worker more likely to worry	Not statistically significant at 0.01 level
In foster care	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level	SEN children not in foster care more likely to worry	More pessimism if not in care
Young carer	SEN children who were not young carers more unhappy	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level	Not statistically significant at 0.01 level

Differences in happiness with aspects of life by SEN

Across most aspects of their lives, children with SEN were just as happy as children overall. Across all aspects of life asked about in The Big Ask, the largest relative difference between children with SEN and children without SEN was in the share of children unhappy with their personal safety.[44] Children with

SEN were slightly more likely to be unhappy with their personal safety than children without SEN (6% vs 4%).

Differences in happiness with personal safety

Girls, children in Black ethnic groups, with a social worker, in foster care, children who were young carers and children in more deprived neighbourhoods were also slightly more likely to be unhappy with their personal safety:

- 5% of girls were unhappy with their personal safety, compared to 3% of boys.
- 5% of children in Black ethnic groups were unhappy with their personal safety, compared to 4% of children in White ethnic groups.
- 9% of young carers were unhappy with their personal safety, compared to 5% of children who weren't young carers.
- 9% of children with a social worker were unhappy with their personal safety, compared to 4% of children without a social worker.
- 8% of children in foster care were unhappy with their personal safety, compared to 4% of children not in foster care.
- 5% of children in the tenth most deprived neighbourhoods were unhappy with their personal safety, compared to 4% of children in the tenth least deprived neighbourhoods.

Unhappiness with personal safety and the interaction effect between SEN and other characteristics

There is a statistically significant interaction effect between SEN and whether a child was a young carer, between SEN and whether the child had a social worker and between SEN and aggregated ethnic group (see table A1, A2 and A3 in Annex B). This means that the differences between children with SEN and children without SEN vary depending on these other characteristics. In particular:

- Among young carers, the same share of children with SEN were unhappy with their personal safety (9%) as children without SEN (9%) whereas among children who were not young carers, children with SEN were more likely to be unhappy with their personal safety (6%) than children without SEN (4%).

- Among children with a social worker, children with SEN were less likely to be unhappy with their personal safety (8%), compared to children without SEN (9%), whereas among children without a social worker, children with SEN were more likely to be unhappy with their personal safety (6%) than children without SEN (4%).
- Among children in the Black ethnic group and Mixed ethnic group, 9% of children with SEN were unhappy with their personal safety, compared to 5% of children without SEN. There were smaller differences (2 to 3 percentage points) between children with SEN and without SEN in the White ethnic groups, Other ethnic groups, and Asian ethnic groups.

There is no statistically significant interaction effect between SEN and the child's gender, whether they were in foster care or their school's IDACI quintile. This means the difference between children with SEN and children without SEN did not change depending on these characteristics.

Differences in future priorities by SEN

Children in The Big Ask were asked to select up to five priorities. The top two priorities were the same for children with SEN and without SEN: 'A good job or career' and 'Enough money to buy the things I need'. The largest absolute difference between children with SEN and without SEN was in the share of children who chose 'having a good education'. Across the share of children choosing each priority, this was the largest absolute difference and second largest relative difference between children with SEN and children without SEN.[45] The largest *relative* difference was in the share of children who chose 'being part of a good local community' as a top priority (6% for children with SEN and 5% for children without SEN). Children with SEN were more likely to choose 'Having a good education' as a top priority than children without SEN (58% vs 51%).

Differences in choosing education as a future priority

Boys, children in Asian ethnic groups, children with a social worker, children who were young carers and children in more deprived neighbourhoods were also more likely to select 'Having a good education':

- 55% of boys chose 'having a good education' as a top priority compared to 50% of girls.
- 63% of children in Asian ethnic groups chose 'having a good education' as a top priority compared to 59% of children in Black ethnic groups, 58% of children in Other ethnic groups, 54% of children in Mixed ethnic groups and 49% of children in White ethnic groups.
- 58% of young carers chose 'having a good education' as a top priority compared to 52% of children who weren't young carers.
- 58% of children with a social worker chose 'having a good education' as a top priority, compared to 52% of children without a social worker.
- 57% of children in the tenth most deprived neighbourhoods chose 'having a good education' as a top priority compared to 49% of children in the least tenth deprived neighbourhoods.

Education as a future priority and the interaction effect between SEN and other characteristics

There is a statistically significant interaction effect between SEN and gender, between SEN and whether the child had a social worker, and between SEN and IDACI quintile (see tables A4, A5 and A6). This means that the differences between children with SEN and children without SEN vary depending on these characteristics. In particular:

- Gender: there was a particularly large difference in the share of girls who chose 'having a good education' between girls with SEN and girls without SEN (58% vs 49%) while among boys there was a smaller difference (60% vs 54%).
- Among children without a social worker, there was a particularly large difference in the share of children who chose 'having a good education' between children with SEN and children without SEN (58% vs 51%) while among children with a social worker, there was a smaller difference (60% vs 56%).
- Among children in the least deprived neighbourhoods, there was a larger difference in the share of children who chose 'having a good education' as a top priority between children with SEN (57%) and children without SEN (48%) than among children in the most deprived neighbourhoods, where 62% of children with SEN chose education as a top priority compared to 56% of children without SEN.

There is no statistically significant interaction effect between SEN and the child's ethnic group, whether they were in foster care or whether they were a young carer. This means the difference between children with SEN and children without SEN does not change depending on these characteristics.

Differences in future worries by SEN

Children in The Big Ask were asked to select up to five future worries. The future worries chosen were similar for children with SEN and without SEN. The biggest difference between children with SEN and without SEN was in the share of children who chose 'having a good education'.[46] More children with SEN were worried about having a good education (22% for children with SEN vs 17% for children without SEN).

Differences in choosing education as a future worry

Children in Other ethnic groups, children who had a social worker, children who were in foster care, children who were young carers and children in more deprived neighbourhoods were also more likely to select 'Having a good education' as a top worry:

- 24% of children in an Other ethnic group chose 'Having a good education' as a top worry compared to 19% of children in an Asian ethnic group, 19% of children in a Black ethnic group, 18% of children in a Mixed ethnic group, and 17% of children in a White ethnic group.
- 26% of children with a social worker chose 'having a good education' as a top worry compared to 18% of children without a social worker.
- 25% of children in foster care chose 'having a good education' as a top worry compared to 18% of children without a social worker.
- 27% of young carers chose 'having a good education' as a top worry compared to 18% of children who weren't young carers.
- Children in the most deprived tenth of neighbourhoods were more likely to be worried about having a good education than children in the least deprived tenth of neighbourhoods (21% vs 14%).

Education as a future worry and the interaction effect between SEN and other characteristics

There is a statistically significant interaction effect between SEN and whether the child was in foster care and between SEN and whether they had a social worker (see table A8 and A9). This means, the differences between children with SEN and children without SEN vary depending on these characteristics:

- Among children in foster care, children with SEN and children without SEN were equally likely to worry about their future education (24%). However, among children not in foster care, children with SEN were more likely to worry about their future education than children without SEN (22% vs 17%).
- Similarly, among children with a social worker, children with SEN and children without SEN were almost equally likely to worry about their future education (25% and 26%), whereas among children without a social worker, children with SEN were more likely to worry about their future education (21%) than children without SEN (17%).

There is no statistically significant interaction effect between SEN and the child's ethnic group, gender, whether they were a young carer and their IDACI quintile. This means the difference between children with SEN and children without SEN does not vary depending on these characteristics.

Differences in whether life will be better than parents by SEN

Children in The Big Ask were asked "When you grow up, how likely do you think it is that you will have a better life than your parents?".[47] While the same share of children with SEN and without SEN said it's likely they will have a better life, a slightly higher share of children with SEN said that it's unlikely they will have a better life compared to children without SEN (11% vs 9%). A slightly lower share of children with SEN were neutral about whether they would have a better life than their parents (37%) than children without SEN (39%).

Differences in whether life will be better than parents

Children in White ethnic groups, children who had a social worker, children who were in foster care, children who were young carers and children in least deprived neighbourhoods were also more likely to be pessimistic about their life chances compared to their parents:

- 10% of children from White ethnic groups said it was unlikely they will have a better life than their parents, compared to 9% of children from Other ethnic groups, 8% of children from Mixed ethnic groups, 6% of children from Asian ethnic groups and 6% of children from Black ethnic groups.
- A higher share of children with a social worker said it was unlikely they will have a better life than their parents than children without a social worker (12% vs 9%).
- A slightly higher share of children in care say it's unlikely they will have a better life than their parents than children without a social worker (14% vs 9%).
- A slightly higher share of young carers said it was unlikely they will have a better life than their parents than children who were not young carers (13% vs 9%).
- 10% of children from the least deprived neighbourhoods said it was unlikely they will have a better life than their parents compared to 8% of children from the most deprived neighbourhoods.

Unlikely to have a better life than their parents and the interaction effect between SEN and other characteristics

There is a statistically significant interaction effect between SEN and whether the child was in foster care and between SEN and IDACI quintile (see table A9 and A10). This means, the differences between children with SEN and children without SEN vary depending on whether the child is in foster care and the deprivation level of their school neighbourhood.

Among children in care, a lower share of children with SEN (11%) said it was unlikely they will have a better life than their parents than children without SEN (13%), whereas among children not in care, a higher share of children with SEN (11%) said it was unlikely they will have a better life than their parents than children without SEN (9%).

In all quintiles of neighbourhoods, children with SEN were more likely to say it was unlikely they would have a better life than their parents. Among children in the most deprived fifth of neighbourhoods and the least deprived fifth of neighbourhoods, there was a 3 percentage point difference in the share of children who said it was unlikely they would have a better life than their parents. Among children in neighbourhoods in the middle of IDACI distribution (second, third or fourth quintile), there was a smaller 1-2 percentage point difference in the share of children who said it was unlikely they would have a better life than their parents'.

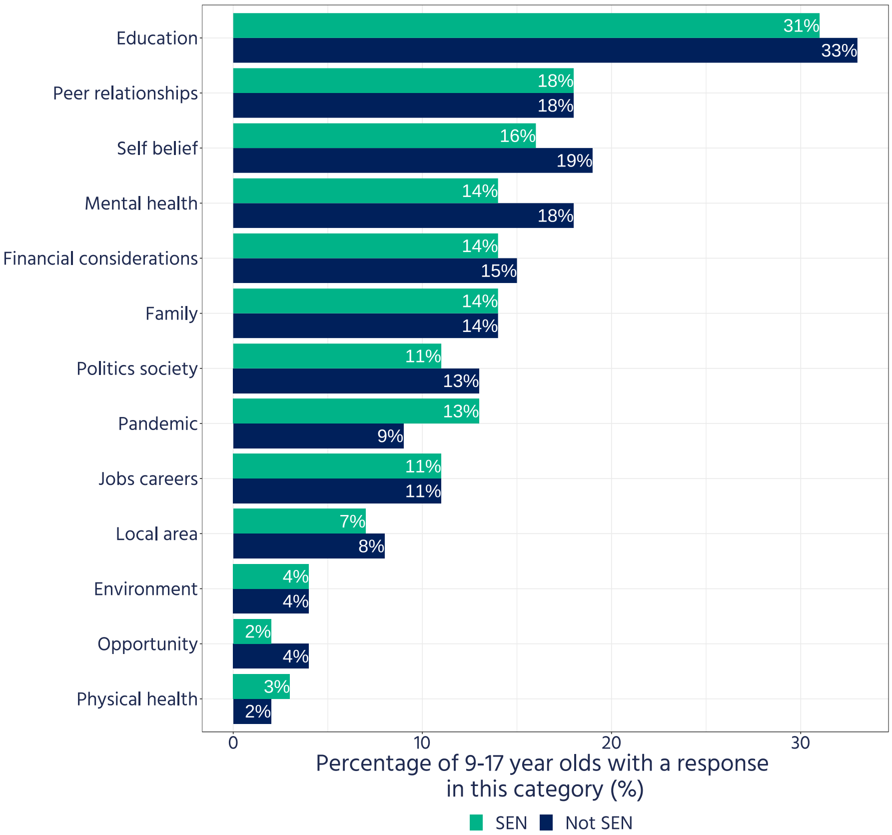
There is no statistically significant interaction effect between SEN and the child's ethnic group, gender, whether they had a social worker or whether they were a young carer. This means the difference between children with SEN and children without SEN does not change depending on these characteristics.

