



Disabled
Children's
Partnership

Failed and Forgotten

Research by the Learning Hub at the
Disabled Children's Partnership

Executive Summary

Introduction

The Disabled Children's Partnership is a coalition of over 100 organisations that campaign for improved health and social care for disabled children, young people and their families. The Learning Hub, established in 2020, is a collaboration with Pears Foundation to build the evidence base for disabled children in response to the disproportionate impact that the COVID-19 pandemic had on their lives and futures.

Disabled children and their families are currently facing the most challenging times yet. Post-covid recovery has left disabled children facing "record breaking" delays and backlogs to health and social care services. The support disabled children and their families rely on is uncertain, subject to reforms by government such as the Special Educational Needs and Disability Green Paper¹, the Independent Social Care Review² and the schools White Paper³. Already families with disabled children faced higher costs and now the record levels of inflation have resulted in a cost of living crisis, driving up the price of food and essentials. Even before this crisis, disabled people faced extra costs of £583 a month on average. 24% of families with disabled children were spending more than £1000 per month on average⁴. Combined with an energy crisis, in terms of cost and possibly supply, the pressure on families with disabled children is at an all time high with many living with shortfalls in support and post-covid recovery.

To understand the current experiences of families with disabled children, between 5th October and 20th November 2022 parent carers were invited to take part in our latest survey. This report is based on 2200 responses received from parent carers who look after approximately 2900 disabled

children and 1900 siblings. It also reports on freedom of information (FOI) requests to Integrated Care Boards in July 2022 and Social Care services in October 2022, and available NHS datasets.

We are grateful to all those who took the time to tell us about their experiences.

Key Findings

Our survey found that just 1 in 5 parents said that their family received the support needed to enable their child to fulfil their potential. This leaves parents to fill the gaps in order to care for their disabled child safely. Just 1 in 7 said that their disabled child has the correct level of support from social care, 1 in 5 from health services and 1 in 3 from their education setting. Such stark figures give some insight into pressures placed on families, day to day, throughout the lifetime of their disabled child. Moreover, looking towards adulthood and routes towards independence, just 12% of parents reported that their disabled child gets the correct level of support from their training, employment or voluntary placement.

3 in 4 parent carers told us that they have had to give up employment, or their whole careers, due to the lack of support available. Almost half of parents tell us that they are unable to work and are experiencing poverty. The full impact of the cost of living and energy crisis has been felt this winter. 3 in 4 parents say that financial constraints due to the cost of living crisis will have a significant impact on their disabled child.

Once again, as we reported during the pandemic, it is disabled children and their families that will be disproportionately affected by the current social climate. Disabled children are not immune from the record-breaking waiting times, backlogs and

workforce issues across health and social care. NHS data shows that the proportion of disabled children waiting for treatment is equivalent to adults, and disabled children waiting for equipment, such as wheelchairs, are likely to wait longer than adults. Disabled children and their families rely on multiple services and 1 in 5 parents told us that they are experiencing delays with more than 10 health services.

Parents report the most common delays are for reviews within health services and assessments from social care. Half of families are experiencing delays with medication reviews and ophthalmology services. It is vital that such reviews take place to ensure a good quality of life for disabled children, so that they are able to attend school with the best chance of taking advantage of educational opportunities but most importantly so that they are safe and free from pain. Of those who are experiencing delays with therapy services, both physical and talking therapies, almost 3 in 5 are waiting more than 12 months for appointments. 1 in every 2 disabled children experiencing delays seeking support for self-harming, self-injurious and high-risk behaviour are also waiting for more than a year to be seen.

The Children Act 1989 says that all disabled children are 'children in need'. However, 1 in 4 parents have been told that their disabled child does not meet the threshold in order for a social care assessment to take place. Families who are fortunate enough to have had a completed social care assessment still face delays in receiving the support they were assessed to be needing. 70% of disabled children and young people needing a personal assistant are facing delays due to the lack of availability of the workforce. Half of disabled children are facing delays in assessment for support for household

tasks, household equipment and adaptations, and 39% of parents report delays to short breaks. This is before disabled children attempt to attend school, college or training.

