

'We all have a voice'

Disabled children's vision for change

October 2023



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Foreword from Dame Rachel de Souza

As Children's Commissioner, it is my mission to ensure that all children are given the opportunity to reach their potential, and lead healthy, happy lives. My 2021 survey of over half a million children, The Big Ask, showed clearly that young people of all backgrounds and abilities, right across the country, aspire to the same things. However, what is also apparent is that some children face additional barriers to achieving their goals. The good news is that, if the right support is put in place quickly and locally, then children are happy. It can be done, and everyone working with and for children needs to work together to make this true for all children. I have a statutory duty towards children in care, those living away from home, and those with a social worker. Disabled children are disproportionately represented in these groups, and this is one of the reasons why a focus on these children is so important to me.

Earlier this year, I was delighted to be commissioned by the Cabinet Office's Disability Unit to explore in-depth the lives, experiences and needs of disabled children in England. Through this work I am keen to inform the Unit's forthcoming Disability Action Plan. Since then, my team and I have spoken to children, young people, parents and practitioners across the country to understand the challenges disabled children face, as well as what they want to see change.

The reality is that even today, in 2023, children and young people are coming up against the same obstacles that have existed for decades. Schools and other public services are not designed around their and their family's needs, and rather than children's uniqueness and diverse strengths being celebrated, they can be met with hostility and closed doors. Too many children and parents are having to do too much to receive even basic support. There are though lots of dedicated professionals, across the education, health and care systems, who are doing an incredible job supporting children, and I pay tribute to them. But often a postcode lottery exists, and children are being met with a system that is diagnosis-led, rather than needs-led.

Every child will need some kind of support at some point in their childhood. This ranges from the everyday things that parents and carers do to support their child with the routine obstacles that children face, to more acute care and support that some children need to be happy, healthy and safe. That might mean an adjustment to make sure they can sit their exams, or they might have a diagnosed additional need that requires therapeutic or clinical support. It might mean some additional speech and language support, help with managing their mental health and wellbeing, or more serious clinical support from doctors, social workers or psychiatrists. Children who are disabled may well be within this group, for some – or all – of their lives. I want to see an overhaul of how we think and talk about disabled children's experiences: it is not the job of one department, or one funding pot. We must consider what every child needs to fulfil their potential and feel pride in what they can achieve. For example, making public transport more accessible must go hand in hand with making sure all children have somewhere fun, safe and accessible to go. Improving the support given to children must sit alongside improving their transition to adulthood. This report will set out recommendations for what we need to see implemented over the next year, and beyond.

I want to express my immense gratitude to the hundreds and thousands of children, young people and parents whose voices contributed to this report. Change is possible and within reach, and I hope that the Government will seize this opportunity to be led by what disabled children tell us they want and need for a better world.

Executive Summary

'...We all have a voice - if it's by iPad or by mobile phone, or eye gaze, or a communication book'

– Boy, 17 (The Big Ask)

'[Disabled young people] all have dreams for this future, they shouldn't be silenced'

- Young man, 22.

This report brings together quantitative and qualitative research conducted by the Children's Commissioner's office (CCo) as part of a commission by the Cabinet Office's Disability Unit ahead of developing its Disability Action Plan 2023-24.¹ The Cabinet Office was particularly interested in understanding children's experiences of transitions, an important theme which is explored in this report. It also discusses other key barriers that disabled children face and puts forward recommendations based on what children say they want and need for a more inclusive society.

This report focuses on the experiences of disabled children – that can include children with autism and other neurodevelopmental needs, additional social and emotional needs, as well as physical needs.

There is a range of language used to describe the children we focus on – disabled children, children with disabilities, or children with 'special educational needs' (SEN) and 'special educational needs and disabilities' (SEND). The office is clear that what is crucial is that no child should be defined by a label, and that there is understanding that a child is disabled by a lack of inclusion. Sometimes it is more useful to use terms such as SEND when engaging with certain policies, or existing research and statistics.

Key findings:

- The number of children in England who are disabled is not known. There are different definitions and understandings of disability, resulting in a lack of consistent, centralised data.
 - In the Equality Act 2010, disability is defined as a physical or mental impairment that has a substantial or long-term negative effect on a person's ability to do normal daily activities. While data on the number of children who meet this exact definition are not available, the 2021 census of England found that 6% of children aged 0 to 14 (590,908) were limited in a little or a lot in their day-to-day activities by long-term physical or mental health conditions or illnesses.²
 - In the academic year 2021/22, 16.6% of children (1,485,409) and young people had either an Education, Health and Care Plan (EHCP) or were receiving SEN (Special Educational Needs) support in school. Many of these children will meet the definition of disability under the Equality Act, but some will not - and the size of the overlap is unknown. Using special educational needs and disabilities (SEND) as a proxy for disability is often necessary, but does not give a comprehensive picture of the number of children who are disabled in England.
- The Big Ask, CCo's survey of nearly 600,000 children found that children identified as having special educational needs and disabilities (SEND) have very similar aspirations for the future as other children - a great job and family life, and were just as happy as children overall. Children with an additional need, who were being supported in mainstream schools, were happier than the overall cohort.
- The Big Ask does highlight demographic differences that exist between children with and without SEND. Children with SEND are more likely than children without SEND to be attending a school in the most deprived fifth of neighbourhoods (18% vs 15%), to be in foster care (1.5% vs 0.6%), and to be a young carer (3% vs 1%).

- **This Big Ask also highlights the distinct challenges children with SEND face:**
 - Children with SEND are less likely to feel safe. Across all aspects of life asked about in The Big Ask, this was the largest relative difference between children with and without SEND (6% of children with SEND were unhappy with their personal safety, compared to 4% children without SEND).
 - A slightly higher share of children with SEND said in The Big Ask that it's unlikely they will have a better life than their parents compared to other children (11% vs 9%).
- In the Children's Commissioner's March 2023 nationally representative survey of 3,593 children, children with special educational needs and disabilities (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.
- In this survey, the proportion of parents who had never sought help for the mental health of their child with SEND was 22%, lower than other parents (73%), but also illustrating that not all parents of children with SEND see a need to seek help for their child's mental health.
- Disabled children face a number of barriers, including:
 - **Their needs not being identified early enough** – with children often waiting too long to get the help they need, and sometimes not until they have reached crisis. The time to receive support, and what support they receive at that point, is too variable;
 - **Schools not being a place where children with additional needs can thrive** – resulting in children being excluded from mainstream education, often where their needs could have best been met there;
 - **Inaccessible activities** – be that playgrounds, toilets, public transport or leisure activities that are not designed with the needs of disabled children in mind;
 - **Poor quality care** – particularly where it is not regulated, and too many children with the most acute needs are living away from home in settings that do not provide them with the high-quality care they should receive;

- **Bullying, discrimination and feeling unsafe** – with people often targeting children because they are disabled;
 - **Disruptive transitions between services** – with children and young people facing cliff-edges in support across their care, education and housing;
 - **Worrying about their parents, carers and families** – who are often put under strain by a system which does not take a whole family approach.
- Disabled children are clear about what they want for a better world:
 - To be understood, seen and heard;
 - To benefit from a fantastic, ambitious education in mainstream school where possible and support at school when they need it;
 - For all activities and services to be accessible;
 - To receive high-quality care locally and quickly;
 - To be free from harassment and discrimination;
 - For transitions to be smooth and prepare them for adulthood;
 - For services to see them as part of a family, and to take a whole family approach.

Recommendations:

1) To be understood, seen and heard

Early identification

1. The Department for Health and Social Care should prioritise early diagnosis of children's conditions and impairments by reducing waiting times for assessment and support in children's mental health services and community health settings. The Children's Commissioner will be publishing research into children's waiting times for different service types and pathways to support in early 2024 to support this priority.

Better data

2. The Cabinet Office should work with the Department for Education to ensure that all government departments and public bodies have a clear understanding of how special educational needs and
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disabilities (SEND) should be understood in relation to duties under the Equality Act 2010. Many children with SEND will meet the definition of disabled under this legislation, and it is important that different definitions and language to describe children's needs do not mean they miss out on support.

3. Central and local government should introduce a consistent, unique identifier for children, to facilitate better data matching between health, education and social care, to ensure disabled children do not fall through the cracks between information systems.
4. The Office for Health Improvement and Disparities should publish improved data on outcomes from the two-year-old Health Visitor check, including how often children are referred on for additional help.