Qualitative findings

Differences in perceived barriers to success for children with SEN and without SEN

Children with SEN and children without SEN were asked a question about the barriers to success. In response 27,000 children with SEN and 224,000 children without SEN wrote answers. The topics raised were very similar. Both groups were most likely to discuss education, peer relationships, and self-belief. Children with SEN were more likely to bring up the pandemic (13%) compared to children without SEN (9%) and less likely to bring up mental health (14%) compared to children without SEN (18%). See Table A11 for a full list of the terms we searched for among the written answers, and categorised into these topics.

Figure 2 – Topics raised by children with and without SEN



n=27286 for children with SEN and n=223626 for children without SEN

Specific barriers related to disabilities

Findings from this section are drawn from *Findings from The Big Ask on Special Educational Needs and Disabilities*.[48]

Over a thousand children with and without SEN mentioned disability as a potential barrier to achieving success in adulthood. These children raised concerns around preparing for the future, accessibility of public spaces, discrimination and bullying and challenges in education.

Preparing for the future

Some children with disabilities mentioned concerns about being prepared for the future and succeeding with their education.

'*Children with disabilities are not prepared for the future as they should. They are not taught the skills that they really need to achieve in live after. Social skills, self help, managing emotions and travel training are introduced too late. […] We need individual tailored curriculums and people who believe in us*' – Boy, 15, The Big Ask.

'*I have been under the hospital for all my life going through lengthy operations with time healing wounds to medication I have to stay on for the rest of my life and it scares me that I have missed out on so much of my school life. […] I am terrified I cannot get the job of my dreams, working with animals. [..] I hope I can achieve my own*' – Girl, 16, The Big Ask.

'*I have Crohn's disease so that has cut me off from a lot of things. Seeing my friends, doing physical stuff and much more. I don't like thinking about the past or future, it scares me quite a bit. I don't think I'm doing very well in school and I'm not sure if I'll catch up like everyone else. […] I also don't know what I want to achieve in the future, it's all messed up in my head*' – Girl, 12, The Big Ask.

Accessibility

The accessibility of public spaces, particularly for children in wheelchairs or with mobility difficulties was mentioned as a barrier by older children and as something younger children would change to make their lives better:

'*I am in a wheelchair and there is nothing for me in my area. I can't make friends, I can't even get into most places*' – Boy, 14, The Big Ask.

'*More accessible playgrounds, wheelchair accessibility areas. No barriers for wheelchair users and disabled people. Support to get me where I need to be*' – Boy, 6, The Big Ask.

'*More places that are wheelchair accessible. There are so many places I can't go to because there are no toilets for me (proper changing places with hoists)*' – Girl, 8, The Big Ask.

For one girl, even getting around at home could be a challenge:

'I would like a bigger house so I can move around better in my wheelchair' – Girl, 7, The Big Ask.

Physical accessibility includes accessible lifts, doors, changing places and toilets, transport, parking, shops, play and leisure facilities, venues and safe places to cross roads.[49]

But accessibility should not be understood only in terms of physical barriers. It can mean a warm welcome, willingness to be flexible, or a quiet place to go if things get too much.[50] How teachers understand and respond to a child with autism, for example, will be important to whether they can access their education fully.[51] It may not be helpful to consider accessibility issues from a disability frame. This is because research has found adults with autism consider themselves 'different' or 'neurodiverse', rather than the more stigmatised 'disordered'.[52]

Equality, discrimination & bullying

Similarly to being able to access public spaces, children with disabilities talked about wanting to be treated equally and not be judged on the basis of their disability.

'*Physical access to things and people judging me and thinking I can't do something before they know me. I'm in a wheelchair but my head is perfect'* - Girl, 11, The Big Ask.

'I have a disability - downs syndrome. I am afraid I am not going to be treated fairly - whether this means getting a good job, being able to stay on my own, or being part of the community. If the community and the wider world aren't aware of my disabilities, and what I can achieve, I won't be even be given a chance to prove what I can achieve' - Girl, 17, The Big Ask.

For one girl, the main thing she would change to make her life better would be to simply have friends and to not be bullied for her disability:

'To have friends I have no one to help me I get bullied cuz I have a bad genetic disease and cancer I'm bald and they make fun of me they call me minion and that makes me sad' – Girl, 8, The Big Ask.

Children discussed discrimination as a barrier to jobs in the future:

'*Discrimination on people with disabilities both physically and mentally, makes children feel unsuccessful and like they can't do top jobs, which stops them reaching further. Disability shouldn't be a barrier for entry to things'* – Girl, 16, The Big Ask.

'*Not supporting those with special needs, and their families […] it's not easy to get a job that you want and the life you want. If you have a disability, it's much harder'* – Girl, 11, The Big Ask.

Challenges in education

Many children with SEN were quite vocal about challenges they had experienced in education. These children wanted teachers to have more training to equip them with learning materials and teaching approaches that would work for them. They also wanted easier routes to diagnosis within school, easier access to treatment, and more awareness within school of different types of SEND.

'*I am dyslexic and I don't feel there is enough support and resources in school to help me. Teachers are not trained in dyslexia so it takes a long time to be diagnosed so you just feel stupid for a long time which makes you unhappy'* – Girl, 12, The Big Ask.

'*Our current education system is not suited to… those with ADD, ADHD and autism. Teachers aren't educated in the teaching styles that are appropriate, or don't care enough to implement the techniques to help students'* – Girl, 16, The Big Ask.

'*Not enough mental health help or educated teachers in noticing students who may have issues. In my case, I was recently diagnosed with ADHD at 17 and for the whole of lower school only 2 teachers listened when I was frustrated'* – Girl, 17, The Big Ask.

For children who were home educated or were not in any education, the most consistently mentioned barrier was the lack of support for SEND. This included access to timely diagnoses, support from the school and teachers and lack of suitable adjustments or provisions to meet their needs, resulting in them not being able to participate in mainstream education.

'*There aren't enough school places for young people with SEN. Mainstream school is really hard to cope with. I have been out of school for a very long time, and I don't see friends, it can be really lonely. I don't* *think people always understand autism and it's hard to fit in. I need an education so I can get a good job, but I am stuck because there is no school where I fit in'* – Girl, 16, not in education, The Big Ask.

'*I have never had the help I need my education has been non-existent and I now live I care because my family didn't get help to care for me. I have Tourette's syndrome and I am isolated with no friends. I spend my whole time with adults'* – Girl, 17, not in education, The Big Ask.

Many children with SEN talked about how hard their parents had to work to secure support for them in school.

'*I'm autistic and they didn't help me at school. Even after my parents got an EHCP they still didn't help me. […] My mum and dad spent a lot of money for me to see therapists to help me. School didn't do any of that. I'm worried for people like my brother because he has severe learning disabilities and my mum and dad are always trying to get him the right help but they don't help. I'm scared for him because I know they put people like him in special prisons called ATUs […] It's not fair and I want to tell Mr Johnson to help people like us'* – Girl, 13, The Big Ask.

'*My mum is trying to get me support for my bad anxiety attacks and ADHD but everyone she contacts tells her to contact another place and she is going round in circles. School makes me so anxious because I can't learn as quickly as everyone else and I struggle with my concentration'* – Boy, 12, The Big Ask.

'*I have autism and I struggle with school, I want to do well but the system doesn't work for me and I have been excluded 4 times due to my condition. I wish it was easier to go to a school that I liked but mum and dad are very sad that they have to work hard to fill forms in and fight to get me what I need'* – Boy, 10, The Big Ask.

'*I was not given a language system until I was 9 and so I had no way of communicating even my most basic needs. […] It also meant I could not make friends and didn't have a single friend. I was hurt by other children. My mum had to do a lot of work to get me the help I need. She had to give up her job to support me […] since she did all of things she managed to get me into a different independent special school'* – Boy, 13, attending a school for deaf children, The Big Ask.

Findings from focus groups and interviews with disabled young people

Participants had different reactions to the term 'disabled'. One boy did not like the expression and said he thinks of himself as having a special need, not a disability. He preferred not to be voice recorded, which might have been due to him feeling unsure about whether he should take part in the research or not. The CCo is not aware of research investigating what percentage of children say they identify as disabled. Other qualitative research has found ambivalence among children with disabilities about the use of the category of 'disabled' to describe themselves.[53]

Children may be defined as disabled under the Equality Act 2010 definition without necessarily self-identifying as such. In the 2021 census of England, 6% of children aged 0 to 14 (590,908) were limited a little or a lot in their day-to-day activities by long-term physical or mental health conditions or illnesses.**54**

Higher proportions are assessed as having mental health problems when using a standardised measure, rather than when asking young people to self-identify: as of 2022 in England, the NHS estimated that 18% of children aged 7 to 16 years and 26% of those aged 17 to 19 had a probable mental health disorder.[55]

A larger number had a plan or support provided in their school or nursery for their special educational needs or disabilities. In academic year 2021/22, 1,485,409 children and young people had either a EHCP or SEN support: 16.6%.[56] The minority, 355,566, had a Education, Health and Care plan due to their special educational needs or disabilities (4.0%),[57] a larger number were receiving SEN support without having a EHCP (1,129,843 or 12.6%).[58] In contrast to many adults, children generally experience good health. In the 2021 census, 97% of children in England aged 0 to 14 were in good or very good health.[59]

Talking about transitions

There are life transitions unique to children, like starting school, moving from primary to secondary school, and entering adulthood. For some children with health conditions and disabilities, transitions may be delayed or different from the mainstream experience of most children. There are also transitions, such as the onset of a disability, or moving between mainstream and special education, that are unique to children with disabilities.

Changes relating to school and education

The first topic we spoke about with children and young people in most cases was education, and changes they had experienced during their education. Children mentioned different issues around the wider topic of changes.

Support at school

Children really valued support at school. At one independent special school, children generally felt well supported and were fond of their teachers. The teacher of one of the groups received very positive feedback; the young people regarded them as a friend. One boy said:

'I like that I can tell teachers about my family and issues' - Boy, 15.

However, children at mainstream schools often felt misunderstood and talked about the need for more teacher training. We heard that some children have to wait in mainstream schools until places became available in special schools.

One parent contrasted the experiences of her two sons, one in mainstream education and the other in a special school:

'I think people with disabilities are so, they're underestimated. And it goes back to the whole, being uneducated. I think education on disabilities should be a big thing because […] my other son, being in mainstream school, he has been advocating for himself. And he has taught a lot of people about his condition and opened up a lot of education himself just by being in mainstream school. He's, they're never going to learn that in school. They get that from being around him and getting to know him, and people with disabilities, the government are seeming to listen, but they're not acting on anything that's being said to them. And they make it so hard for people with disabilities to just have, be accepted in society' - Mother of 2 children with disabilities.

About 9 in 10 children with SEND are educated in mainstream settings, and 1 in 10 in specialist (special) schools.[60] In academic year 2021/22, 146,000 children attended special schools (either state-funded, or non-maintained).[61] On average, children with disabilities and special educational needs fall behind academically at school and achieve fewer qualifications.62

We asked children at the independent special school we visited what their ideal school would look like. Among other things, they said they would value longer breaks and more sensory toys. For full details see the box below. One 13-year-old girl suggested learning sign language in school.

We were told by professionals and parents that some families of children with high-need, low prevalence disabilities such as vision impairment chose residential special schools to ensure their child receives the best education possible. The move from mainstream to special schools can therefore also represent a transition in children with disabilities' lives. While the schools were able to provide quality specialist education, they are often far from the child's home and friends, which can be difficult.