Half of parent carers said that their disabled child's therapy, mental health or communication needs were not met within their education settings. Of those pupils waiting to see an educational psychologist, half are waiting for over a year meaning that, during extensive periods of a disabled child's life, they are attending school without their needs identified or met. Lack of support concerns parents. Half of parent carers are concerned that their disabled child or young person is vulnerable to being exploited or coerced into behaviours or relationships that may put them at risk emotionally and physically due to the lack of support available.

It is not surprising that parents reported poor outcomes for their disabled children and their wider family. 7 in 10 parents told us that their disabled children's health has deteriorated and they are more anxious due to the lack of support available. 7 in 10 reported that their disabled children's behaviour is more challenging due to stress, anxiety and pain, and more than half state that their child's development has regressed. The impact of the lack of support for parents is high levels of mental health problems (87%) and physical health problems (82%). Siblings too are impacted by the lack of support available, with more than half taking on more caring responsibilities. Anxiety and isolation levels reported for them are high (69% and 67% respectively), with more than half experiencing deteriorating levels of confidence. Therefore, the chance of disabled children and their siblings to fulfil their potential is drastically reduced.

Our analysis shows that 50% of local authorities plan to cut budgets for disabled children during this financial year, not including the High Needs Funding Budget. Parents taking part in our latest survey confirmed that the lack of support has had a detrimental impact on their disabled child's health, as well as that of their other children and their own. However, families are once again faced with long waits and delays for support they need in order to combat the consequences brought about initially by a lack of support in the first place. Our research shows that the isolation levels are highest during the school life of a disabled child. The SEND and social care system has to ensure disabled children's needs are identified and appropriate support is provided at the right time, so that they can fully participate in society and reach adulthood prepared to lead productive and fulfilling lives.

Recommendations

The Minister for Disabled People, working with the network of Ministerial Disability Champions, must ensure that the needs of disabled children and their families are prioritised across all parts of the public sector.

The Department for Education, working with the Department for Health and Social Care, must ensure that its reforms to special educational needs and disability do not make it harder for parents to get the support their children need. They must invest in support, develop a workforce strategy and strengthen accountability.

In taking forward reforms to Children's Social Care, the Department for Education must include a specific focus on disabled children and their families in the proposed 'Family Help' arrangements, build on the lessons from the Short Breaks Innovation Fund and increase the focus on disability within children's social work training.

The recent announcement of a review by the Law Commission into the legal framework for disabled

children's social care presents an opportunity to improve the complex nature of the current law that families rely on. It is vital that it is taken forward in full partnership with parents and young people.

The Department for Health and Social Care and NHS (England) must ensure all Integrated Care Systems have clear plans for eliminating the backlogs in assessments and therapies/treatments for disabled children.

The government must support families with disabled children during the cost of living crisis including

- An energy assistance payment for families of seriously ill and disabled children to cover the cost of running lifesaving medical and disability equipment.
- Bring forward the further £150 Disability Cost of Living payment and benefit uplift announced in the Autumn statement.
- Reverse eligibility changes to the Warm Home Discount that excluded disabled people.
- Social tariffs for households on disability benefits.

Detailed Findings

This report outlines the experiences of parents of disabled children gaining support from across health, social care and education. It commences with a discussion of families' experiences within the current SEND system, which is acknowledged by the government to be bureaucratic, over complicated for parents to navigate and failing to provide the support children and families need.

In order for the correct level of support to be in place for disabled children and young people, parents and siblings, assessments, reviews, treatments and support must be provided in a timely manner. Health, social care and education services must work closely together to benefit disabled children and their families. However, this often does not

happen, with parents having to repeat themselves to multiple agencies across a number of sectors. The latter part of this report will discuss integration from the perspective of disabled children, drawing on the results of our most recent FOI requests from health and social care.

The impact of inadequate support on the whole family is presented in section 7. The patterns of isolation are discussed, with attention drawn in the final section to the current system of support and lack of accountability for providers when support needs are not met.