Access to advocacy

5. The Department for Education should extend the commitment to provide opt-out advocacy to all disabled children, and ensure that the proposed advocacy standards clearly set out what high-quality, independent, non-instructed advocacy for disabled children looks like. Specialist training must be available for advocates. The Children's Commissioner is currently carrying out an advocacy audit to look at the quality of advocacy provision across the country.

2) Good education and support at school

Improving the SEND and alternative provision system

6. The Department for Education and the Department for Health and Social Care should swiftly implement the SEND and AP Improvement Plan, and publish a detailed roadmap setting out when each commitment in the plan will be delivered. Support needs to be local, consistent and responsive to children and families' needs. The Children's Commissioner continues to support and monitor this work through engagement with the SEND & AP Implementation Board.

Tailored support for attendance

7. Integrated Care Boards (ICBs) should monitor local school attendance data and make school attendance their priority. Local authorities should convene multiagency panels to discuss entrenched cases of school absences. ICB Leads for Children should sit on these panels and help to develop joint action plans to support disabled children to attend school, making adjustments where needed.

Championing inclusion

8. Ofsted should ensure its regulatory frameworks for schools focuses on the needs of disabled children, including their attendance at school and their wellbeing as key outcomes. They should do this by making sure that they speak to disabled children, and their families, during inspection. This would help to ensure that no service that is not welcoming and supportive of disabled children is graded 'outstanding'.

Use of restraint – safety as a priority

9. The Department for Education should urgently publish its updated guidance on the use of physical restraint in schools, including the prevalence and impact of restraint on disabled children and young people. This guidance should be clear restraint must only be used as a last resort and not routinely in the course of 'maintaining good order', the transparency of data and monitoring should be improved, and the guidance should set out a clear policy for informing parents and carers when their child has been restrained. The Department for Education should promote good practice happening in schools and alternative provision where restraint is not used, and only ever as a last resort, and where children feel safe and professionals feel in control.

3) Accessible activities

Fun holidays for every child

10. The Department for Education should award funding to each local authority for its Holiday Activities Food (HAF) programme based not only on the number of children who are eligible for Free School Meals in the area, but also the number of children who are *also* disabled - to ensure there is adequate funding for the additional expertise and resource required to make these
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programmes accessible to disabled children. Joined up local health, social care and education data would help to identify eligible children.

Accessible places to play and go

11. The Department for Levelling Up, Housing and Communities should set out, in its new guidance for local authorities on community engagement in planning, how areas should meaningfully engage with and be accountable to disabled children and young people, and their parents/carers/advocates where appropriate.
12. The Cabinet Office (CO) should make voluntary standards for playground accessibility mandatory.

4) High-quality care

Regulating care

13. The Department for Health and Social Care should expand the definition of 'personal care' to ensure the Care Quality Commission (CQC) can inspect all services and settings where care is being delivered to children, including care in families' own homes and in residential children's homes.
14. Where local authorities are funding care for disabled children, either directly or indirectly through payments to parents and carers, this care must be delivered by a regulated provider – including any childcare provision.
15. The recommendations from the national safeguarding practice review into safeguarding children with disabilities and complex needs in residential settings should be implemented in full. An ambitious, alternative model of care – jointly delivered by health and children's services – should be developed to provide a loving, caring alternative when children cannot live at home. The Department for Education and the Department for Health and Social Care should work together to review and revise the regulatory framework for residential settings for disabled children with complex needs, making clear where Ofsted and CQC are responsible for inspection, and where joint inspections are needed.

Workforce

16. Building on the commitments made in the SEND and AP Improvement Plan to increase the number of SENCo staff and educational psychologists, the Department for Education and the Department for Health and Social Care joint steering group for SEND workforce planning should develop a strategy to address the wider shortage of trained and qualified carers and personal assistants for disabled children. This strategy should also address the diminished population of school nurses, mental health nurses, learning disability nurses and health visitors – who are key to identifying children’s needs at the earliest opportunity.

Childcare

17. CCo welcomes the Department for Education’s recent consultation on potential changes to the Special Educational Needs Inclusion Fund Project (SENIF). CCo is very supportive of expanding the requirement on local authorities to establish a SENIF which is inclusive of all early years children - including children under 3.

Mental health support

18. The Department for Health and Social Care should work with the Office for Health Improvement and Disparities to ensure the distinct mental health needs of disabled children and young people are reflected in the mental health pillar of the Major Conditions Strategy.
19. The Government should bring forward proposed changes to the Mental Health Act to ensure that fewer disabled children are detained in inpatient settings.

5) Freedom from harassment and discrimination

Tackling bullying

20. Whole school anti-bullying programmes, with teachers appropriately trained, should be made mandatory and delivered to all children in PSHE lessons. Ensuring the delivery of these programmes should be a part of school inspections.
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Supporting disabled child victims

21. The Ministry of Justice should meaningfully consult disabled child victims and survivors in the development of its refreshed Victims Code of Practice, so that it is accessible and responsive to their distinct needs. The duty to collaborate in the commissioning of victims' services in the Victims and Prisoners Bill must be informed by robust data on disabled child victims in the local area.

6) Smooth transitions and preparing for adulthood

A whole child approach

22. Integrated Care Partnerships (ICPs) and Integrated Care Boards (ICBs) should strategically prioritise disabled children and young people's experiences of transitions in their strategies and Joint Forward Plans, including identifying who is locally accountable for ensuring smooth transitions between services.

Age-appropriate care for 16- and 17-year-olds

23. The Department for Health and Social Care should publish national guidance on admitting 16- and 17-year-olds to adult wards, and collect data which can be disaggregated by protected characteristics, including disability. Centralised data is currently only available for children in adult mental health wards.

Preparing for adulthood

24. The new standardised Education, Health and Care Plan (EHCP) template, a key proposal in the SEND and AP Improvement Plan, should support professionals to strengthen the transition pathway for disabled children from Year 9.

7) A Whole family approach

Inclusive Family Hubs

25. The Department for Education and Department for Health and Social Care should roll out Family Hubs to every local area, and update the programme guide to include information about ensuring
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the service is accessible to disabled children and their families, including where a parent or carer is disabled themselves. Family Hubs should be integrated with local schools, GPs, and health visitors in the neighbourhood as part of a local network, and make better use of the school estate. The Department for Education should develop a proportionate inspection model for Family Hubs which includes assessing their SEND inclusivity.

Joined up support

26. Department for Education should swiftly respond to the Children's Commissioner's *Family Review*, including the recommendation that in implementing the SEND reforms, social care reforms and Integrated Care Systems, children and families reaching the threshold for support in one element of the system also get support from other services, and there is no postcode lottery for support.

Reforming needs assessments

27. The Department for Education should clarify in its updated Working Together to Safeguard Children guidance how the primary need and purpose of a needs assessment will shape how the assessment is completed. The purpose of an assessment and the nature of a plan will be quite different for children who are referred because they are disabled compared to children who are referred for a safeguarding reason. Currently some of the guidance about how assessments should be conducted, and how progress can be monitored – by considering how much improvement parents and carers have made - would not be relevant to all disabled children's plans.

A note on language

Where possible, this research principally refers to 'disabled children and young people' in line with the social model of disability.³ This model identifies barriers in society as disabling, rather than people's impairments or health conditions. This research does however occasionally mirror terminology used by central and local government to identify children who may be disabled, including references to children with 'special educational needs' (SEN) and 'special educational needs and disabilities' (SEND). This includes instances where previous CCo research has used SEN/SEND as a framework to identify and

characterise children's needs, such as The Big Ask survey. Many children with SEND will also be disabled, an unknown overlap which is explored further in this report. To differentiate disabled children from all other children, this research refers to 'non-disabled' children and young people, or 'children without SEND' where relevant.

Not all children who meet the legal definition of being disabled will identify as 'disabled', and not all children who do not will identify as 'non-disabled'. As with any protected characteristic under the Equality Act 2010, individual preferences around language should be respected. One boy who participated in a CCo focus group said he thinks of himself as having a special need - not as being disabled, for example. Whether a child is born with an impairment or acquires one may also impact on how they choose to identify. Where this research has quoted children and young people, it has avoided diagnostic labels – instead leaving children to describe their impairment or condition in their own words, should they choose to.

1. Introduction

1.1 Definitions and concepts of disability in childhood

In the Equality Act 2010, disability is defined as a physical or mental impairment that has a substantial or long-term negative effect on a person's ability to do normal daily activities. 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.⁴ Children for whom this is the case may or may not identify as 'disabled' or as having 'disabilities'. The most recent Family Resources survey found that 11% of children are disabled under the Equality Act definition.⁵ The number of children in England who consider themselves disabled is unknown.