'Families approach this separation with a great feeling of loss' – Parent of a disabled child.

Support in post 16 education provision

For young people who were currently going to college or had been in the past, experiences were mixed. Some didn't like their experiences at colleges, others did.

'It was quite a negative experience for me. It was just not the right place for me, at college: I think it's just the fact that because I was with people that I didn't know, they didn't understand where I was coming from. So and, at time I don't think I was diagnosed with autism so it was a bit tricky' - Young man, 24.

Students at the onsite college at the residential special school used words such as happy to describe their experiences.

For many children with disabilities, post-16 education including college can present an opportunity to access new and different types of support.

'Many children will go to university and suddenly have access to a lot of technology they have not used before' **-** Professional working with vision impaired children.

Experiences of young people with disabilities at college and at university are likely to differ; a topic beyond the scope of this research. We heard that some specialist colleges offer additional bridging years between GCSE and A levels for to focus on independence skills. This is particularly important for students who had previously attended a mainstream school which may not have been equipped with the same adaptive resources and was unable to provide disabled students with opportunities to work on tasks independently. One professional working in the special education sector gave the example of vision impaired students joining college having never learnt to log on to a computer.

Another professional recounted a teen who was excited to transition to college and *'learn how to be blind.'*

As with schools, we heard that some colleges were better than others at understanding and responding to the needs of disabled young people.

Pressure at school

Previous research based on analysis of the survey Understanding Society has found children in the UK aged 10-15 with a long-term health problem or disability to be statistically significantly less happy with school than their peers.63

Children spoke about the pressures that they experienced at school. One significant theme was balancing studying for exams and taking care of one's health.

'There is lots of pressure on children at Secondary school around GCSEs. It's all they ever talk about – they say things like 'if you don't pass your GCSE's, you'll end up in prison'. There is also pressure on SATs at primary school, but not as much. It's only about what you need to achieve. I don't think it's good for children to be pressured like that' - Girl, 14.

[T]hroughout them five years in high school, I struggled like mad. And especially with going through GCSEs as well, instead of putting my health first, I put education first and now I've started college, I'm getting to the realisation where I'm thinking to myself, I need to put my health first. [...] you have this amount of pressure of having to do them well. But at the end of the day, you should do yourself proud, you should do yourself well, and not anyone else' - Girl, young carer, 17.

Children also reported feeling pressured and rushed at school generally.

'I think my last school was better. There were no teachers hanging around rushing students' - Girl, 15.

'I would change the lunch system so you have more time, longer breaks, more sports, movie time' - Girl, 15.

Some settings use warning systems or 'manage feelings' systems as part of behaviour policies. Children at the Independent Special school mentioned the 5-point system in place, that might not work for everyone. While on the one hand, they noted it shouldn't have to exist in the first place, they also expressed that a warning system put pressure on them and made them feel worried what might happen if they did feel very angry.

Preparing for the future

Children shared some ideas for how schools could better prepare them for the transition to adult life. One girl, for example, mentioned that she would find more practical lessons helpful. This is something that CCo hears frequently from children.

'I think, thinking for the future, more on mortgages and actual life skills, because they teach us a little bit about politics, but they don't ever teach us enough about the real world. [...] And so when we step out into the real world, we rely on our parents to give us the information' - Girl, young carer, 15.

Young people would also find more specific information on employment opportunities, or college courses helpful. One girl mentioned she'd like to learn more about what exact grades she would need for which course.

'I would like there to be better information and support on college courses. Like what are they like? What requirements and qualifications do you need?' - Boy, 17.

'My ideal school would have kind TAs and teach you how to be a role model. It would teach you about life and how to work independently. College is scary and it would be nice to have more support' – Boy, 17.

The independent special school CCo visited had recently made it possible for young people to stay at school a bit longer, so the transition to college was made easier. The young people valued this opportunity.

'*It has a college so I can stay longer until I'm 19. I don't like changing schools'* – Boy, 19.

This was also the case for the residential special school which had a college on site.
As with schools, we heard that some colleges were better than others at understanding and responding to the needs of disabled young people, the young people we spoke to who were currently attending or had previously been to college, experiences were mixed. Some didn't like their experiences at colleges, others did.

'It was quite a negative experience for me. It was just not the right place for me, at college: I think it's just the fact that because I was with people that I didn't know, they didn't understand where I was coming from. So and, at time I don't think I was diagnosed with autism so it was a bit tricky' - Young man, 24.

Previous research has described the transition between the teenage years and adulthood as often very difficult.[64] This was due to becoming ineligible for a range of support services and leisure activities overnight, a sudden lack of the structure and certainty provided by school, and uncertainty and difficulties in finding employment. Sadly, these can result in feelings of purposelessness, isolation or hopelessness.

Bullying

Children also spoke about bullying and discrimination during their time at school. For some children, they experienced more bullying when they moved to secondary school.

'*we're going back years now from primary to high school. I think one thing that hit me most was the fact that I had so much discrimination. And to this point, to this day now, I still do. OK, fair enough, the* *majority of those aren't aware of what you've got wrong with you or how you do everything, but at the same time, what gives them the right to treat you like unfairly and with like no respect?'* - Girl, young carer, 17.

One boy told us that bullying led to him changing schools.

'Well I had friends that were idiots and that's why my parents had me transferred' – Boy, 14.

Accessibility

A variety of factors affect accessibility, including the physical environment but also technological barriers and social factors such as behaviours and policies. One group wanted to speak about accessibility. They felt strongly that inaccessibility of the physical environment had a big impact on their learning.

'I think accessibility is a huge thing that needs sorting out. Because, for example, in my school we've got one lift that's completely broken and it needs fixing, but they've just not got the money to fix it. And there's plenty of, plenty more upstairs classrooms that are inaccessible for some people' - Girl, young carer, 15.

Students at the onsite college at the residential special school felt strongly about the lack of accessible toilets generally. They pointed out that even toilets that are marked as accessible are not. They also pointed out that also the carer would have to use the toilet at some point and there was no safe space for them to wait for their carers. Talking about her experiences of the lack of accessible toilets, one young woman said:

'I can't stand it, it's ridiculous' - Young woman, 22.

Young people who use assistive technology to help them with their disabilities need help to learn how to use and get the most from it. We heard that this support could be patchy, in that some services had better provision, and the support may not extend to training parents and carers in the use of the technology.

'I'm relying on him helping me' – Parent of a vision impaired child.

One professional explained that specialist settings benefit from concentrated resources but also facilitate peer-learning which is particularly important for different types of adaptive technology such as braille machines where parents and teachers cannot be expected to be experts on their functionality.

Activity – Imagine your perfect school - What would it look like? What would it have?

3 groups at the independent special school took part in this exercise. The young people wrote their ideas on sticky notes. Ideas were discussed together with the young people.

Group 1 More cooking lessons, no uniform, music studio boxing lessons, English lessons 1 to 1, more practical lessons, more school trips; all teachers be flexible, longer break times, 8 hour school, school at night at 3am, we need Maths and English, we need to do more art at school; music club, fashion club, teachers don't tell students to hurry up, celebrities or famous people come in (e.g singers, cartoonists, painters, activists, chefs, models, artists, animators); I would let kids bring in snacks and I would let them play football all day, fun stuff to do; favourite teacher as head of school, comfy chairs, gaming room, surf club, fashion lessons, bring in what you want, longer break times, vending machine, school trips more often; computing and art lessons, in the city, leaving at any time, phones are allowed, eat what you pay for, different trips; start at 8am and leave at 2pm, choose your own subjects, favourite teacher as head teacher, more maths, more sports

Group 2 Have nice time in school; there should be more school trips, I like to be in school to be with my friend, my favourite lesson is maths, having a lot of friends in school; classrooms smell nicely; no exams; more sensory toys for students to focus more, more break times like movement break, more singing lessons in my dream school, more support for the school, more teaching assistants, dream playground; I like drama, I don't like maths; tennis, kickboxing, karate, football, talking with friends; some schools open on open house weekend in September, I will earn more money when I go to College, this school has another school, I might do the Duke of Edinburgh gold award when I go to College

Group 3 Let the pupils go to the toilets for as long as they want to, be more patient with the pupils, have chewy toys for the pupils, more than one sensory room, longer break time, I like arts, change the lunch system; Treat every pupil fairly; Bring siblings to the school, explore the whole school, have longer break time, I like English and Maths; Sports field, to watch about German cars and about WW2, that I can tell my teacher about my Grandpa; put more signs; longer break; Swimming pool, more toys; Big playground; Books; More arts, more games; Longer breaks; Sensory room with more toys

Future careers

CCo asked some of the groups for their ideas for the future. Children had many different ideas for careers.

'I'm going to be a professional car influencer!' - Boy, 16.
'I want to be a travel blogger' - Boy, 14.
'Maybe a teacher?' - Boy, 16.
'Electrician' - Boy, 16.

When asked about whether they feel they have got the necessary support to achieve these goals, most young people said they did. Many young people spoke of their families as very supportive.

'*Definitely. I know my parents have got my back'* – Boy, 16.
'I got support from my parents to get me out of the house' - Young man, 22.

in particular, young people were happy with the support they had received in thinking about the future. The college had supported them in finding work or volunteering opportunities by forming strong partnerships with local organisations and companies. They emphasized that they focus on promoting disability awareness and inclusion through weekly scheduled work experience placements. One of the young people was volunteering for the National Trust. He was going to sites and assessing how accessible the sites were for wheelchair users like him. He presented his findings back to the National Trust who has promised to make changes based on his recommendations. Another one of the young people worked at the school reception. She told us how she enjoyed interacting with people and answering the phone. She had also learned about GDPR. When asked what they would like to do in the future, one of the young people said he'd like to work at a train station as he was interested in railway. However, after conversations with railway companies, it wasn't considered feasible and safe for him to pursue a career in railway.

Moreover, one of the young people in this group mentioned he'd like to attend university, and professionals also noted they had aimed for another young person to attend university. However, without the right qualifications in Maths and English, which a professional said *'is never going to be completed to that level',* it wasn't possible for these young people to attend the university courses they wanted to pursue. Staff noted that university is about so much more than the academic background, it is about social life and forming friendships, a world which the young people would be closed off from. Staff pointed out that while universities claim to be accessible, they are actually not and they felt strongly that the two young people in the room have had opportunities taken away from them.

CCo often hears from young people that they tend to be happier at college compared to school as they feel more understood by others around them, and have more choice in what they would like to study. Young people with disabilities also speak about their own 'coping mechanisms' to cope with potentially stressful situations or environments that they might find overwhelming.

'Yeah, I enjoy going, I just don't get along with one of the people in my class, because with them being an extrovert I don't like, love people or places, so I've gotten used to it but now that I've gotten used to it, it's just, it overwhelms me and so I just, I have like a small bag in my bag with like different stress and anxiety toys to help me cope with it or I just listen to my music really loud just to block him out' - Girl, 18.

One young person told us about how he feels college *'[tries] to define your future'.* This is because if it was up to him, he would have studied something else.

'I was thinking, I could do music in college [...] but I was told by others, "you can't do it, too much paperwork" [...] and when I was in school, I was told I was really bad at doing my lyrics [...] so I thought fine' - Young man, 22.

It is important to note that this young person stated he was still very happy with where he was at now and that college supported him finding a paid job. Also, college had put a transition phase to work in place, which he thought was a great model. There were regular meetings with college staff, useful resources, and an easing in into work through meeting future colleagues. At the same time, he felt others around him were opinionated and that colleges claim they are shaping young people's futures, *'look what we've done with them',* when really, young people's dreams should be more encouraged.

'They all have dreams for this future, they shouldn't be silenced by going into education [...] I do feel for me music in my future has been silenced because of others' - Young man, 22.

Adults supporting the young people did voice their concerns about future employment opportunities.