1. Demographics

2200 carers took part in this latest survey. Of those:

- 86% of parent carers were mothers, 7% fathers, 4% grandparents and 3% were siblings or another form of guardian.
- 21% had one child, 43% had two children and 35% had three or more.
- 74% had one disabled child, 20% had two disabled children and 6% had three or more disabled children.
- The most common forms of disability reported were autism (64%), learning disability (57%), speech language and communication challenges (55%), social emotional and mental health (48%), physical disability (31%) and ADHD (28%).
- Responses were also received from parent carers of young people with genetic disorders, multi-sensory impairment, rare disorders, visual impairments, life limiting disorders, acquired brain injury, hearing impairment, undiagnosed conditions and newly acquired disorders.
- 77% of parent carers taking part in our survey had an EHCP in place for their disabled child.
- Parent carers responding to this survey looked after disabled children and young people up to the age of 25 years. 31% are 11-15 years, 23% 6- 10 years, 20% 16- 19 years, 18% 20+ years and 7% 5 years and under.
- 83.4% were White British, 13% black, Asian, minority ethnicity and 4% from other ethnic minority groups.
- 19% of families live in the South East, 13% in the North West or South West, 12% London, 10% West Midlands, 9% Yorkshire & Humberside, 8% East Midlands, 7% East of England or North East.

- The four most common settings disabled children and young people attended were: special needs schools (34%), attended mainstream schools (26%), currently have no identified place (15%) and post 16 college or training settings (14%).

2. SEND System

The government SEND Green Paper “*Right Support, Right Place, Right Time*”¹ highlights that the current system results in poor outcomes for children and young people with special educational needs. In addition, navigating the SEND system is too often a negative experience for children, young people and their families. It is common for parents to describe the ‘battle’ or the ‘fight’ to ensure adequate support for their disabled child⁵. The process of identifying needs, and then gaining a diagnosis and, subsequently, appropriate support can be complex and lengthy⁶.

It has been reported that 95% of local authorities had parents or carers using the tribunal system in relation to their child’s education, health and care plan⁷. Government data demonstrates that, once at tribunal, 96% of judgements are agreed in favour of the parents⁸.

‘We had to go to tribunal to get this level of support, not perfect but he is at residential college to learn independent living and hospitality skills. The second SEND tribunal really affected my mental health. I also have had to fight for healthcare, benefits and have failed to access any social care or respite ever’

The decision to proceed to tribunal is not taken lightly by a parent or carer and not an option for all families, due to the costs involved. A survey of parents by the Let Us Learn Too campaign reported that families often have to use savings or give up their jobs to devote the time needed to fight for their children’s rights, with 3 in 5 stating that the process had left them with lasting money worries⁹.

Parents taking part in our survey reported on their experiences and reasons for going to tribunal. Reasons included the local authority disputing a child’s diagnosis, failing to include evidence from professionals during the assessments, specialist staff who were needed not being available within the area, staff training not being provided to the staff responsible for the disabled child’s needs and to appeal school exclusions.

Many parents reported taking part in more than one tribunal, with a parent stating “*this seems to now be a pattern throughout my child’s life*”. As the quotes below demonstrate, for many families a tribunal is not a one-off, unique experience.

We fought long and hard for the good level of support we currently have. 3 tribunals. Sold our house.

We have a legally binding EHCP and for the last 8 months, nothing is being delivered. We have 60 hours of social care documented that has not been in place since January 2022. We are currently in Tribunal for his EHC plan.

This has been a pattern throughout my daughter’s life, resulting in me retiring when she was 6 to advocate for her. We took her school / local authority to tribunal to assess her and again to Judicial Review to assess her for autism. We won both.

An efficient system of support with positive outcomes is vital for disabled children to reach their potential. However, our survey reveals that just 1 in 5 parents said that the correct level of support is currently in place for their disabled child to reach their potential in the future. Disabled children and their families rely on support across health, social care and education. Yet parents reported that their disabled child does not get the correct level of support to meet their needs across multiple sectors.

Asking and pleading for help has turned into being a difficult parent. All systems keep piling on more handles like “you need to call this number before we

can proceed with your case” or “you need to go back and work with the council”. The system has broken me down rather than helped.

Table 1: Proportion of parents that said that their disabled child’s needs are met by health services, social care, education, training or employment.