Definitions are difficult and may partly explain the lack of data on disabled children, who are not flagged as such in many public service data systems. Various definitions and understandings of disability exist, meaning that often central and local government struggle to determine how many children are disabled. This makes it difficult to commission sufficient and appropriate services, since commissioners do not have a clear picture of the prevalence and type of need. Another challenge of determining how many disabled children there are in England is that some conditions and impairments come and go over time – meaning that the figure will be smaller at a single point in time than over a time period. It is important to take a holistic view of children and young people's distinct and sometimes overlapping experiences of impairments, physical and mental ill-health, special educational needs, and neurodiversity – and to understand how the response to these can be disabling. Better data is needed to identify where children's experiences meet the Equality Act definition of disability, and to understand how children choose to describe their experiences.

This research is situated in the context of this complexity and breadth of experience. For more on disability concepts, definitions and data, please see this report's Annex.

1.2 Methodology

This study is based on new research and analysis by the Children's Commissioner's office (CCo), supplemented by a literature review and secondary analysis of published data. As part of this work, CCo conducted 11 focus groups and 5 interviews in 2023 with a total of 101 people – 51 children and 50 parents. CCo also carried out new analysis of 743 cases involving disabled children heard through Help at Hand, the Children's Commissioner's advice and representation service for children in care, children who have a social worker, children living away from home and care leavers. Finally, this report is informed by analysis of survey responses from The Big Ask, a national survey of over 500,000 children carried out in 2021, which included 51,007 children identified as having special educational needs and disabilities (SEND). The work also draws on insights gathered for the report, *Beyond the Labels: A SEND system which works for every child*,⁶ as well as previously unpublished findings from a nationally representative March 2023 survey commissioned by the office. For further information on the methodology and data presented in this report, please see the Annex, published separately.

1.3 Disabled children's characteristics

How disability is defined has important implications for understanding disabled children's characteristics, and any inequalities that exist.

Under the definition adopted for The Big Ask survey (see Annex), CCo explored differences and similarities between children with and without special educational needs and disabilities (SEND). This analysis did find some statistically significant patterns, for example, children with SEND were more likely to be boys and in a white ethnic group. The analysis also highlighted that when compared to other children, children with SEND are more likely to attending a school in the most deprived fifth of neighbourhoods (18% vs 15%), to have a social worker (8% vs 2%), to be in foster care (1.5% vs 0.6%), and to be a young carer (3% vs 1%). Statistics from the Office for National Statistics on the characteristics of pupils receiving SEN support/Education Health and Care Plans (EHCPs) show similar disproportionalities. The link between SEND and poverty is particularly strong, with 41.1% of pupils with an EHCP and 37.5% of pupils with SEN support eligible for free school meals in 2023, compared to 23.8% of all pupils in schools.

This analysis is also somewhat limited, as not all children's impairments and additional needs are equally and consistently identified. Research shows that there are ethnic and gendered disparities in how often children's needs are identified, and how they are diagnosed (see Annex). As examples, boys are overrepresented in the SEN population, and pupils from the Chinese ethnic group are underrepresented. This was something a 14-year-old young person reported as their experience in The Big Ask: *'I've found it is increasingly difficult for women to get diagnoses for many neurodivergent issues, such as autism, ADHD [...] simply because the stereotypes of most of these apply mostly to people of the male gender.'*

Disabled children have overlapping characteristics, and may consider other parts of their identity as equally or more significant. These other characteristics will also shape their needs and experiences as a disabled child or young person, and more research should endeavour to better understand this intersectionality.

1.4 Policy Context

In its Special Educational Needs and Disability (SEND) Code of Practice, the Government sets out its vision for children with SEND as being 'the same as for all children and young people – that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives.'⁷

Following its 2021 Disability Strategy, earlier this year the Government published its Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan.⁸ This plan included many welcome measures to reform the SEND and AP system, including improving Education, Health and Care Plans (EHCPs) templates, a focus on early help for children and families, and plans to develop a set of National Standards for what children can expect from the care and support they receive.

As this report highlights, a good education and support in school is a top priority for disabled children in particular. Swift implementation of this plan is therefore an urgent priority, and something the Children's Commissioner is pushing for through her participation in the plan's Implementation Board. However, the determinants of children and young people's life chances and wellbeing extend beyond the school gates.

Disabled children are not receiving consistent, adequate care. The national safeguarding practice review into safeguarding children with disabilities and complex needs in residential settings revealed what can go tragically wrong when disabled children aren't treated with the love and care they deserve.⁹ The appalling abuse and harm that was allowed to take place in three residential special schools in 2018 to 2021 speaks to a much wider, systemic problem of disabled children's voices not being heard. This must be a wake-up call to us all.

Disabled children also continue to experience exclusion and discrimination in other aspects of their life. Despite equalities legislation paving the way for so many important, positive changes for disabled people this report contributes to the substantial evidence base that often 'reasonable adjustments' to include disabled children are simply not put in place, and bullying and harassment can go unchallenged.¹⁰ It is therefore critical that children are at the centre of any cross-government action plan aiming to improve the lives of disabled people. This action plan must align with and drive positive change across different departmental policy programmes, from a much-needed update to mental health legislation, to reforms in children's social care, plans to improve children's safety online, and ability to access justice and support services as victims and survivors. Only then will the goal of all children leading happy and fulfilled lives be truly within reach.

2. Barriers faced by disabled children

In The Big Ask, over a thousand children mentioned disability as a potential barrier to achieving success in adulthood. In this survey, children were also asked “*When you grow up, how likely do you think it is that you will have a better life than your parents?*”. Overall, the barriers children perceived were very similar regardless of disability status, but a slightly higher share of children with SEND said that it was unlikely they would have a better life than their parents compared to other children (11% vs 9%). From this survey, as well as the focus groups and Help at Hand case analysis, a number of themes emerged around the key barriers disabled children face to fulfilling their potential.

‘Any teacher or any adult or just anyone in general that tells a child that they will never make it will give the child a negative mindset and make them think that they can’t do it, especially if they hear this phrase repeatedly’ – Girl, 14 (The Big Ask).

2.1 Needs not identified early enough

Many children’s impairments and conditions are particularly disabling because their needs are not identified, and the right support is not put in place. This can be detrimental to a child’s ability to lead a happy life, including being able to make friends and participate fully in school and their community.

‘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’ – Boy, 13, attending a school for deaf children (The Big Ask).

Often children have to reach a point of crisis before they get any support. In some extreme circumstances, this lack of support can result in children being taken into care as the strain placed upon families becomes too great. CCo analysis of data from The Big Ask shows that children with SEND are

slightly more likely to be in foster care than other children. This is supported by national statistics which show that over half (57.4%) of children who have been in care for at least 12 months have SEN, compared to 16.3% of the general pupil population.¹¹

'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 condition] and that we didn't know was [my condition] at the time...the support I was getting wasn't what I needed...I think it would have made everything 10 times easier' – Care-experienced young woman, 22.

Parents and families of children are often the first to pick up on their children's needs, but this does not always lead to swift diagnosis and support. Children's healthcare waiting times continue to rise, including for mental health services¹² and vital community health services, such as those which provide autism and attention deficit hyperactivity disorder (ADHD) assessments and diagnosis.¹³ The Children's Commissioner is determined to continue shining a light on this issue, and will be publishing research in early 2024 on waiting times for neurodevelopmental assessment and support across different health services. Children are also waiting long periods of time for their EHCP, with only half (49%) issued within the statutory 20-week time limit in 2022 (worse than the 60% issued in 2021).¹⁴ The proposals to standardise and digitalise EHCPs put forward in the Government's SEND and AP Improvement Plan are very welcome, and will help to tackle some of the backlogs in the system.¹⁵ They must be implemented as an urgent priority.

'The most disappointing thing is that we still don't have an EHCP. I don't know how to get it or any support. I feel like we've just fallen off a cliff' – Mum of girl, aged 12 with autism, attending mainstream school.¹⁶

As was highlighted earlier in this report, a child's characteristics – for example their age, gender and ethnicity – can impact on whether and when their needs are identified. Children with invisible impairments or conditions may be particularly at risk of being missed.