'*Day to day, you get on with it, there's nothing we can do about it. We try not to let it impact you day to day. But in terms of future employers for [my son] when he becomes an adult, [...], if people with disabilities are being perceived as 'poor them, they can't do this, they can't do that', what prospects people, children now got in the future when this is how they're perceived in society as a future employee?'* - Mother of 2 disabled young people.

'*The whole stigma of having a disability affects the whole future'* - Mother of 2 disabled young people.

Professionals at the residential special school told CCo that visits to the job centre were not helpful. Essentially, the job centre could not support the young people in finding employment opportunities that were suitable for them. One young person stated there should be an easily accessible website that would present the job opportunities in the area. Professionals also noted that some young people had to present to the job centre so the job centre could mark them as 'unable to work'. The professionals said this causes uncomfortable experiences for young people and their families that can be avoided.

Throughout this project, we noticed a lack of consistency in the approach to paying young people with disabilities for their work and time.

The young people CCo met at the community café worked there on a voluntary basis. The reason behind this was explained by the founder; some young people would do a lot of work, while others would not due to their needs and it was difficult to find a balance for payment. They had seen a variety of different concepts across the country, from young people being paid to young people paying to do their shifts with the money going back to them for example for activities and trips.

While the young people themselves did not mention unpaid work as an issue, and instead spoke about the opportunities the café offered to them very highly, the issue of disabled young people not being paid for their time has been raised with CCo previously.

We met one young person who was being paid for two shifts a week in a café. He said:

'The team there are fantastic, they know how to deal with me [...] it's really fun' - Young man, 22.

Education, Health and Care Plans (EHCPs)

We asked some groups about EHCPs as this is something the Disability Unit was interested in finding out more about. CCo has recently published a response to the SEND improvement plan[65] as well as an analysis of EHCPs[66]. The most common disability recognised in Education, Health and Care plans, listed as a primary need in almost 1 in 3 plans, is autistic spectrum disorder.[67] The most common type of need among the larger group of pupils receiving SEN support is speech, language and communication needs, for example children with dyslexia. Next most common are social, emotional and mental health needs, and moderate learning difficulties. Smaller numbers have EHCPs or SEN support primarily due to their physically disabilities, hearing impairment, vision impairment, multi-sensory impairment, or other difficulty or disability.

Generally, most young people knew whether they did or didn't have an EHCP, but they didn't know much else about it, and didn't feel necessarily involved in the considerations behind the plan. '*I don't know what one of those is*', a 13 year old girl said who did have an EHCP. Department for Education statutory guidance requires that decisions about plans should be made openly and collaboratively with children, and it should be clear how the child has contributed to the plan and how their views are reflected in it.[68]

'I ended up saying I didn't want it because there was no actual support on there that was useful, they gave me a TA in some of the session which I didn't ask for or wasn't helpful [...] It wasn't very specific, it was just like these are the things we can offer, here you go, have a TA [...] it's not the support that I need [...] The EHCP I was very cross about because I didn't understand what they were going to offer me. It was in place because of my mental health. I didn't feel involved in writing it, I remember when I saw it the way it was written was horrendous. It was calling me manipulative [...] it was horrible, the way it was written, if it was meant to be a children's plan, it was horrible. [...] I can remember there being a lot of meetings [that I wanted to be involved in, but wasn't] I didn't really know what was coming from my EHCP ever' -

However, two young people spoke of their EHCPs positively:

'I think it's a positive because all staff have access to it and it shows consistency, and it tells staff what to do say if I have two seizures in a day, or it tells them what stairs I can and can't go up. And it just, it

clarifies things and then I don't have to reiterate my story' - Girl, young carer, 15.

'I have one, and it helps me to get support in school. I don't get any help from anyone else (health and social care)' - Girl, 14.

The residential special school CCo visited had many transition points: children first joined them, between different buildings, and into the on-site college. It had processes in place to ensure students could make these transition as easily as possible. This school held transition meetings before transitions, and meetings to discuss the transition afterwards. They also tracked students' mood every half an hour throughout the school day to understand which subjects the students enjoyed, what helped them feel calm, and how a transition went for them. A dedicated transitions coordinator supported the students in their transitions. The school, who had recently moved buildings, also actively involved students in the move, e.g. they packed boxes with them and set up the new rooms together with them, so students could get used to their new environments. EHCPs also played a role in the transitions, and the school aimed to be guided by the goals set out in those. Since the school supported students from over 30 different local authorities, they noted that having EHCPs more streamlined would be beneficial in ensuring the best transitions for their students.

When we asked about EHCPs, professionals working with vision impaired children reported that they were limited by a lack of standardisation and inconsistent engagement with healthcare services. They also highlighted the lack continuity of care between education and health settings due to funding shortages and waiting lists.

'*Children and families are overwhelmed by next steps'* – Professional working with vision impaired children.

Early diagnosis

In relation to EHCPs, one young person told us he had missed out on support at school, and if he'd had an early diagnosis his experience at school would have been different.

'Because when I was younger I used to be labelled as the naughty kid, because people at the time didn't understand what I had. So when I moved from primary school it wasn't a very nice place at the

time because I was picked on because I was different. But at the time I didn't know I was different and people picked on me because I was different and I was a naughty kid. They just labelled me as the naughty kid for years and years and years. And then for a bit in (inaudible) I had like, I think I went to like, youth learning support, I had a lot of learning support for that and stuff, but it was only in 2017 when I got diagnosed so it took a long time. But it felt, it probably felt better when I got diagnosed because feel like people would now understand me more being diagnosed. But for a long part of my life I wasn't understood properly because I didn't know. They didn't know what was wrong with me.' - Young man, 24.

Also another young person told us about not being diagnosed with her disability until adulthood.

'There was no chance in hell that I was going to get a diagnosis [for my disability] through the NHS [...] I wasn't gonna stay in the area and the waiting list was just phenomenal [...] so I did private diagnosis' - Young woman, 22.

This young person also spoke about professionals stating she didn't match the presentation of others with the same disability. Again, having the diagnosis did make things a bit easier for her. She said that now she understands herself better and is able to do her university work better.

'Just having that understanding of why that education part of life is difficult and these are the things I need to do. That's made it easier for me to understand myself [...] it's helped me explain things to people and know what I need' - Young woman, 22.

Professionals also raised with us how important an early diagnosis can be. We were told about examples of settings that wouldn't support young people because they 'didn't tick a certain box'.

'If they couldn't tick the learning disability or autism box technically they shouldn't have been helping them. They have helped some people, but we've also seen that there's quite a lot of young people when they leave college and they're in that category and they go into a black hole, they might not have a diagnosis specifically, but they're not able to go onto and, or access mainstream services. And it's really frustrating for us because we can see with the right support they would be able to get a job' - Professional.

Extra-curricular activities

Many of the young people we spoke with took part in a range of different activities, from youth clubs to sports teams.

'*I go to youth club sometimes. I really like it and I get to see my friends'* - Boy, 14.

Many children with disabilities are being successfully supported to take part: Sport England finds that levels of physical activity among 5 to 16 year olds with a disability or long-term health condition are the same as for those without one.[69]

'I enjoy reading. I also just like to talk with my friends, go out with my friends and, you know? I will put like more important things like education and stuff first, obviously. But I try to do after school clubs, I'm quite fond of music. I'm in a choir, I also go to the theatre group, so I'm quite like, I am, I do lots of stuff. But at the end of the day, education comes first' - Boy, young carer, 13.

They also had ideas for activities that their schools could set up.

'TVs? More school trips? It gets boring sitting inside. We should go outside and enjoy nature. Maybe see some animals at the zoo' - Boy, 17.

Professionals we spoke with emphasise the importance of sport for children with disabilities because it often combines fitness, access to nature and outdoor spaces, and other essential developmental skills such as teamwork. However, specialist teams or training are harder to come across and often prohibitively expensive.

Disabled students in mainstream schools may have 1:1 support during the day but often is only funded up to the end of the school day, meaning that children are limited in taking part in after-school activities as a parent or friend would need to attend and provide support.

'We're relying on goodwill' – Parent of a disabled child.

Sports and extra-curricular clubs often serve to promote children's independence, but this element is limited for children with disabilities who cannot access the activity without support.

'Teenagers don't want their parent there all the time' – Parent of a disabled child.

Other research has found a requirement in some cases for parents to accompany their disabled child or young person to activities, which may not be what they want.[70] Students at the onsite college at the residential special school told CCo about activities they would like to take part in but that are difficult for them to access. Research has found that children with disabilities who attended special schools away from their local area had reduced social community-based activities.[71]

They mentioned that public transport is too narrow. When the class wants to go out together on the bus, it is not possible as only one wheelchair would fit onto a bus. It was noted when going to the theatre or the restaurant with another friend who was a wheelchair user, it wasn't possible for them to sit together as there is not enough space for two or more wheelchairs. At the cinema, they would always have to sit in the front. They also noted they would benefit from quiet times in shops and galleries. There are some places which have those in place, but it is not the case everywhere.

Young people attending a youth club for children with SEND enjoyed going there. However, it is also important to note that many activities are for children with SEND only, which can also make them feel isolated from others in society. A literature review of the out-of-school lives of physically disabled 8 to 15 year olds in the UK found some wanted to share experiences and do the same things as other children and young people of their age, but some preferred to be involved in 'disabled – only groups' as they felt more comfortable with others like themselves.[72]

Another issue raised was the sustainability of accessible activities – professionals told us of well-intentioned beginners' classes which were not followed up with longer-term opportunities for children to take part regularly in the adapted activity.

Access to other forms of support

Professionals at the residential special school told us about a '16 to 18 void' in the NHS which they experience frequently. For example, they explained that one of the young people aged 17 recently had to attend hospital and was placed in the adult ward. They felt this was inappropriate as this young person was very vulnerable. They also explained that it seems that at the age of 16 neither children's nor adults' services want to pay for products that are essential to the young people and have been prescribed. They used the example of incontinence. It was difficult to make sure young people received the right products they required. They described the case of one of the young people who had recently turned 18. This young person had been using pull up pads, which they found suited them and enabled them to go to the bathroom on their own. However, under adult services, only wrap around pads were being given to this young person. The staff felt the young person's independence was taken away as they were now no longer able to go to the bathroom on their own.

CCo visited a community café in the Midlands, which was set up by 2 parents of disabled young people a few years ago. The café made it possible for young people to volunteer, learn new skills such as food hygiene and learning to be a barista, and to socialise with other members of the community.

'So and we really wanted something for our young people, with all sorts of additional needs really, to be able to do something in our town and to be part of the community and mix with everybody, not just, because there's a lot of opportunities where young people with additional needs can go off somewhere and do something in groups, but we really wanted to get them mixing with the whole community really, showing that they could learn all these great new skills and hopefully move, some of them will move on to other volunteering or in apprenticeships or employment' - Professional.

The young people we met at the café spoke highly of their experience. They enjoyed meeting others and getting out into the community. Some of them would spend time outside their shifts in the café. They also had other opportunities that came from their involvement in the café.

'I enjoy meeting all types of people, making them happy, feel welcome, keeping all the toddlers entertained. I enjoy working the till and stuff like that and having a quick chat with customers when I'm on the till, trying to multitask. It sometimes works, doesn't always work. So I like meeting, greeting, chatting to people' - Young man, 24.

'They're really supportive for young people getting work experience' - Young man, 22.

Yet, initiatives like this are not available to disabled young people everywhere. Children as well as professionals spoke about different opportunities being available in different locations.

'This is where the postcode lottery things comes into play as well. Everywhere's so different, where it shouldn't be. We should be able to access all the same things, no matter where we live, you know? [...] it shouldn't be a postcode lottery. It shouldn't be a case of another child with [a disability] can access something 20 minutes down the road across the border, but [he] can't because he lives in a different postcode' - Girl, young carer, 17.