Statement	Proportion agree or agree strongly
My disabled child currently receives the correct level of support to meet their needs from health services	21%
My disabled child currently receives the correct level of support to meet their needs from social care	13%
My disabled child currently receives the correct level of support to meet their needs from education services	33%
My disabled child currently receives the correct level of support to meet their needs from training, employment or their voluntary placement	12%

If the correct level of support is not put in place by services, not only are disabled children unable to reach their potential but families are left to plug the gaps in support. This means that the whole family is restricted in their opportunities. Wider research indicates that parents and carers spend around 60 hours a week looking after their disabled child⁹. Compared with other carers, parents of disabled children are twice as likely to care for more than 100 hours per week¹⁰. As a result, less than one in four parents or carers are able to work full time¹¹.

Availability of childcare for families remains an issue. A survey by Working Families¹² reported that over half of parents said that the availability of childcare impacts their capacity to work. In addition, parents from low and middle income households are twice as likely as those with higher incomes to say that affordability was a barrier. A survey by Family Fund found that more than two thirds said that their capacity to work was affected by the lack of care, and that they were unable to work as much as they would like¹¹.

Our survey revealed that 3 in 4 parent carers had given up their career or employment to care for their disabled child due to the lack of support available from services. More than half of those responding told us that they would have to give up their employment, career or reduce their current hours within the next twelve months if the support does not improve for their disabled child during that time.

I've had significant amounts of time off work sick due to the stress of fighting for what my child needs. I am the main earner in our household and have been forced to reduce my hours due to lack of support for my child. They've been out of school now for nearly 3 years due to lack of suitable placement

Support gets worse the older children get. Adult services are a joke. Second parent already reduced working to minimum to help because 2 young adults are too much for one parent to support. Mental health of whole family is at lowest point. And financial situation is dire.

Having two disabled children has been a really hard battle. I've had to fight for everything from DLA appeals; chasing hospital appointments; chasing results; referring and re-referrals to CAMHS; liaison with charities that support their rare genetic condition. The list is endless. I had to give up my career when both children were admitted to hospital at the same time. I loved my job but, without the

support I so desperately needed, I had no alternative but to start claiming benefits for myself to survive.

Prior to the current cost of living crisis, research by the Working Families Index reported that 60% of respondents found making ends meet and raising a family more difficult over the last 3 years¹².

Almost half of parent carers (46%) in our survey stated that they were unable to work and were experiencing poverty as a result. The lack of support also affected relationships, with 38% of parent carers indicating that their marriage or relationship had broken down within the last twelve months.

I have had to reduce my hours to manage and my relationship with my children's father broke down when they were young because of the stress and lack of support at the time.

I'm home working at present. I work 18 hours but struggle to even fit these in whilst caring for my son. I lost tax credits when he turned 20, but I can't claim UC, so I'm really struggling now. My mental health is very poor and affects all relationships. It's exhausting having to fight and challenge for everything.

The current SEND system places significant administrative burdens on families. Parents are required to complete huge amounts of administrative tasks, spending time on communication, follow up and coordination across health, education and social care. Almost a third of families (31%) spend more than 10 hours per week on essential administrative tasks to ensure that their disabled child gets the support they need.

Filling in copious forms - waiting for professionals to get back to you to sort out appointments, it's incredibly time consuming & soul destroying.

You have meetings, you all agree on an action plan then nothing happens. There is a complete lack of communication, no one rings you back, you are continuously chasing people and services.

My daughter (mother of grandson for whom this relates) is very stressed as she is trying to hold down a job in order not to have to claim benefits. The amount of admin and sending of repeated amounts of 'evidence' to the LA as it has been 'lost' (nine items of evidence), is ridiculous. No transport had been arranged for September start at school, even though forms were submitted in April.

Parents have to attend a number of assessments across health and social care, both to ensure their disabled child's diagnosis and needs are understood and to get the right support. Pressures on parents, as discussed further below, increase the time period during a disabled child's childhood where their needs are not identified or assessed correctly and, so, are not met appropriately, resulting in barriers to their education and future life outcomes.

In the education setting, a child's needs are assessed by an educational psychologist. However, almost half of parent carers (47%) reported waiting over 12 months for an appointment with an educational psychologist. The process to obtain support also relies on reports from other professionals and, therefore, delays, not just in education but across health and social care too, have a detrimental impact on the correct support being in place at the correct time for disabled children and young people.