2.2 Schools not being welcoming and inclusive

The Children's Commissioner's extensive work on school attendance has highlighted that children want to be in school, but many face difficulties accessing education. CCo's *Attendance Audit* shows that unmet needs around mental health and SEND are two key factors associated with children missing school.¹⁷ This is reflected in national attendance statistics, which show that in the last full academic year, the rate of persistent absence was 38% and 33% for children with Education, Health and Care Plans (EHCPs) and children receiving SEN support, respectively. This compares to 22% for pupils with no identified special educational needs.¹⁸ The Children's Commissioner's report on looked after children who are missing out on education showed that looked after children with an EHCP were more likely to not be in school than those without an EHCP.¹⁹

Even when a child has a diagnosis or an EHCP, this does not always mean their needs are effectively understood by professionals. Many disabled children in contact with the Children's Commissioner's Help at Hand advice service have difficulties attending school, often due to lack of infrastructure and equipment for disabled pupils, such as wheelchair ramps, lifts, sensory rooms, hydro/physiotherapy sessions, fidget toys, weighted blankets, as well as problems with their EHCPs not being followed. Of the cases relating to disabled children identified in this research, almost a third (28%) of inquiries were about education – the most commonly raised issue. This theme also came through children's testimonies in The Big Ask. Often schools and teachers are not equipped to be able to effectively support children in mainstream settings, leading to children becoming persistently absent and even dropping out permanently.

'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 more upstairs classrooms that are inaccessible for some people'

– Girl, young carer, 15.

'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' – Girl, 16 (The Big Ask).

'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 am dyslexic and I don't feel there is enough support and resources in school to help me'

– Girl, 12, attending mainstream school with an EHCP (The Big Ask).

Children also report feeling that their impairment can be met with punitive responses, and that their need for adjustments, such as for more regular breaks, fiddle toys, or alternative ways of learning, can be misunderstood and mis-labelled as 'non-compliant behaviour'. Ofsted reports have also highlighted that despite the Government publishing guidance on Reducing the Need for Restraint and Restrictive Intervention in 2019,²⁰ inappropriate use of physical restraint is still being used on disabled children in some schools, which can be highly distressing and traumatising.²¹ Currently how restraint is recorded and reported continues to be at the discretion of individual schools.²²

'Mentally ill or neurodivergent students [are] labelled as "lazy" rather than trying to locate an underlying issue' – Girl, 17 (The Big Ask).

'When I was younger I used to be labelled as the naughty kid, because people at the time didn't understand what I had' – Young man, 23.

This is resulting in children not attending education, they have higher absence rates and higher suspension and exclusion rates.

'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' – Boy, 10 (The Big Ask).

Recovering from the pandemic

Children, parents and professionals have highlighted to the Children's Commissioner's office (CCo) just how profound the effect the pandemic and lockdown has been on disabled children. In The Big Ask survey, children were asked a single open text question which was thematically analysed to highlight some of the most common themes. One of the topics children with SEND were more likely than children without SEND to bring up in their written comments was the pandemic (13% vs 9%).

Previous research by CCo highlights that despite children with an EHCP being classified as "vulnerable" and allowed to attend school during lockdown, only 6% of children with EHCPs attended school on average from the start of the first lockdown in March 2020 until the end of May 2020.²³ Research into why those children eligible to attend school during this period did not suggests that parents thinking it was "too risky" to send their child to school was the most common factor.²⁴ It may also reflect a continuation of a pre-pandemic trend, with children who already felt their needs were not met in school continuing to stay at home.

However, many families struggled to meet the needs of children with EHCPs at home. Very few parents have the specialist skills needed to effectively teach their children, meaning that progress previously made was lost. The pandemic also meant that children were not accessing other vital services, such as healthcare. Emergency legislation during the pandemic meant that councils and local health bodies were only required to make "*reasonable endeavours*" to deliver these services.²⁵ Statutory timescales for assessing and issuing EHCPs were also temporarily relaxed through the 2020 Coronavirus Act, which has contributed to the backlog in children's needs being identified and them getting help.²⁶

While some children and parents found the lockdown a welcome respite – with school not always an inclusive place that supports children in the way they need, for many neurodiverse children and children who were already struggling with their mental health, the pandemic and lockdowns have exacerbated their social anxiety, with children struggling to return to school where before they were able to, or even to leave the house.²⁷

'I have ADHD and dyspraxia and have felt a lot more stressed and upset feeling isolated' – Boy, 16, in response to CCo Covid stress survey.²⁸

Children living in hospitals, children's homes and other care settings were cut off from in-person visits from their families and support networks, which was highly distressing for many children and young people. As one child who was living in an inpatient mental health ward during the pandemic said: *'Everyone else can hug their parents, but I can't.'*²⁹

For some children, the pandemic has created new mental health challenges which they need support to address to feel safe coming back to school.

'I'm worried about the poor mental health repercussions as a result of these lockdowns...the increased number of people (including young people) with anxiety, depression, agoraphobia, OCD, etc.' – Girl, 9 (The Big Ask).

2.3 Inaccessible activities

School is just one arena that is often not accessible enough to disabled children. Many other activities and public services are also exclusionary of children with impairments or additional needs.

All children should have safe and fun spaces to play with their friends. Accessible playgrounds are an important part of this, and CCo welcomes the Cabinet Office's consideration of introducing mandatory accessibility standards and supporting guidance. It is also important to consider where else children want to spend their free time. Sadly, not all disabled children have access to inclusive and fun extra-curricular activities. Disabled students in mainstream schools may have 1:1 support during the day, but parents told CCo this is often only funded up to the end of the school day, meaning that children's ability to take part in after-school activities is limited. As one parent of a disabled child put it: *'we're relying on goodwill'*. Not all playschemes, summer camps, and other programmes are set up to support children with impairments, health conditions or additional needs in practice, meaning the holidays can be a lonely and boring time for many children.

In The Big Ask survey, the accessibility of public spaces, particularly for children in wheelchairs or with mobility difficulties was mentioned as a key 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).

'[There needs to be] 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).

Pupils at the residential special school told CCo about activities they would like to take part in but that are difficult for them to access. One example given was when the class wants to go out together on the bus, but it is not possible as there is only one wheelchair space. Young people also said this problem exists when going to the theatre or a restaurant with another friend who is a wheelchair user, as often there is not enough space for them to sit together.

Public toilets are often also a barrier. Even toilets designed for disabled people are not always accessible, for example those which do not have a safe space for disabled children and young people to wait for their carer while they are using the facilities.

2.4 Poor-quality care

Tragically, we continue to see institutional neglect and abuse of children. The recent national safeguarding practice review into safeguarding children with disabilities and complex needs in residential settings in Doncaster in 2018 to 2021, revealed appalling, systematic abuse of children.³⁰ The recommendations from that review must be implemented in full in order to drive up the standards in residential care. But equally it is essential that a more ambitious model of care is developed for children who may need residential provision, particularly those children who are at risk of being deprived of their liberty. Too often we focus on what settings shouldn't be, rather than what a familial, caring, loving, positive alternative would be. The introduction of Regional Care Cooperatives are an opportunity to trial

new joint ways of working between ICBs, NHS and local authorities to develop care pathways and models of care that can allow children to live fuller, freer and more fulfilling lives.

While this is among the most serious and extreme safeguarding violations, children's experiences of poor-quality care are sadly not uncommon.

The lack of regulation of children's care is part of the problem. Many services providing care to disabled children, such as care in private homes and day care settings for children over 8 years, are unregistered (and are not required to be). In one case heard by Help at Hand, a concerned employee reached out regarding an organisation purportedly providing a day centre (non-residential care) to disabled children aged over 8, which was being recommended by the local authority to families of disabled children. The concerns ranged from physical abuse of the children, to providing services that should have been regulated. Despite reporting this abuse, because the service is unregulated, few sanctions could be imposed below the threshold for criminal prosecution.

Another problem is carers who support children in their homes not being properly regulated. In one case heard by Help at Hand heard in 2022, parents of a child with physical and mental impairments were struggling to cope, but were keen that their child stay at home. They requested respite but the local authority provided this in the form of carers in the home (instead of via short breaks, which is what they wanted). Unfortunately, the care staff were inconsistent, some were inexperienced and ill-equipped to manage the child's needs, and there were regular cancellations so the family often did not receive the hours they had been funded for. This inconsistency had a negative impact on the child, who was unable to form relationships with the carers, and whose behaviour escalated. It also meant his parents felt they couldn't leave the carers alone with him, so the arrangement did not provide the respite they needed and they became exhausted to the point of breakdown, which further impacted on the child.

Another theme to emerge from the Help at Hand case analysis is the problem of some local authorities not finding appropriate care for children, and sometimes shifting this responsibility onto parents. In one case study heard by the Help at Hand team, many parents of very severely disabled children accessed personal care through a Care Quality Commission (CQC) registered agency, and this was coordinated by the local authority. The CQC raised concerns about this agency and the local authority decided it was

not safe to use them. The children all lost their personal support overnight, and the local authority said the families could have direct payments instead, citing the pandemic. Most of the families CCo spoke to could not find anyone who would do this work. The stress on the families in having to carry out all the care for these children was extreme and some considered placing the children into care as they felt they could not cope. The local authority said the problem was due to a depleted workforce. While some children and parents may prefer direct payments, this should always be a genuine choice.