One professional emphasised that geographical variations often disadvantage children with disabilities with disabilities in rural areas. We heard that families with children with disabilities have to travel further than other families to reach accessible activities, as fewer places offer these activities than their mainstream equivalents.

Parents and professionals had even more oversight of the coordination between the different services that are available to young people in their local areas. One mother felt she herself needed to make things happen so services would speak with each other. This is also something that CCo hears about frequently.

'And again, I've had to be the main driving force to getting people to talk to each other, and you're constantly repeating yourself. And it's key to having access to certain things to support [my son]. School, it's hard because there are so many positives from certain services that are involved with [my son] that have been really helpful, but them talking to each other, working together has definitely been not great. And they all link into each other. I've had to self refer to try and, for some sort of family support, purely because, to get people talking' - Mother of 2 young people with a disability.

Housing

The Disability Unit was particularly interested in finding out more about disabled young people's experiences with housing. Housing was a big theme during CCo's visit to the residential special school.

As spaces at special schools are difficult to obtain, an issue CCo heard lots about for the Attendance Audit[73], some children are placed in residential educational settings by their families who decide they like the school and feel their children living there is the best solution for the whole family. However, as professionals pointed out, living at a residential special school is not only a transition for a young person, but also for the family. Some families would feel guilty about their decision to place their child far away from home. The school provides a family flat so families can come and visit on the weekends. It also involves professionals requesting points of contact for the families which are organised in line with the families' and the young people's wishes. Some families have five points of contact throughout the day.

The natural progression for children at the residential special school would be to the onsite college. However, a college place, which sometimes comes with a place at one of the houses on site, is not guaranteed for a young person. Again, it depends on the funding opportunities available, and the decision often sits with the Local Authority.

CCo met three young people aged 13, 18, and 18, who were living together in one of the houses on site. They each had one dedicated support worker, and 2-to-1 support throughout the day, as well as support throughout the night. These young people were attending school. At the end of the academic year, the local authority will have to find a new place to live for both young people aged 18. Professionals told us that the young people need to be prepared for the transitions to their new environments. However, more often than not, placement moves are decided on at the last minute, if at all. We heard that it has occurred more frequently in recent years, that nothing was put in place for the young people. In one case, with the aim of avoiding the young person becoming homeless, the residential special school had offered a care package as an extension for a year, which offered activities, but this does not compare to going to college. We heard that another solution had yet to be found within the coming year. Extensions to the young person's time at the school also keep their place from another young person who might need it.

At the onsite college, CCo met three young people aged 22-23. Two of them lived on site, one of them had her own apartment which was fully accessible and where she was supported. This young woman was very happy about her living situation, and felt independent in living on her own. The young people were due to finish college this year. The other two young people were moving back in with their families. Professionals told CCo that this was far from an ideal or sustainable situation. One of the young people was moving back home, which was unsuitable. However, as the local authority had found no other suitable accommodation for them, this was the solution for them for now.

Wanting to feel understood

Wanting to feel understood and listened to by others came up across the groups. Often, it was mentioned that children did not necessarily feel understood by their teachers and other adults around them. This sometimes meant they had to explain themselves which made them feel uncomfortable.

'I would probably educate the teachers more and the staff, because with my disability, I sometimes have to leave lesson. And when, the teachers are just like, oh yeah, I get it. But it's like, you don't properly, you don't fully understand why. And multiple times I've been stopped by teachers and been told to go back to lesson when [...] I've got to be going somewhere to, for my disability. And [...] they just don't understand that I need to' – Boy, young carer, 13.

'People don't get it, and if they did get it a little bit more, things would be a lot easier for [my son] - Mother of 2 children with disabilities.

Again, where teachers did have a lot of training, for example at the Independent Special School CCo visited, children did feel listened to and understood.

'I like that I can tell teachers about my family and issues' - Boy, 15.

Similarly, the college students at the residential special school spoke of their experiences as *'happy'* and about all the teachers as *'very kind'.* Staff spoke about an ethos around transitions, and said thinking about smooth transitions was always at the forefront of their minds. This was also due to the different processes, such as transition meetings, which were in place to support young people with the changes they experienced. The head teacher wanted to highlight their focus on the themes of destination and aspiration for every student, which would be repeatedly highlighted, reflected on and discussed during every meeting. The school felt strongly that giving meaning to destination and aspiration makes the experiences of transitions so positive.

This group of college students also noted without judgement that when they were in public spaces, such as a bank, where their money would be discussed, the bank staff would speak to the adult they were with rather than with them directly. This may have been due to their visible disabilities.

Young carers

The Disability Unit was particularly interested in the experiences of young carers with a disability. CCo spoke with one group of 3 young carers and a parent, and also with a group of 6 professionals working with young carers. Below are the points they raised specific to their situations.

Service provision

The professionals agreed that there was an increase in need for services working with young carers. They also agreed that the needs of young people had become more complex over the last few years.

'I think we're very much here today because we too are noticing a huge, a hugely greater level of attendance from children, it's becoming far more prevalent that children with their own needs are attending our opportunities' - Professional 2.

Analysis of the two most recent censuses of England bears out this view. Children who provide more unpaid care tend to be in worse health than children who do not, and the proportion in less than good health grew between 2011 and 2021.

The 2021 census in England recorded 118,951 young carers - children aged 5 to 17 who provide at least some unpaid care a week, or 1.4% (the census does not record any unpaid care being provided by under 5s). Children tend to be in good health overall, with 97% of 5 to 17 year olds reporting good or very good health in the 2021 census of England. However, this fell to less than four in five (78%) among the young carers providing the most unpaid care (50 or more hours per week).

In 2011, young carers aged under 25 providing the most unpaid care (50 or more hours per week) were mostly in good or very good health (84%), but a substantial minority of 16% were in fair, bad or very bad health.[74]

There was a fall in the prevalence of unpaid caring among under 25s, from 2.5% in 2011 to 2.0% in 2021. This was an absolute fall of around 69,300 children and young people, from around 404,000 to around 334,000. Young carers were more likely to report fair, bad or very bad health in 2021, compared to 2011. In 2021, 13.2% of young carers aged under 25 reported less than good health. In 2011, this was 8.7%.

The professionals we spoke to raised their concerns about the services not being able to meet the complex needs of young people. Some mentioned that the service couldn't do justice to children with additional needs and those without at the same time.

'We want to make sure that our young carers get, our young carers are getting a break from their caring role and sometimes we're mixing our young carers that have additional needs with that. They're not necessarily getting a break that they need' - Professional 1.

What is more, young people face long waiting times before they will be seen by the service. Professionals raised concerns about what happens for a young person during that waiting time. Similarly, professionals stated that they are not able to work with young people beyond the time that they are being commissioned for.

'And I suppose one of our challenges is probably the fact that we're commissioned for a six months period with the young people and then we close that family and don't have any further contact with them' - Professional 5.

Whole family approach

Professionals and parents mentioned the need to consider the whole family when thinking about support services. This is also something that came out strongly in CCo's report 'Family and its protective effect: Part 1 of the family review'.[75] There is a lack of services that support the whole family, but a child's unmet needs, have an impact on everyone in the family.

' So you've got a group of sibling young carers who've got their additional needs that then has a significant impact on the parent carer [...] Again we had a case [...] where [...] you had the young people who all had their own additional needs, none of which quite qualified for support in their own right and so actually mum was left desperate for support [...]. And so I think that's just one of that, that whole family approach to how you try and meet the needs [of everyone]' - Professional 4.

'[Y]ou do meet up at lunchtime and stuff [with other parents]. But other than that, there's no support groups and the onus is very much on parents and the children themselves to get the ball rolling with that. Now having two children with disabilities, I actually run a support group for my other son, so I haven't got time to be doing that for him as well. And that's no disrespect to [my son], but I can't do it

all. And I think there's a lot of pressure on families to do these things. Because [my son is] a young carer as well as a child with a disability. So […], there's a lot of pressure, I feel there's a lot of pressure' - Parent of 2 children with a disability.

Transition Assessment

Specifically relating to transitions, the professionals raised the difficulties for young people becoming adults. With a young person turning 18, the offer of services changes. Professionals noted that they felt the processes behind transition assessments for young carers were not clear.

Transition Assessments for young carers, introduced by the Care Act 2014, are separate from Young Carer's Assessments. They are about the changes that might happen as a disabled young person approaches turning 18.

'I think this particular group of young people who I'd say as young carers are the target audience for transitions assessment in terms of actually what support they might need if they are likely to continue having caring responsibilities when they hit 18. And I think again there's, from a national perspective there's a real lack of insight as to how transitions assessments are happening under the Care Act for young adult carers in practise' - Professional 4.

Not only did they think it was unclear how the Young Carer's Assessment is being carried out, they also thought there were huge disparities in what was available for young carers as they turn 18 in different areas of the country – similar to the post-code lottery for services mentioned by young people above.

'But again it's a mixed bag as to, so in the previous area that I used to cover, [area] and [area] but also [area] there wasn't a commissioned young adult carers service, you had young carers and then at 18 they transitioned to adult carers. And so, and the services were worlds apart in terms of what the model looked like. And so I think that transition to support and what can be provided to help them as they enter adulthood is really key, particularly for this group of young carers' - Professional 4.

'And that's really key and that that seamless service to holding this young carers, because that age group in 18 to 25 is so, their needs are so different and bespoke that we, and then you add disabilities on top of that it's a real complex, and if you lose them in that transition, [...] then they can get lost and responsibility then becomes their ownership' - Professional 2.

Schools

Professionals also spoke about the need for more secondary school provision to support young carers into adulthood.

'I think there's a lot more work to do around that secondary school provision and actually then getting the right support at that level because those are the young carers that eventually turn into young adult carers who are looking at balancing their exams and being a carer and making their next life choices about whether they could go Further Education or not' - Professional 3.

Similarly, a young carer spoke about how he felt there was more support available for him at primary school.

'I mean there are other teachers, [...], every so often they need to check on me. Hi, [name], how are you doing? Go back to, go back and do their work. Whereas in primary school it was like constantly, if I thought that anything was wrong, I could go to my one to one, you know, talk to her about it. [N]ow it's a case of [...] there's not really, really many people that understand me, not really many staff that like know, that understand my situation' - Boy, young carer, 13.

Transition booklet

One professional mentioned a good example of a resource that schools can used to support young carers with their transition to secondary school. The charity Caring Together co-designed this resource together with young carers. They state that: "This pack ensures that helpful and important information on the young person is recorded and not lost when they move up. This means that young carers don't have to tell their story repeatedly."

https://www.caringtogether.org/professionals/schools-colleges-universities/young-carers-the-transition-to-secondary-school/

Disabled young people who are care experienced

The Disability Unit was also interested in hearing from children who are care experienced and have a disability.

Children with disabilities are not flagged as such in many public service data systems, including children's social care national data returns. Some systems use SEN status as a proxy. In 2022, concerns about the child's disability or illness were a factor in 23,850 child in need assessments carried out by local authority children's services departments, a small minority of the 645,070 completed assessments.[76] A further 54,670 noted a child's learning disability as a factor, and 87,750 noted concerns about children's mental health (more than one factor can be noted).

CCo spoke with four young people who are members of CCo's care experienced advisory board, who were interested in speaking with us. CCo did not ask them about the specifics of their disabilities. Many of the things they noted were very similar to what CCo hears from other care experienced children. While the young people also talked about their disabilities, it seemed more the care experience that was front of mind for them, especially when thinking about transitions in their lives.

Other qualitative research with disabled young people who have experienced child protection enquiries similarly found that the children talked more enthusiastically about who or what was important to them than about their impairments.77 The study of 11-18 year olds identified a need for children to be kept informed and involved in decision-making, and for practitioners' to adopt an enabling approach to their impairments, respecting their own views on their support needs.

School

When thinking about the move from primary to secondary school, one young person told us that she felt she wasn't listened to and if it had been up to her, she would have preferred to go to another school.