Salma's story*

Salma has complex physical and learning impairments. All professionals and her family agree she is not able to attend a school setting.

However, she does want and need educational input and activities during the day. The local authority has struggled to find professionals who can offer this, and have told Salma's mother that she can find them and they will pay her through direct payments.

Salma's mother feels she already has so much to organise and do for her child's care, and that she cannot also oversee and source her educational provision.

**Not her real name*

Luke's story*, 2022

Luke has severe autism and distressed behaviours. He lives at home and is not in education due to multiple school placement breakdowns.

His parents were really struggling to cope with his behaviour, which was at times violent and a risk to his siblings. The local authority did not have any available respite, daytime or overnight, and could not find a care agency in the region to meet Luke's needs.

They provided direct payments for carers, but his parents also could not find any agency able to take on this role, meaning the situation reached the point of breakdown.

Ultimately, a family member offered to be Luke's carer and direct payments were set up for them (after some delay) but this was only a short-term solution, and the local authority made it clear that the absence of high-quality care agencies in their area was a critical issue.

**Not his real name*

Many disabled children also struggle to access mental health support. The Children's Commissioner's nationally representative 2023 survey highlighted that parents of children with SEND were much more likely to report having ever sought help for the mental health of their child when compared to other parents (71% vs 18%). However, as has been highlighted by the Children's Commissioner's annual mental health briefing, average waiting times between a child being referred to mental health services and starting increased from 32 days in 2020-21 to 40 days in 2021-22, and the percentage of children who had their referrals closed before treatment has also increased for the first time in years.³¹ The next annual mental health briefing in 2024 will update these numbers.

2.5 Bullying, discrimination and sense of safety

Inaccessible services are not the only way children and young people experience discrimination. Children also spoke about the prejudice they face throughout their childhood, adolescence and early adulthood – from the playground right through to the world of work.

'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... what gives them the right to treat you unfairly and with no respect?' – Girl, young carer, 17.

'I have a disability – Down's 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'
– Girl, 17 (The Big Ask).

All children want to feel included and connected, and bullying is a problem that both disabled children and non-disabled children spoke about in The Big Ask. However, research shows that disabled children

are particularly vulnerable to bullying³² – and often report being bullied by their peers because of being disabled. Despite disability being a protected characteristic in the Equality Act 2010, harassment provisions do not currently extend to pupil-pupil harassment.³³ However, this experience can have a profound impact on a child's mental health and self-esteem, and may help to explain why CCo found that children with SEND were more likely to report being lonely. In the Children's Commissioner's 2023 nationally representative survey, 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.

'If somebody has a mental disability or is bullied they will feel bad about themselves and possibly become depressed, which makes them sad so they won't want to come to school because they'll think that they'll just get bullied more if they go in' – Girl, 10 (The Big Ask).

'A friend of mine with autism found she had little learning support and no protection from the bullying she was put through as a result of her autism' – Girl, 17 (The Big Ask).

Later in life, disabled young people also speak about experiencing discrimination in work settings. Disabled children are ambitious about their futures. However, application processes and work environments can be exclusionary of disabled applicants and employees.

'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 [an impairment] - that appears at first glance contradictory' – Young woman, 22.

Another dynamic that came out through speaking to young people was the discrimination they experienced based on where they live. While some local areas have a good range of inclusive and disability-friendly charities, organisations, and work opportunities, this is not the case everywhere. Regional inequalities exist, as well as a disparity in available provision between urban and rural areas. CCo heard that families with disabled children in rural areas often have to travel further than other families to reach accessible activities, as fewer places offer these activities than their mainstream equivalents.

'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.

Many disabled children will experience discrimination not only on the basis of being disabled, but also due to their gender, age, race, ethnicity, sexual orientation, religion and other aspects of their identity and social circumstances. These experiences of discrimination overlap, often compounding the levels of exclusion and prejudice a child or young person faces. This was something children and young people responding to The Big Ask often highlighted as the biggest barrier they face to achieving their goals:

'[The biggest barrier is] discrimination and hate crimes, particularly towards children of BAME backgrounds or those who are disabled.'

'For disabled people of colour and any minority it can be very damaging to mental health to know that you may not be able to do what you want in the future because of accessibility.'

Concerningly, children with special educational needs and disabilities (SEND) are all also less likely to feel safe than other children. Across all aspects of life asked about in The Big Ask, the largest relative difference between children identified as having SEND and children without SEND was in the share of children unhappy with their personal safety. Children with SEND in Black and Mixed ethnic groups were more likely to be unhappy with this than White and 'Other' children with SEND, as well as Black and Mixed ethnic children without SEND. More positively, where children with SEND reported receiving help from a social worker, they less often reported being unhappy with their personal safety than children with SEND but no social worker.

Children's sense of safety is determined by many aspects of their life and environment. As well as experiences of bullying and discrimination being likely to erode children's sense of safety, it is significant that disabled children are more likely to be victims of crime. The latest (2023) statistics for England and

Wales show that disabled children aged 10 to 15 were more than twice as likely to have been a victim of crime in the past year than other children (22% compared to 9%).³⁴

2.6 Disruptive transitions between services

There are many life transitions which are unique to children, like starting school, moving from primary to secondary school, and entering adulthood. For some disabled children, transitions may be distinct from and occur at different times to most children. This may include moving from mainstream to specialist services, from living with their family to residential educational settings, from children's health and social care services to adult ones, and for some young people, it may be transitioning to living independently. Care-experienced disabled children and young people often experience additional transitions, such as care placement moves which can result in knock-on changes to schooling and the area they live.

When these transitions do not involve meaningful consultation with children, are not effectively planned for, or are not properly supported, they can be disruptive and traumatic for the child or young person. While some children reported very positive experiences of transitioning between services and support, for others it can be overwhelming and destabilising. The variation in children's experiences is sometimes exacerbated by the postcode lottery of effective support for transitions.

'It felt like a chaotic situation because there was so much going on...I was taken away from where I had grown up...It threw me into a situation where I didn't know anyone...It was very much having to get used to so much at once which caused quite a few meltdowns in the fact that I was just so overwhelmed...I couldn't quite cope' – Young woman, 21.

Spotlight on transitions in a residential special school

The CCo visited children and young people living in a residential special school, who discussed how moving into and on from these schools involved changes not only to their education, but also their

living arrangements. Smooth transitions were made harder by the limited provision of residential places, and suitable move-on options.

When children come to the residential special school, it is a transition for both the child and their family. While some residential schools are able to cater for families to visit on the weekends, it is a huge change to move from cohabitation to arranging points of contact.

The natural progression for children at the residential special school is 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. It depends on the funding opportunities available, and the decision often sits with the local authority.

A further transition takes place when young people finish college. At the end of the academic year the local authority must find a place for young people to live. Professionals told CCo that the young people need to be prepared for the transitions to their new environments. However, more often than not, placement moves are decided at the last minute, if at all. CCo heard that it is increasingly common that nothing is put in place for young people due to lack of appropriate move-on accommodation. In these circumstances, children may have emergency extensions to avoid becoming homeless. As well as creating uncertainty for the young person, this means there is no space for new young people joining the school to live on-site. Other children may be forced to move home again. At the onsite college, two young people who were due to finish college this year were moving back in with their families. Professionals told CCo that this was far from an ideal or sustainable situation for these young people and their families. However, as the local authority had found no other suitable accommodation for them, this was the solution for them for now.

Sharp cliff-edges in support, particularly around the transition from children to adult's services, is something children experience across a range of services. Professionals at the residential special school spoke about one young person they had been supporting who recently turned 18. This young person had been using pull up pads to date, 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.

The transition from children to adult's services can be particularly stark for young disabled people who do not have a formal diagnosis. While many young people will have struggled up until that point anyway, there are some children who may have been benefitting from informal, additional support from professionals who know them and their needs well. This support then falls away at the point of transition. This was something one professional working in a college described to be the case: *'There's quite a lot of young people...when they leave college and they're in that category, they go into a black hole. They might not have a diagnosis specifically, but they're not able to go onto 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.'*

Even before children turn 18, professionals speak about a '16 to 18 void' in the NHS which many of the children they support experience. 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. There is currently no centralised data on children admitted to non-mental health adult wards. In terms of mental health inpatient settings, most children are treated in Children and Adolescent Mental Health Services (CAMHS), and guidance states that children should only be admitted to adult wards in 'exceptional circumstances'.³⁵ However, previous research by CCo has highlighted that the number of children being admitted to adult mental health wards is rising,³⁶ a trend that has continued.³⁷

Professionals interviewed by the Children's Commissioner's office also spoke about the '16 to 18' void in relation to children falling between the gaps of support. They explained that it seems that at the age of 16 neither children's or adult's services want to pay for products that are essential to the young people, even those that have been prescribed.

Furthermore, young people mentioned that it was difficult to know which services could support them when they were moving between different local authorities, for example which local authority was responsible for their EHCP and which NHS trust they can access. When services don't speak to each

other, children and their families can be forced to re-tell their story to multiple professionals – all of which may be working within different models of care and with different thresholds for support.

Spotlight on care-experienced disabled children's experiences of transitions

As well as experiencing big transitional life changes associated with their impairment or health condition, care-experienced disabled children also face parallel changes in their education, housing and care – sometimes having to leave behind their friends and everything they know. Some children are even separated from their siblings. For this reason, children who do consider themselves disabled may consider other identities, such as being care-experienced, as equally or more significant.

The Children's Commissioner's office recent report on Looked After Children Not in School brought to light the challenges faced by children in care with an EHCP who are placed out of area.³⁸ While a looked after child's home local authority is responsible for their care plan, the local authority where the child is living (if placed out of area) is responsible for their EHCP. Often there is confusion over which local authority should pay for any costs associated with getting the child the right education through their EHCP, which contributes towards delays in looked after children finding an appropriate schools – and disruptive transitions.

Many of the disruptive transitions disabled children and young people face are even more daunting for those in care, who may have less support from family or carers. As one young woman put it: *'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.'*

Measures are in place to support care-experienced young people transition to adulthood, such as appointing a Personal Adviser and developing a Pathway Plan, however often this cannot replace having support from family and carers. One young person felt that because she did not leave on good terms with her foster parents, she had no one to support her with independent living in adulthood.

Some children in care do of course have very supportive carers and foster parents. However, arbitrary thresholds, such as a child's 18th birthday, can cause unnecessary disruptions in their care.

Henry's story*, 2021

Henry is a care leaver with profound impairments - 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 move 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.

**Not his real name*

2.7 Worrying about parents, carers and family

A striking theme to emerge from the research is children's concern for their parents, carers, and families. Children's testimonies reveal the immense pressure the system can place on families, with getting the support their child needs often a very involved process. There is also often a lack of support for helping families better manage their child's impairment, such as adaptations to home infrastructure and hiring

carers to help with household duties or take the children out to school, play or other activities. Children are clearly grateful for their parents' unconditional support, but worry that this is putting too much stress on them.

'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'
– Boy, 13, attending a school for deaf children (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' – Boy, 12, (The Big Ask).

Children use combative language to describe what can be an adversarial process to get help for their impairment or health condition, such as getting an EHCP or an appropriate school place. Families can be forced to enter protracted complaints processes, mediation, tribunals and court proceedings with a range of services – for example schools, local authorities and children's social care. Government statistics show that the number of registered SEN appeals to HM Courts & Tribunals Service in the academic year 2021/22 - 11,000 - was 29% higher than the previous year.³⁹ Of the cases where an outcome was reached by the tribunal in 2021/22, 96% were in favour of the appellant – that is, the families of disabled children.⁴⁰ Statutory services often feel as though their hands are tied by huge backlogs and waiting lists, and a lack of resource and available local specialist support. Sadly, this leads children to feel as though they are 'fighting a battle'.

'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).

'My EHCP, it took 3 years to actually get one, it got pushed back. My parents and [special school] had to fight for us to get one.' – Boy, aged 16, attending a special school.⁴¹

This often has huge costs for the family, including legal fees and potentially having to pay for private assessment, advice, treatment and care in the interim. Some families will get into debt to be able to afford the support their child needs. The stress and financial pressure involved in accessing support can take its toll on the wellbeing of the whole family. Many disabled children and young people have to

grow up quicker than other children, who can enjoy their childhoods without worrying that their care is burdensome on their parents or carers.

'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' – Girl, 13 (The Big Ask).

3. What disabled children want

All children want to live in a world which enables their ability, nurturing and supporting them to thrive. This report highlights that while children share many of the same aspirations in life, there are considerable differences in what is holding them back from achieving their dreams. Disabled children face many hurdles in life that do not exist for other children. Children and their families show incredible resilience every day in developing strategies to manage and overcome these barriers - but no child should have to grow up in this way. The fact that disabled children are more likely to feel lonely, unsafe, need help for their mental health, and doubt they will have a better life than their parents is a stark indication that we are failing a huge cohort of children.

Disabled children and young people are clear about what they want for happy, fulfilling lives. They want to be understood, seen and heard; to receive an excellent education and support at school; to have access to fun activities in their area; to enjoy high-quality care; to live their life free from harassment and discrimination; to get help for their families; and to be supported for big life changes and adulthood. This report sets forward recommendations based on these priorities. We must be as ambitious for children's futures as they are.

'[Disabled young people] all have dreams for this future, they shouldn't be silenced' – Young man, 22.

3.1 To be understood, seen and heard

First and foremost, disabled children want their voices to be heard. Article 12 of the UN Convention on the Rights of the Child states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. For this to be possible, early identification of children's needs, together with high-quality support, is essential. Some children wait until adulthood until their needs are fully understood and the appropriate adjustments are put in place.

'I think it should be mandatory for every primary and secondary school to test all students once a year for any learning disabilities [...] as learning disabilities can even develop over the years'

– Girl, 17 (The Big Ask).

Children with impairments affecting their communication may find it particularly challenging to be heard. Adults and professionals must be sensitive and responsive to children's diverse ways of communicating, which may change over time – from touch to gestures, eye contact, body language, sounds and facial expressions. Children who can speak, but who experience sensory and/or emotional dysregulation may also struggle to communicate their needs, and also need the adults around them to be responsive to this.

'People with disabilities are very intelligent in their own way, we all have a voice - if it's by iPad or by mobile phone, or eye gaze, or a communication book' – Boy, 17 (The Big Ask).

Too often, because of their age, children are not at the centre of decision-making about their lives. This is perhaps particularly acute for disabled children, who often have many professionals involved in their lives, and are subject to decision-making processes which are not always inclusive. One young woman told CCo she did not feel empowered to speak up as a child about being adopted.

'The only issue with [the adoption] 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, 24.

This young woman 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 a meeting, for others it may be better to record a video. Young people told CCo that the right support comes down to being child-centred, rather than having to choose from a list of things that are available and nothing else. As one young woman put it: *'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.'*

Effective, child-centred advocacy can play an important role in ensuring children's voices are heard, and other professionals are challenged where necessary. Help at Hand, the advice line provided by the Children's Commissioner's office to children in care and children living away from home, is just one example of this kind of support. The SEND Code of Practice states that 'advocacy should be provided where necessary. Local authorities must provide independent advocacy for young people undergoing transition assessments, provided certain conditions are met.'⁴² However, the continued need for all disabled children to have access to opt-out advocacy was a key finding from the national review into safeguarding children with disabilities and complex health needs.⁴³ Care-experienced disabled children have additional statutory entitlements to advocacy. However, the Independent Review of Children's Social Care concludes 'advocacy is an afterthought in the current system, with some local authorities failing to provide any service to children who need to raise concerns about their care.'⁴⁴

Maddie's story*

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 being disabled. 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 can speak but due to her impairment and age she worked with an advocate who was able to take non-instructed action on her behalf, based on Maddie's views and preferences. 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.

**Not her real name*

Recommendations:

Early identification

1. The Department for Health and Social Care should prioritise early diagnosis of children's conditions and impairments by reducing waiting times for assessment and support in children's mental health services and community health settings. The Children's Commissioner will be publishing research into children's neurodevelopmental waiting times and pathways to support in early 2024 to support this priority.

Better data

2. The Cabinet Office should work with the Department for Education to ensure that all government departments and public bodies have a clear understanding of how special educational needs and disabilities (SEND) should be understood in relation to duties under the Equality Act 2010. Many children with SEND will meet the definition of disabled under this legislation, and it is important that different definitions and language to describe children's needs do not mean they miss out on support.
3. Central and local government should introduce a consistent, unique identifier for children, to facilitate better data matching between health, education and social care, to ensure disabled children do not fall through the cracks between information systems.
4. The Office for Health Improvement and Disparities should publish improved data on outcomes from the two-year-old Health Visitor check, including how often children are referred on for additional help.