'When I think back from my experience, there was confusion around which school I would go to because all of my biological family members had gone to one school in the area. My foster carer at the time wanted me to go to the school that she had gone to as a child. I didn't want to go to that school

and I did voice that but I feel like I wasn't quite listened to. Where I was so young it was almost like they made the decision for me. So I feel like looking back having some more support around them listening to me and talking to me about school and where to go from my social worker or something like that it would have been better' - Young woman, 21.

Support at school to help with transitions from primary to secondary school varied. Three young people felt there was no particular support but one young person told us about a booklet that their education support officer prepared together with her, which for example looked at the new journey to school. The young person was given the opportunity to create this book and refer to it once she had transitioned into secondary school. This young person was also supported by her designated teacher who set up play therapies where they would talk about what was happening in the young person's life and some sessions would focus on the transition to secondary school.

'[One teacher] in secondary school really helped me making that adjustment to being in secondary school and helped with not getting too overwhelmed and things like that. She gave me coping mechanisms that I could then use and still use to this day' - Young person, 21.

Support at school also varied between primary and secondary and different schools. It is unclear whether, on average across England, support is perceived by children with disabilities as better at primary or secondary school. Young people really valued having a designated teacher which they had a good relationship with who made sure to check in on them and offer activities, such as paint therapy.

As noted above, more practical lessons at school, were also brought up by young people who are care experienced. They said they struggled with being an adult and all the different responsibilities that come with it such as having to pay bills.

'Something that could benefit children in care but also children who aren't in care is just to talk about things like bills and budgeting, how you manage those bills on top of life, a job or College, how public transport works […] how to manage banking, credit cards, what they are, how they're useful but also dangerous [...]' - Young person, 21.

What is more, young people told us about their struggles to manage College with having to work. Many children in care have the added challenge of having to be financially self-sufficient.

'[O]therwise it's 16-year-olds who have just come out of school but now they have to be thrown into a job because they have to pay for their flat. How they can then manage that job as well as other things like college. It's one of the things that I struggled with, being at college and getting all of that college work done when I was working until 10 o'clock at night.' - Young person, 21.

One young person also mentioned that not everyone leaves on good terms with their foster parents, so wanted to raise that there is virtually no one to support those young people with independent living.

Changes might be the norm for children in care. One young person said how she just assumed she was moving school when she was moving foster placements. What is more, she felt that there wasn't necessarily a separation between her home and her school life and keeping the two more separate would have been helpful.

'[G]oing through transition needs to be important for anyone at any stage of their life, especially children, if they are in care. Do I have been in care, or do you have a disability because it having a change can impact. [...] So for example, when I first moved schools, [...] I just assumed that I move schools and I'm leaving placement. I'm leaving home because that's how I went into care, so I always associated moving school. That's how I was being moved home. So, I think trying to differentiate between what happens at school stays at school and what happens at home stays at home. So, you've got two different support networks' - Young woman, 23.

Young people also spoke about being labelled as lazy or troublemakers at school, when really, the problems they were facing at school were the experience they had with changing environments, at home and at school.

'I think that there's a lot of stigma and judgment and judgment around children in care' - Young woman, 22.

Foster placement moves, moving into care, and adoption

It was clear that moving between foster placements was the biggest life change for young people. The foster placement affected everything in the young persons' life. Young people had to move schools, leave their friends and everything they had known so far behind. Young people had experienced between 2 and 5 moves. Some moved between residential settings, foster placements, and moving to adoption. Some were separated from siblings.

'They didn't really help or understand when it came to me changing foster placements when I had just come into secondary school as well because that had obviously uprooted everything. It made me have to think about how I am going to adjust. I then had instead of a 15 minutes' walk, a 40 minutes' car journey every morning [...] and they didn't quite understand how that was affecting me, how I had to adjust to my new home as well as my new school. [...] It felt like a chaotic situation because there was so much going on. […] I was taking me away from where I had grown up [...] It threw me into a situation where I didn't know anyone. I had to choose my GCSEs without actually experiencing the lessons in the school. [...] It was very much having to get used to so much at once which cause quite a few meltdowns in the fact that I was just so overwhelmed [...] I couldn't quite cope' - Young woman, 21.

Similarly, another young person told us about the difficult transition moving into adoption as a child.

'I had to obviously leave that primary school to move to get adopted here. And then I went to another primary school and the same year in September. So it's quite a difficult transition really [...] Yeah, it was very difficult because obviously it's a different area. You're not used to it and like being thrown all their support and you've only just been adopted and you, you don't know what's going on. So it's difficult.' - Young woman, 24.

The added difficulty for young people of social workers changing was also mentioned. Lack of consistency in the people who support you doesn't make a transition easier. This is unfortunately an issue that CCo hears about frequently.

'Yeah, there's just no communication. I think you just be nice to be able to have the same person where you can build that relationship and trust' - Young woman, 24.

We heard from one young person how social workers they'd never met before would turn up at school wanting to speak with her, which felt very strange to her.

'Why would I want to speak to someone now if I don't have a clue about who they are and never met them in my life' - Young woman, 22.

One young person said looking back at her experience of moving placements, she could see that it was for the best, but that was difficult to see as a child going through this experience.

An adopted young person told us she found the term 'forever home' damaging, which again makes the point of how important it is to really take the time to talk children through what will happen, make sure they have a chance in the issues that affect them, and the chance to ask questions.

'Tterm that sometimes they use is called forever home? I'm not really keen on that kind of term. I think that shouldn't be allowed. They should explain in a different way. I think it can be quite damaging to children to call it a forever home cause you feel like you kind of like stuck or something. You know, you have to be there' - Young woman, 24.

This young person also highlighted how important it was for older children to get a chance to be adopted.

'I just think people should start to adopt older children. Yeah, it's difficult. And they remember things, but it's honestly, it's hard work, but it's so rewarding because you can see how much they change over time' - Young woman, 24.

One young person told us that she felt if she'd been diagnosed with her disability earlier, she might not have moved into care.

'Nothing was diagnosed until adulthood [...] To some extent I think I probably wouldn't have ended up in care if I'd been diagnosed earlier because I think looking back and reflecting on the circumstances that led to me being in care I think a lot of those were difficulties which were exacerbated by [my disability] that we didn't know was [my disability] at the time [...] the support I was getting wasn't what I needed [...] I think it would have made everything 10 times easier' - Young woman, 22.

Other support and services

Young people told us that the right support comes down to making sure that it is person centred, rather than having to choose from a list of things that are available and nothing else, as one young person put it.

'There is a bit of disconnect between we don't want to offer it to individual students as part of disability and accommodation because it's really hard to do that […] but actually it's not is it […] you can have reasonable adjustments if it's one of the reasonable adjustments on this list, that's largely how I would describe it' - Young woman, 22.

'I think the main overarching thing is the need to actually make the support individual to the person and their needs […] I think for leaving care and EHCPs […] the one size fits all approach doesn't work for leaving care, EHCPs, transitions between schools […] And I think adults perceiving difficulties in a particular way, I think for me as a child how adults interpreting what I was struggling with was the biggest barrier to getting support and that was potentially compounded by the fact that I was in care because there were more professionals involved. Who is gonna listen to a 14-year-old who everyone has already decided is a bit difficult'- Young woman, 22.

Young people also said that it was important to make sure young people feel involved in the issues that affect them and get a genuine say in the issues that concern them. While one young person was satisfied with the support she received, she also noted that she didn't feel empowered enough to speak up as a child.

'The only issue with that process is actually getting the child to speak up and actually getting them to be aware that they have a voice in those meetings, because they are about them' - Young woman, 21.

'Think I would have liked to someone to explain what was happening beforehand being adopted wise. I was never told I was going […]. I was never told until two weeks before I was getting adopted and moved, so I kind of would have liked some time to be able to understand' - Young woman, 24.

This young person also said services need to think about how to engage with young people more. For some young people it might work well to note something down before the meeting, for others to record a video.

Furthermore, young people mentioned that it was difficult to know which services could support them when they were moving between different local authorities. There were issues around which local authority would write the EHCPs, or being able to access NHS services. Also, one young person told us about her difficulties in being able to join up the services. It was not possible for her to access NHS services whilst also continuing to see her private therapist which was important for her.

'It's not joined up enough, it's not taking into account any sort of need' - Young person, 22.

Activities

When asked about activities, it emerged that taking part in activities outside of school, such as after school clubs, was difficult for children in care. One young person spoke about her experience of living some distance away from her school, and it not being possible for her foster parents to pick her up any later, as there were also other children in the house who were waiting for their dinner.

'Because the school was 40 minutes drive away it meant that my foster carers had to take me and to pick me up. So it meant that I couldn't really do any after school clubs. [...] I know it would have been a very big inconvenience for them […] to push everyone else's dinner because it wasn't just me in the house, there was another child in care and also three of their own children [...] how can I expect them to move their whole evening forwards just for me' - Young woman, 21.

Another young person also said there wasn't much available when she was in foster care.

'There wasn't really much that I did in foster care. I couldn't really. There wasn't a lot in the area, to be honest, you know, and on the Council states, etcetera, you know, there's not much there for kids. Not that I knew of anyway. We just played around in the park and stuff like that' - Young woman, 24.

Transition to adulthood

Young people noted that turning 18 might be more challenging for children in care than for children who are not in care.

'They need to do a lot more things that most young people do, they need to keep a house, they need to keep that tidy, they need to pay bills, deal with taxes, how to adjust meters [...] they have a lot more things to worry about than most young people who live with their parents until their mid 20s' or even longer' - Young woman, 21.

There are different options for young people in care to transition to adulthood. When a young person turns 18 a new living arrangement has to be found. They could for example, move back in with a birth family member, 'stay put' and pay rent to their foster parents (which creates a potentially awkward dynamic), or move into supported accommodation. However, young people felt the options were not explained to them very well.

'it's a very long process, and it is all very confusing cause there are so many options for children in care to take [...] It didn't get explained very well to me, it could have been explained a lot better. Because it's such a big decision, and I've only got essentially a year and a half to figure out what I want to do whilst figuring out how I am doing a job, college. As a child what I'm gonna do that weekend is important as well. How do I manage all of this plus now also figuring out where I'm gonna live next year' - Young woman, 21.

The young people also made us aware that there are some local authorities who would act as rent guarantors for young people whereas others wouldn't. Again, the offer and support available to young people is not the same across the country.

One young person told us about negative experiences with her local care leaver team. She felt like they didn't give her the support she was entitled to. At university, she received an email only in her 4th year telling her that there was a care leavers team to support her.

'It just baffled me a bit and I just can't quite get my head around. Why leave everything to the last minute, which is what they always do anyway. But if they're told me earlier it could have been a different situation with university in general' - Young woman, 23.

Employment

One young person spoke about more information around apprenticeships being helpful. The young person said if she'd known more about apprenticeships, she would have done an apprenticeship rather than going to college. Additionally, it would be good to know which companies or organisation are in support of care experienced young people applying, as one young person said:

' so we know they're gonna be accepting of us, we know they're not gonna think we are troublemakers and that sort of stereotype and stigma'.

'I can't think of anything specific to my disability and additional support. But then, I haven't asked, so there might be' - Young woman, 22.

At the same time, some of the options that are available for disabled young people can feel stigmatising.

'There is stuff like the guaranteed interview scheme but it can be hard if it's like oh we have a guaranteed interview if you meet the disability interview and the base criteria. But a lot of interviews I found can be not [disability] friendly. And sometimes I feel like, yeah I could get an interview, but I struggle in interview environments […] I can be nervous putting down that I have a disability or asking for reasonable adjustments because I'm a bit nervy about people seeing me differently because of it […] I don't want people to think I can't do things […] I can say I have all these skills but then I say I've got [a disability] that appears at first glance contradictory' - Young person, 22.

This young person also spoke about a negative experience she had at a previous recruitment round where she had to disclose her mental health and her disability, as well as her care experience. After a very long and drawn-out process her offer was withdrawn and she felt that they had predicted the issues she was going to have .