Access to advocacy

5. The Department for Education should extend the commitment to provide opt-out advocacy to all disabled children, and ensure that the proposed advocacy standards clearly set out what high-quality, independent, non-instructed advocacy for disabled children looks like. Specialist training must be available for advocates. The Children's Commissioner is currently carrying out an advocacy audit to look at the quality of advocacy provision across the country.

3.2 Good education and support at school

'I would probably educate the teachers more and the staff, because with my disability, I sometimes have to leave lessons' – Boy, young carer, 13.

'I have like a small bag in my bag with, like, different stress and anxiety toys to help me cope' – Girl, 18.

In The Big Ask, children were asked to select up to five of their top future priorities. The top two priorities were the same for children with and without SEND: 'A good job or career' and 'Enough money to buy the things I need'. The largest absolute difference between children with and without SEND was in the share of children who chose 'Having a good education' - with children with SEND more likely to prioritise this (58% vs 51%). This difference was slightly more marked for girls, with 58% of girls with SEND saying this was a priority compared to 49% of girls without SEND (among boys, the difference was slightly smaller: 60% vs 54%). There was a similar disparity in future worries: more children with SEND were worried about having a good education than children without SEND (22% vs 17%).

Children who wrote comments about disability in The Big Ask said they wanted easier routes to diagnosis within school, easier access to treatment, and more awareness within school of different types of SEND. Children feel teachers need more training to equip them with learning materials and teaching approaches that play to children and young people's strengths, and challenge the discrimination and bullying they often face inside and outside of school. This would help disabled children to attend and stay in education, and help teachers avoid misidentifying a child's additional needs as bad behaviour. Children prioritised a range of things as part of their visions of an inclusive school, highlighting the importance of flexibility and tailored support (see Figure 1 overleaf).

Figure 1) Imagine your perfect school - What would it look like? What would it have?



Figure 1 - Three 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. Some of their responses are quoted in this report.

The pandemic has had a profound impact on an entire generation of children. Disabled children and young people have been hit particularly hard and must be given additional support to return to education – including for their mental health. It is critical that supporting disabled children to attend and achieve at school is not seen as the sole responsibility of education providers. Often the main drivers of poor attendance are beyond the control and remit of a school. Other agencies, including health and children’s social care, must take equal ownership and accountability of this issue.

Recommendations:

Improving the SEND and alternative provision system

6. The Department for Education and the Department for Health and Social Care should swiftly implement the SEND and AP Improvement Plan, and publish a detailed roadmap setting out when each commitment in the plan will be delivered. Support needs to be local, consistent and responsive to children and families’ needs. The Children’s Commissioner continues to support and monitor this work through engagement with the SEND & AP Implementation Board.

Tailored support for attendance

7. Integrated Care Boards (ICBs) should monitor local school attendance data and make school attendance their priority. Local authorities should convene multiagency panels to discuss entrenched cases of school absences. ICB Leads for Children should sit on these panels and help to develop joint action plans to support disabled children to attend school, making adjustments where needed.

Championing inclusion

8. Ofsted should ensure its regulatory frameworks for schools focuses on the needs of disabled children, including their attendance at school and their wellbeing as key outcomes. They should do this by making sure that they speak to disabled children, and their families, during inspection.

This would help to ensure that no service that is not welcoming and supportive of disabled children is graded 'outstanding'.

Use of restraint – safety as a priority

9. The Department for Education should urgently publish its updated guidance on the use of physical restraint in schools, including the prevalence and impact of restraint on disabled children and young people. This guidance should be clear restraint must only be used as a last resort and not routinely in the course of 'maintaining good order', the transparency of data and monitoring should be improved, and the guidance should set out a clear policy for informing parents and carers when their child has been restrained. The Department for Education should promote good practice happening in schools and alternative provision where restraint is not used, and only ever as a last resort, and where children feel safe and professionals feel in control.

3.3 Accessible activities

While school and a good education is really important to children, so is their leisure time and life outside of school. Many of the children and young people CCo spoke with were involved in a range of different activities, from youth clubs to sports teams. Professionals CCo spoke with emphasised the importance of sport for children who are disabled because it often combines fitness, access to nature and outdoor spaces, and other essential developmental skills like teamwork. However, specialist teams or training are harder to come across and often prohibitively expensive. More investment must be dedicated to increasing the availability of fun, accessible extra-curricular activities for children.

Fun holidays for every child

In August 2023, CCo visited one of the summer activities delivered in partnership by Portsmouth Council and Enable Ability, as part of their Holiday and Activities Food (HAF) programme. Funded by the Department of Education, the HAF programme has been rolled out across the country to support lower income families during the school holidays.⁴⁵ HAF Fun Pompey in Portsmouth is paving the way for the tailored activities it provides to children with SEND.⁴⁶

At Staunton Farm, children with a range of needs were supported by trained staff to enjoy a fun day feeding and petting the farm animals. Throughout the summer, other activities such as accessible cycling and swimming, pizza-making, soft play and trips to the local parks were also on offer. Children said that it was something that they really looked forward to, and a few said that when they are not on the programme they tended to spend the summer holidays at home. For some children, it was the first time they had made good friends, and tried certain fruits and vegetables.

To make sure the programme and each activity is right for the child, Enable Ability visits the child in their home before the programme begins and carry out a thorough needs and risk assessment. Enable Ability will work with the child and their family to create a detailed care plan, including around what adjustments that child may need to be able to participate and to feel safe and secure, the appropriate child-staff ratio for their level of need, dietary requirements, and information about any medication they may take. Through this they will also learn about the child's particular interests and strengths.

HAF Fun Pompey is also committed, where appropriate, to supporting disabled children and young people to participate in their mainstream provision. They have worked with the Council for Disabled Children to collate a Holiday Activities and Food Programme Toolkit to share good practice with other local authorities engaging and supporting children with additional needs.⁴⁷

The biggest challenge HAF Fun Pompey faces is the sheer volume of demand for inclusive activities for children and young people. Developing a truly inclusive programme requires additional resource. It is clear from the children who enjoyed the day at Staunton Farm that this is very worthwhile investment.

Children also spoke about the need for their local areas - like public transport, cinemas, restaurants, toilets and playgrounds, to be designed with them in mind. Being included in these spaces is central to children's wellbeing and sense of belonging.

'[I want] accessible transport, step-free access to offices, stations and other public buildings, support from local councils for young people with disabilities so that we can be equal and independent'

– Boy, 15 (The Big Ask).

Recommendations:

Fun holidays for every child

10. The Department for Education should award funding to each local authority for its Holiday Activities Food (HAF) programme based not only on the number of children who are eligible for Free School Meals in the area, but also the number of children who are *also* disabled - to ensure there is adequate funding for the additional expertise and resource required to make these programmes accessible to disabled children. Joined up local health, social care and education data would help to identify eligible children.

Accessible places to play and go

11. The Department for Levelling Up, Housing and Communities' should set out, in its new guidance for local authorities on community engagement in planning, how areas should meaningfully engage with and be accountable to disabled children and young people, and their parents/carers/advocates where appropriate.
12. The Cabinet Office should make voluntary standards for playground accessibility mandatory.

3.4 High-quality care

Disabled children want excellent health and social care services, wherever they access them. The national safeguarding practice review has identified systemic issues in the care of disabled children, and urgent reform needed to protect disabled children in residential settings.⁴⁸ It is critical that lessons from this review are taken forward, and all settings where disabled children receive support are safe and deliver high-quality care. This includes the care children receive at home, in daycare, short break stays, mental health services and inpatient settings. It is also vital that appropriate support is readily accessible, so that no child and their family is left unsupported.

Recommendations:

Regulating care

13. The Department for Health and Social Care should expand the definition of 'personal care' to ensure the Care Quality Commission (CQC) can inspect all services and settings where such is being delivered to disabled children, including care in families' own homes and in residential children's homes.
14. Where local authorities are funding care for disabled children, either directly or indirectly through payments to parents and carers, this care must be delivered by a regulated provider – including any childcare provision.
15. The recommendations from the national safeguarding practice review into safeguarding children with disabilities and complex needs in residential settings should be implemented in full. An ambitious, alternative model of care – jointly delivered by health and children's services – should be developed to provide a loving, caring alternative when children cannot live at home. The Department for Education and the Department for Health and Social Care should work together to review and revise the regulatory framework for residential settings for disabled children with complex needs, making clear where Ofsted and CQC are responsible for inspection, and where joint inspections are needed.