'They basically rejected me because we don't think you can emotionally handle it. And I was like well, I'm telling you these things that I've got in place and this is the support I've got […] I felt they had made their assumptions on my ability to manage a condition and then rejected me on that condition. We didn't really have very much discussion about what adjustments could be put in place' - Young woman, 22.

Young people also spoke about wanting to give back to other young people through their own experiences. One young person had an idea of how this could be set up practically.

'[For] work experience with social workers or something [...] that would be pretty cool. So that [...] you've got people that have experienced adoption that they can cater for other adults [or] children from a personal experience' - Young woman, 24.

If you were the prime minister…

As a closing activity, some of the groups were asked what they would do if they were the prime minister. These are some examples of what they said.

'More activities in school. Also some schools treat kids like they're in the army' – Boy, 14.

'More support and funding to help people with mental disabilities' - Boy, 16.

'Teach young people how to stay safe. More instructions and road signs near schools' - Girl, 15.

'Lower crime rates' - Boy, 18.

'Help SEND young people and give them more support. So that they don't go beyond a level 3 with their emotions since 5 could make you do something that is against the law' - Boy, 17.

'I would put on a lot of events for younger people to get involved in [...] I would talk about climate change, talk about dreams [...] how we can change it and try to not manipulate it to what other prime ministers have been trying to avoid [...] I would try and get to the point and say "no one is perfect, we all have our own dreams, we are entitled to our own opinions, and never make things up cause life it too short to live a life indoors and not have fun"' - Young man, 22.

'I would [...] say put more funding into training for teachers [...] put more funding into creating more places like this [community cafe]. So if the government [...] could have a special funding system which goes to create some hubs and places where young people with learning difficulties can go and like create their own little community like we're doing, [...] where it could go to setting up many different centres, community buildings, centres for young people to socialise, be a part more of the community' - Young man, 24.

'A council of disabled young people to help government so they make changes with the people who it actually affects' - Young woman, 22.

‘Big life changes’

Both CCo staff and some of the individuals we spoke to noted that ‘big life changes’ is a fairly abstract concept to be asked to speak about. Young children and early teens may not have experienced or needed to reflect on the types of psychosocial life stage shifts we would consider to be included such as moving home or school, sitting exams, or transitioning to adult services, and older children and teens may have experienced these differently or not at all due to their disability.

One young person spoke to us about what big life changes really mean and how they can differ between groups of people.

‘Thinking about life as a whole [...] to me, I would say, [...] life changing is about when people of earth help the earth [e]volve into a massive change, going into like what the future may hold. Because the only way it can change is by us, if we can’t change it, then it can’t change [...] the way some people see earth changing, some of them don’t even care’ - Young man, 22.

We also saw the potential for this topic to be distressing for our participants; one of the girls in group 5 mentioned she felt stressed out by thinking about future careers and one boy told us he would rather focus on the now.

‘[T]o be honest, I'm not quite sure about, I don't want to think too far ahead into the future. I just want to focus on now and how to deal with stuff now. And then I'll get to the future, when it comes to the future, I'll deal with it then. [...] Education, with education, I'm just going to like try and do my best, get an idea of what GCSEs I want to take and then just go from there’ - Boy, young carer, 13.

Analysis of a nationally representative survey of children and parents in England

Impact on children's homes on health

Our March 2023 survey found that 22% of parents of a child with SEND agreed that 'my home negatively affects my child's health' compared to 12% of other parents.

Receiving help for mental health

We asked the parents of children with SEND whether their child had received help or support for their mental health from different services. Parents could give more than one answer. Similar numbers of parents reported that their child had received this help from an NHS service (34%) and from a school service (35%). Together with private and free services, 71% of parents in total reported seeking help. One in ten (10%) reported that their child was on a waiting list. The proportion of parents who had never sought help for the mental health of their child with SEND was 22%, much lower than other parents (73%), but illustrating that not all parents of children with SEND see a need to seek help for their child's mental health.

What you look forward to at school

We asked children 'what do you look forward to at school?' from a list of nine options including 'learning', and 'breakfast club'. The biggest absolute difference in the responses of children reported by their parents to have or not have SEND was in the option 'seeing friends'. While this was, overall, the most popular option (selected by 79% of children), children with SEND were less likely to pick it than children without SEND (65% vs 82%).

Opportunities for children to get Saturday jobs

We asked children whether they agreed or disagreed that 'There are enough opportunities for children still in education to get a job if they want one (such as a Saturday job)'. Children with SEND were less likely than other children to agree. Among children with SEND 36% agreed, compared to 49% of other children.

This greater pessimism does not appear to reflect actual experiences of more limited or less relevant work experience opportunities. There was only a small difference between children with (51%) and without SEND (49%) in their level of agreement with the statement 'I have had at least one opportunity to gain work experience in a job or career that I am interested in'. This may imply that schools and colleges are doing a good job of ensuring that interesting work experience is available to all children.

Aspirations for the future

We did not prompt children directly about their SEND status and any impact this may have had on their aspirations. However, across five statements, children with SEND answers answered less confidently.

The question asked: 'In 10 years, how confident are you that the below statements will be true for you?' and the statements read: 'I will have a job I am happy with'; 'I will have learned the skills I need to get a good job'; 'I will have the education that I want'; 'Job and career opportunities will be equally open to me'; and 'There will be good jobs near where I live'.

This is borne out by children with SEND's answers to the more direct statement 'I've been feeling optimistic about the future'. Their answers were more negative than answers given by children without SEND, with 19% (compared to 11%) reporting feeling optimistic only rarely or none of the time.

Loneliness

In line with other evidence cited in the government's Disability Strategy[78], children with SEND were more likely than other children to say they often or always felt lonely. Over a third of children with SEND (36%) said they often, always or 'some of the time' felt lonely, compared to 23% of other children.

Views on the most important issues facing children

We asked children what they thought were the most important issues facing children in England today. We asked children to select up to three from a list of 12. Among children with SEND 38% selected 'children's mental health and well-being' among their top three issues, compared to 30% of children without SEND. Other issues that children with SEND more often prioritised than other children were 'children being treated fairly' (20% compared to 16%); 'families getting help when they need it' (20% compared to 18%); and 'children's physical health (13% compared to 12%).

Gaming and screen time

Children aged 8 to 17 were asked 'To what extent, if at all, do you think the following things are good or bad for children's health and wellbeing?', in reference to several forms of computer gaming, including virtual reality (VR) gaming, and 7 social media platforms: Instagram, Twitter, TikTok, WhatsApp, Snapchat, iMessage and YouTube.

Gaming

Children, both with and without SEND, were unlikely to think any form of gaming was bad for children's mental and physical health (less than 10% of responses). Of the three forms of gaming, children were most likely to think single player games were good for children's health (67% of children without SEND, 68% of children with SEND) and were least likely to think VR games were good for children's health (46% of children without SEND, 44% of children with SEND).

Children were also asked whether they had ever used a VR headset and who owned the headset(s) they had used. Overall, children with SEND were more likely to report having ever used a VR headset (54% of children with SEND) compared to children without SEND (43%). Of the children with SEND who had ever used a VR headset, 38% had used their own headset, 24% had used a friend's headset, and 16% had used a sibling's headset.

Social media

Children, whether they had SEND or not, tended to see social media platforms as more good than bad for children’s mental and physical health. Across the seven social media platforms mentioned, children with SEND were more likely to perceive social media platforms as bad for children’s mental and physical health, compared to children without SEND.

Children were similarly likely to think YouTube was good for children’s health (72%) but children with SEND were a little less likely to think Twitter was good for children’s health (22% of children without SEND, 21% of children with SEND). Children were most likely to think TikTok was bad for children’s health (25% of children without SEND, 27% of children with SEND - see Table 12).

Children with SEND and other children had similar views on how good or bad YouTube is for children’s health and wellbeing. But their views diverged on other platforms. The biggest difference was for WhatsApp, on which children with SEND had less favourable views.

Table 12. Proportion of children with and without SEND who think social media platforms are good or bad for children’s health and wellbeing

Social media platform	SEND status	Good or bad for children’s health	Weighted percent of group
Instagram	Yes	Bad	24%
		Good	32%
	No	Bad	18%
		Good	38%
Twitter	Yes	Bad	26%
		Good	21%
	No	Bad	20%
		Good	22%
TikTok	Yes	Bad	28%
		Good	37%
	No	Bad	25%
		Good	41%
WhatsApp	Yes	Bad	12%
		Good	52%
	No	Bad	6%
		Good	61%
Snapchat	Yes	Bad	26%
		Good	32%
	No	Bad	20%
		Good	39%
iMessage	Yes	Bad	11%
		Good	36%
	No	Bad	7%
		Good	40%
YouTube	Yes	Bad	7%
		Good	71%
	No	Bad	5%
		Good	72%

Annex A – Topic guide

This topic guide and the activities were adapted for each group.

1. What are children with disabilities' experiences of transitioning into their learning settings? (10 minutes)

Aim: *Finding out from children how easy it was for them to transition into their learning settings, and how that process worked and felt for them.*

1. Setting the scene - Describing their current education setting

- Could you describe what it's like to learn here?
- What do you really enjoy doing here / learning here?
- Do you have a favourite subject and why do you like this subject?
- What would you like to learn more of?

Potential Activity – My ideal school: Question, what would your ideal school have?

Then discuss why they have chosen these things, and ask – is this something that you've had / currently have where you learn?

2. Transition to their current education setting

- How long have you been learning here?
- Have you been at other schools / settings previously? If so, how many different ones have you attended?
- How were these learning environments different from this environment?
- Have you ever been out of education?

Potential Activity: Quick Poll – How many different education settings have you attended?
1 / 2 / 3 / 4 / 5 / more than 5?

Thinking about the future - what do you want to do in 10 years' time? Do you think you have got the support to reach this goal at the moment?

2. **What are children with disabilities' experiences of moving between health and social care (due to changing needs / moving into a new location/transition due to age)?** (15 minutes)

Aim: *Finding out about moving between other services, which might also be impacted by a transition in their learning settings.*

- Do you know what needed to happen for you to be able to learn here?
- Is there anyone who supports you here? E.g. do you have a social worker who supports you here or has supported you previously?
- Do you receive any support from health services? If so, what does this look like?
- Do you receive special support being a young carer?
- Do you know whether you have an EHCP? Do you think your EHCP is helpful?

3. **Do the services (e.g. health and social care, education) children with disabilities access feel well-coordinated?** (10 minutes)

Aim: *How do children perceive of the coordination between other services which are to support them?*

- If there are any people who support you, do you know whether they speak with each other?
- Does everyone offer you something different?
- Would you like more or less support with something?
- How do you think you could be supported better?

Potential Activity: Would you rather

Would you rather be supported by family / social workers / youth workers? Why?
Would you rather find support yourself / be told about support /
Would you rather be supported in person / online ?
Would you rather be supported on a regular basis / be able to check in when you need support?

4. **What kind of access to children with disabilities have to activities outside of school?** (10 minutes)

Aim: *Finding out about other activities that children might have access to outside of school / their learning setting.*

- Do you do any activities outside of school/this setting?

- Which ones do you enjoy?
- How do you get there and how do you get back?
- Is there anything else that you would enjoy doing outside of school?

Potential Activity: Imagine exercise

Imagine a world where you could do any activities you'd like to do. Which activities would that be?

To End:

Saying back exercise
What would you say to your previous school? / support provider?
What would you say to the prime minister?
What would you say if you could change one thing for children in England?

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- has a significantly greater difficulty in learning than the majority of others of the same age; or
- has a disability which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post 16 institutions.

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[34] Department for Education, Characteristics of children in need 2021- to 2022, https://www.gov.uk/government/statistics/characteristics-of-children-in-need-2021-to-2022

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[39] Language varied ('children' or 'young people') between the versions of the survey for 9-12 year olds and for 13-17 year olds.

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[44] See the table comparing responses to the question on happiness with different areas of life for children with SEN and children without SEN in The Big Ask online appendix, available at: https://childrenscommissioner.github.io/thebigask/9-17_happy/pages/9-17_happy_disad.html

[45] as shown in The Big Ask online appendix, available at: https://childrenscommissioner.github.io/thebigask/9-17_important/pages/9-17_important_disad.html

[46] See the table comparing the share of children choosing each worry between children with SEN and children without SEN in The Big Ask online appendix, available at: https://childrenscommissioner.github.io/thebigask/9-17_worry/pages/9-17_worry_disad.html

[47] See the table comparing the responses to this question between children with SEN and children without SEN in The Big Ask online appendix, available at: https://childrenscommissioner.github.io/thebigask/9-17_parents/pages/9-17_parents_index.html

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[54] Children’s Commissioner’s office analysis of Census 2021. https://www.ons.gov.uk/census

[55] Children’s Commissioner’s Office. *Children's mental health services 2021-2022.* https://www.childrenscommissioner.gov.uk/resource/29751/

[56] Department for Education. *Special Educational Needs in England 2021/22*. 2022. Date accessed: 20/04/2023. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england/2021-22

[57] Under the Children and Families Act 2014, a special educational need is "a learning difficulty or disability which calls for special education provision to be made". A child has a learning difficulty if she or he:
• has a significantly greater difficulty in learning than the majority of others of the same age; or
• has a disability which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post 16 institutions.

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[71] Knight, K, Porcellato, L. and Tume, L. 2013. Out-of-school lives of physically disabled children and young people in the United Kingdom: A qualitative literature review *Journal of Child Health Care* 1-11.

[72] Knight, K, Porcellato, L. and Tume, L. 2013. Out-of-school lives of physically disabled children and young people in the United Kingdom: A qualitative literature review *Journal of Child Health Care* 1-11.

[73] Children's Commissioner for England, Voices of England's Missing Children. Available at: https://www.childrenscommissioner.gov.uk/resource/voices-of-englands-missing-children/

[74] The 2011 census findings on the health of unpaid carers are not broken down by age beyond the category 0 to 24 years. The comparison between 2011 and 2021 is therefore based on analysis of unpaid young carers aged under 25.

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Annex B – ANOVA results

Table A1: Two-way ANOVA results, unhappiness with personal safety and the interaction between SEN and aggregated ethnic group

Dependent variable: Unhappy with personal safety

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	13.0	13.0	310.5	0.000
Aggregated ethnic group	4	8.5	2.1	50.8	0.000
SEN * Aggregated ethnic group	4	1.6	0.4	9.4	0.000
Residuals	377284	15853.6	0.0	NA	

Note: This table shows that the difference in unhappiness with personal safety between children with SEN and children without SEN is statistically significant, the difference in unhappiness with personal safety between aggregated ethnic groups is statistically significant, and the interaction term is statistically significant.

Table A2: Two-way ANOVA results, unhappiness with personal safety and the interaction between SEN and being a young carer

Dependent variable: Unhappy with personal safety

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	14.2	14.2	330.3	0.000
Young carer	1	6.7	6.7	155.5	0.000
SEN * Young carer	1	0.4	0.4	8.7	0.003
Residuals	415645	17877.9	0.0		

Note: This table shows that the difference in unhappiness with personal safety between children with SEN and children without SEN is statistically significant, the difference in unhappiness with personal safety between young carers and children who aren’t young carers is statistically significant, and the interaction term is statistically significant.

Table A3: Two-way ANOVA results, unhappiness with personal safety and the interaction between SEN and having a social worker

Dependent variable: Unhappy with personal safety

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	14.2	14.2	330.44	0.000
Has a social worker	1	12.6	12.6	294.08	0.000
SEN * Has a social worker	1	1.2	1.2	28.34	0.000
Residuals	415645	17871.1	0.0		

Note: This table shows that the difference in unhappiness with personal safety between children with SEN and children without SEN is statistically significant, the difference in unhappiness with personal safety between children who had a social worker and children who didn't have a social worker is statistically significant, and the interaction term is statistically significant.

Table A4: Two-way ANOVA results, choosing education as a top priority and the intersection between SEN and gender

Dependent variable: Chose 'Having a good education' as a top priority

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	224.05	224.05	905.07	0.000
Gender	1	210.11	210.11	848.75	0.000
SEN * Gender	1	7.45	7.45	30.11	0.000
Residuals	409491	101371.88	0.25		

Note: This table shows that the difference in choosing education as a top priority between children with SEN and children without SEN is statistically significant, the difference in choosing education as a top priority between boys and girls is statistically significant and the interaction term is statistically significant.

Table A5: Two-way ANOVA results, choosing education as a top priority and the intersection between SEN and having a social worker

Dependent variable: Chose 'Having a good education' as a top priority

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	235.96	235.96	947.92	0.000
Social worker	1	14.99	14.99	60.22	0.000
SEN * Social worker	1	2.47	2.47	9.91	0.002
Residuals	432302	107609.52	0.25		

Note: This table shows that the difference in choosing education as a top priority between children with SEN and children without SEN is statistically significant, the difference in choosing education as a top priority between children with a social worker and children without a social worker is statistically significant and the interaction term is statistically significant.

Table A6: Two-way ANOVA results, choosing education as a top priority and the intersection between SEN and IDACI quintile

Dependent variable: Chose 'Having a good education' as a top priority

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	241.04	241.04	973.29	0.000
IDACI quintile	4	288.44	72.11	291.17	0.000
SEN * IDACI quintile	4	4.71	1.18	4.76	0.001
Residuals	409491	101371.88	0.25		

Note: This table shows that the difference in choosing education as a top priority between children with SEN and children without SEN is statistically significant, the differences in choosing education as a top priority between IDACI quintiles are statistically significant and the interaction term is statistically significant.

Table A7: Two-way ANOVA results, choosing education as a top worry and the intersection between SEN and being in foster care

Dependent variable: Chose 'Having a good education' as a top worry

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	82.9	82.9	564.2	0.000
In foster care	1	9.4	9.4	64.2	0.000
SEN * In foster care	1	1.3	1.3	8.5	0.003
Residuals	427190	62750.0	0.1		

Note: This table shows that the difference in choosing education as a top worry between children with SEN and children without SEN is statistically significant, the difference in choosing education as a top worry between children in foster care and children not in foster care is statistically significant and the interaction term is statistically significant.

Table A8: Two-way ANOVA results, choosing education as a top worry, intersection between SEN and having a social worker

Dependent variable: Chose 'Having a good education' as a top worry

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	82.9	82.9	564.6	0.000
Had a social worker	1	47.6	47.6	324.6	0.000
SEN * Had a social worker	1	6.5	6.5	44.5	0.000
Residuals	427190	62706.5	0.1		

Note: This table shows that the difference in choosing education as a top worry between children with SEN and children without SEN is statistically significant, the difference in choosing education as a top worry between children with a social worker and children without a social worker is statistically significant and the interaction term is statistically significant.

Table A9: Two-way ANOVA results, thinks it’s unlikely they will have a better life than their parents, intersection between SEN and being in foster care

Dependent variable: Unlikely to have a better life than their parents’

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	14.6	14.6	174.7	0.000
In foster care	1	2.6	2.6	31.5	0.000
SEN * In foster care	1	0.8	0.8	9.8	0.002
Residuals	375301	31423.0	0.1		

Note: This table shows that the difference in responding that it’s unlikely they will have a better life than their parents between children with SEN and children without SEN is statistically significant, the difference in responding that it’s unlikely they will have a better life than their parents between children in foster care and children in foster care is statistically significant and the interaction term is statistically significant.

Table A10: Two-way ANOVA results, thinks it’s unlikely they will have a better life than their parents, intersection between SEN and IDACI quintile

Dependent variable: Unlikely to have a better life than their parents’

	Df	Sum of squares	Mean Square	F	Pr(F)
SEN	1	10.9	10.9	135.3	0.000
IDACI	4	10.3	2.6	32.0	0.000
SEN * IDACI	4	1.4	0.3	4.3	0.002
Residuals	350684	28138.5	0.1		

Note: This table shows that the difference in responding that it’s unlikely they will have a better life than their parents between children with SEN and children without SEN is statistically significant, the differences in responding that it’s unlikely they will have a better life than their parents between IDACI quintiles are statistically significant and the interaction term is statistically significant.

Annex C – Topic and index words used to classify written comments in The Big Ask

Table A11: Topic and index words

Topic	Index words			
Education and school	School	Skills	Learn	Curriculum
	Education	College	Maths	Lessons
	Homework	Exam	A-levels	Subject
	Teach	Test	Academic	Skills
	GCSE	College	Educated	Lessons
	Grade	Results	Uniform	
	Study	Pupil		
Politics and society	Government	Black	Prejudice	Economic
	Racism	Homeless	Background	LBGTQ
	Society	Racist	Race	Racial
	Discrimination	White	Conservative	Culture
	Capitalism	Minister	Social pressure	Sexist
	Stereotype	Treated fairly	Politics	Societal
	Equal	Social mobility	Economy	Religion
	Gender	Community	Classism	Sexuality
	Skin	Communities	Social standard	Class[1]
	Colour		Homophobia	
Financial considerations	Money	Expensive	Debt	Wage
	Poverty	Cost	Income	Better house
	House	Financial	Student loan	Buy things
	Billionaire	Afford	Nice food	Minimum pay
	Rich	Bills	Prices	Housing

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[1] Class was used with the rule that the response also included system, social, lower, middle, upper, divide, gap, poor or working, to differentiate from uses of the word class to refer to education.

	Wealth	Housing	Living conditions	Material deprivation
Local area	Crime	Area	Safety	Park
	Gang	Violence	Surroundings	Local
	Knife	Play	Clubs	Town
	Drug	Environment live	Sport	Place
	Alcohol	Road man	Facilities	Street
	Chav	Facility	Smoking	Illegal
Jobs and careers	Job	Singer	Career	Dancer
	Footballer	Police man	Famous	Youtuber
	Vet	Train driver	University	Nurse
	Doctor	Designed	Universities	Work experience
	Artist	Qualification	Football player	Apprenticeship
	Player	Volunteer	Work experience	Employment
	Police officer	Employ	Qualification	
	Gamer		Horse rider	
Physical	Physical health	Illness	Healthy	Junk food
Family	Parent	Home life	Divorce	Husband
	Family	Sister	Upbringing	Sibling
	Social class	Brother	Mom/ Mum	Child abuse
	Dad	Families	Baby	Abusive parent
Peer relationships	Bully	People opinion	Rude people	Judging
	Social media	Judgement	Negative people	People think
	Peer	Mean people	Expectation	People discourage
	Influence	Other people	Bullied	Wrong crowd
	Friend	Social pressure	Bullies	hater
Self-belief	Motivation	Doubt	Determination	Shyness
	Confidence	Procrastination	Motivate	Belief
	Laziness	Dream	High expectation	Effort
	Fear	Attitude	Work ethic	Ambition
	Believe	Esteem	Negative thought	Lack encouragement
	Failure			
Opportunity	Opportunity		Opportunities	
Mental health	Mental	Stress	Pressure	Wellbeing
	Depression	Suicide	Mentally	Metal Health

	Anxiety	Mental Illness	Depressed	Worry
Pandemic	Covid	Pandemic	Pandemics	Covid-19
	Coronavirus	Lockdown	Covid19	Social Distancing
	Corona	Viruse	Virus	Cronavirus
Environment	Climate	Litter	Plastic	Earth
	Environment	Animal	Earth	Throwing Rubbish
	Global Warming	Plastic	Nature	Eco friendly
	Pollution	Planet	Rubbish	Trees

CHILDREN'S
COMMISSIONER

**Sanctuary Buildings, 20 Great Smith
Street London, SW1P 3BT**

020 7783 8330

@childrenscommissioner
@ChildrensComm
@childrenscommissionersoffice