Workforce

16. Building on the commitments made in the SEND and AP Improvement Plan to increase the number of SENCo staff and educational psychologists, the Department for Education and the Department for Health and Social Care joint steering group for SEND workforce planning should develop a strategy to address the wider shortage of trained and qualified carers and personal assistants for disabled children. This strategy should also address the diminished population of school nurses, mental health nurses, learning disability nurses and health visitors – who are key to identifying children's needs at the earliest opportunity.
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Childcare

17. CCo welcomes the Department for Education's recent consultation on potential changes to the Special Educational Needs Inclusion Fund Project (SENIF). CCo is very supportive of expanding the requirement on local authorities to establish a SENIF which is inclusive of all early years children - including children under 3.

Mental health support

18. The Department for Health and Social Care should work with the Office for Health Improvement and Disparities to ensure the distinct mental health needs of disabled children and young people are reflected in the mental health pillar of the Major Conditions Strategy.
19. The Government should bring forward proposed changes to the Mental Health Act to ensure that fewer disabled children are detained in inpatient settings.

3.5 Freedom from harassment and discrimination

Disabled children want to lead lives free from discrimination, harassment and victimisation, and be treated with dignity and respect – as is their right under the Equality Act 2010.⁴⁹ Children should not have to fear for their personal safety when they leave the house or go to school. Tackling bullying in schools is particularly important when thinking about how and where disabled children are likely to experience abuse. While taking a whole school approach to tackling bullying is proven to make a particularly positive difference for disabled children,⁵⁰ fostering an inclusive learning environment is good for all children.

Children also want to feel safe in their communities. It is shocking that disabled children aged 10 to 15 are more than twice as likely to have been a victim of crime in the past year than other children (22% compared to 9%).⁵¹ When children do sadly experience harm – they must be given access to safety, support and justice.

'[The thing I'd like to change is] 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).

Recommendations:

Tackling bullying

20. Whole school anti-bullying programmes, with teachers appropriately trained, should be made mandatory and delivered to all children in PSHE lessons. Delivery of these programmes should be a part of school inspections.

Supporting disabled child victims

21. The Ministry of Justice should meaningfully consult disabled child victims and survivors in the development of its refreshed Victims Code of Practice, so that it is accessible and responsive to their distinct needs. The duty to collaborate in the commissioning of victims' services in the Victims and Prisoners Bill must be informed by robust data on disabled child victims in the area.

3.6 Smooth transitions and preparing for adulthood

Disabled children want support to have good experiences of transitions, and be equipped with the life skills they need for adulthood. There is growing awareness of the importance of this for children and young people, which is reflected in key policy and legislation.⁵² However, the reality is that many services still struggle to smooth the transition from children to adult's services – with examples from health and social care highlighted in this report. Some of the children CCo has spoken with do describe very positive experiences, with dedicated teachers who guided them, supportive families, and benefitting from local disability organisations with expertise in supporting transitions.

'[One teacher]...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.

Supporting children with transitions in school

Young people based at a residential special school spoke positively about the ethos of focusing on transitions. There is a dedicated transitions coordinator to support the students in their transitions, and the school holds transition meetings before and after any transitions - such as moving classes or starting a new subject. The Headteacher highlighted their focus on the themes of destination and aspiration for every student in every meeting. Staff 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 is going for them. The school, who had recently moved buildings, also actively involved students in the move, for example involving children in packing boxes and setting up the new rooms, so students could acclimatise to their new environments.

The transition to adulthood is particularly important for disabled children. Children and young people must have opportunities to set goals for what a fulfilling, happy adulthood looks like for them as an individual.

For some children, developing life skills that will enable them to live independently is a priority. In one focus group, a young person said it would be useful to know about *'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.'* In the Big Ask, a 15-year-old boy named *'social skills, self-help, managing emotions and travel training'* as essential skills children should be equipped with earlier. These life skills were particularly important to disabled young people preparing to leave care and live independently. As one young woman said: *'[Care-experienced young people] 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.'*

For some children and young people, preparing for adulthood means gaining practical, vocational skills. At the college CCo visited, young people spoke positively about the support they had to unlock these opportunities through scheduled work experience placements that focus on promoting disability

awareness and inclusion. One young man was volunteering at a large charity, assessing the accessibility of different sites for wheelchair users like him. Another young woman was working at the school reception, and told CCo she enjoyed interacting with people and answering the phone, and had learned about data protection. Young people working at the Community Café in the Midlands also spoke very positively about the new skills they were gaining, such as food hygiene, barista skills, multi-tasking and developing social skills with other members of the community. Sadly, these kinds of opportunities are not available in every area, and it tends to be a postcode lottery – with young people in rural areas particularly disadvantaged.

'I enjoy working the till and stuff like that, and having a quick chat with customers when I'm on the till, trying to multi-task' - Young man, 24, speaking about working at the Community Café.

Of course, for some disabled children and young people, their complexity of need may mean that independent living or employment is not a desirable or realistic goal. Instead, they should be supported to set goals for what a good adult life looks like for them, for example volunteering or becoming more involved in their communities – both offline and online - where they feel safe and connected to others.

Professionals CCo spoke with highlight the important role EHCPs can play in facilitating smooth transitions and preparing for adulthood, based on a child's specific needs and strengths. Guidance states that local authorities must ensure that the EHCP review at Year 9, and every review thereafter, includes a focus on preparing for adulthood.⁵³ Professionals at one school supported students from over 30 different local authorities, and noted that making EHCPs more streamlined would be beneficial in ensuring the best transitions for their students.

Recommendations:

A whole child approach

22. Integrated Care Partnerships (ICPs) and Integrated Care Boards (ICBs) should strategically prioritise disabled children and young people's experiences of transitions in their strategies and Joint Forward Plans, including identifying who is locally accountable for ensuring smooth transitions between services.

Age-appropriate care for 16- and 17-year-olds

23. The Department for Health and Social Care should publish national guidance on admitting 16- and 17-year-olds to adult wards, and collect data which can be disaggregated by protected characteristics, including disability. Centralised data is currently only available for children in adult mental health wards.

Preparing for adulthood

24. The new standardised EHCP template, a key proposal in the SEND and AP Improvement Plan, should support professionals to strengthen the transition pathway for disabled children from Year 9.

3.7 Whole family approach

Children and their families are experts in their own experiences, and must be listened to, supported, and treated with respect. Family matters to children, and it is important to them that support services work with the whole family in a joined-up way. This is also something that came out strongly in CCo's report *Family and its protective effect: Part 1 of the family review*.⁵⁴ A child and/or a parent's unmet needs impacts on the whole family, however there remains a gap in services which respond to this reality.

A whole family approach ensures that parents and carers have the support they need to be able to care for their disabled child. This may include practical support - such as childcare, short breaks, and support navigating different systems - as well as emotional and mental health support, such as counselling and support groups. In the *Family Review*, parents of disabled children talked about the challenge of finding appropriate childcare and support for their children, and feeling that they are alone in advocating for their child.⁵⁵

'You 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' – Parent of two disabled children.

Working in this way also ensures that young carers get the support they may need to help their parents. Disabled children may have disabled parents or siblings, who possibly require distinct and/or more support than them. One professional highlighted how this dynamic of a child's needs not being identified in conjunction with other family members can have a negative feedback loop effect:

'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...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.

Importantly, by taking a holistic approach and ensuring every family member is supported in the way that they need – children can enjoy their childhood, and not worry that their care is burdensome on the people who look after them.

Recommendations:

Inclusive Family Hubs

25. The Department for Education and Department for Health and Social Care should roll out Family Hubs to every local area, and update the programme guide to include information about ensuring the service is accessible to disabled children and their families, , including where a parent or carer is disabled themselves. Family Hubs should be integrated with local schools, GPs, and health visitors in the neighbourhood as part of a local network, and make better use of the school estate. The Department for Education should develop a proportionate inspection model for Family Hubs which includes assessing their SEND inclusivity.

Joined up support

26. Department for Education should respond to the Children's Commissioner's *Family Review*, including the recommendation that in implementing the SEND reforms, social care reforms and Integrated Care Systems, children and families reaching the threshold for support in one element of the system also get support from other services, and there is no postcode lottery for support.

Reforming needs assessments

27. The Department for Education should clarify in its updated Working Together to Safeguard Children guidance how the primary need and purpose of a needs assessment will shape how the assessment is completed. The purpose of an assessment and the nature of a plan will be quite different for children who are referred because they are disabled compared to children who are referred for a safeguarding reason. Currently some of the guidance about how assessments should be conducted, and how progress can be monitored – by considering how much improvement parents and carers have made - would not be relevant to all disabled children's plans.

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