Parent Carers' experiences of health services are reported in the next section.

“I have had to reduce my hours to manage and my relationship with my children's father broke down when they were young because of the stress and lack of support at the time.”

3. Health

To ensure that disabled children reach their potential, when attending education, training or employment settings, their disability and conditions need to be appropriately managed. They need to be free from pain, and to be supported by equipment and devices to meet their needs and therapies to support their development. Therefore, the Health Service have a vital role to ensure that disabled children have the correct level of support in place to enable them to succeed.

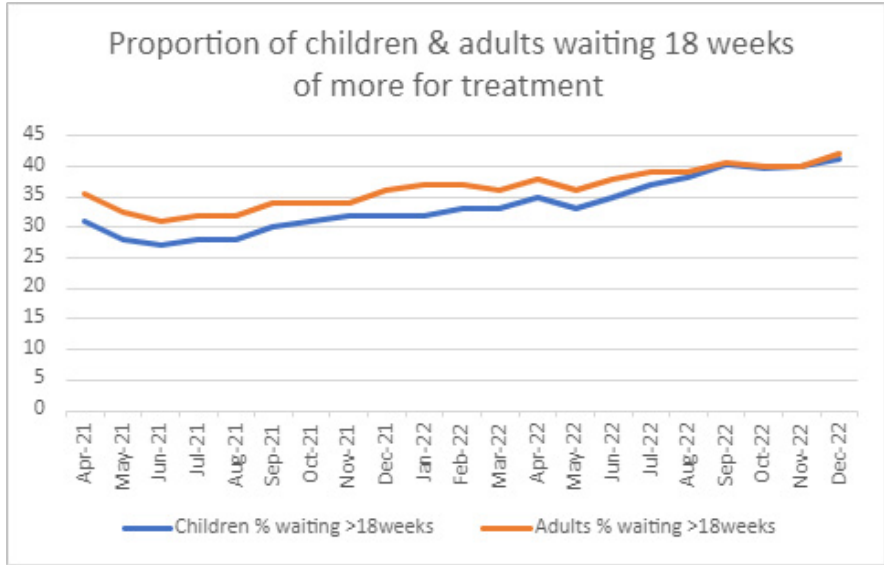
However, as reported above, just 1 in 5 parent carers said that their disabled child receives the correct level of support to meet their needs from health services. This section will outline the types of challenges facing families currently and the impact this will have on their disabled children.

3.1 Waiting Times

Increasing NHS waiting times are frequently reported, with 7.2 million people¹³ currently on the NHS waiting list, a record high. Disabled children are overlooked and lost in the wider narrative, with an apparent presumption that they are not as affected as the adult population. However, the most recent NHS data¹⁴ reveals that disabled children are not immune to problems arising from pressures on services.

NHS data reported up to September 2022¹⁴ illustrates how the situation is deteriorating for children. The proportion of children waiting longer than the NHS standard of 18 weeks from referral is increasing, with 2 in 5 children waiting in excess of that target. The gap between the proportion of children and the proportion of adults waiting longer than the NHS standard has narrowed, (Figure 1), with families of disabled children facing the same barriers to treatment and care as the wider population.

Figure 1: Proportion of children and adults waiting more than 18 weeks from referrals to treatment



Parent Carers responding to our survey were asked to indicate the delays to health services that they were experiencing. The services with the most common delays are listed below:

- 49% Diagnosis
- 44% GP appointments
- 38% Occupational Therapy
- 35% Speech and Language Therapy
- 29% Equipment
- 28% Dental Services
- 28% Treatments
- 26% Medicines Management
- 24% Physiotherapy
- 22% Self-harm, self-injurious and high-risk behaviour
- 22% Support device or aids
- 22% Talking therapies

Waiting times for a diagnosis and medication are ridiculous. You wouldn't expect someone with a condition like diabetes to wait 2-3 years to be seen and yet ADHD/ASD are expected to wait that long. All the guidance says that they should be able to access support while waiting on a diagnosis but in reality that isn't true in most cases.

There has been a general lack of support and services throughout the pandemic and now they are all so far behind because the waiting times for appointments have increased drastically. It's taken 2 years from diagnosis to get an appointment for adhd medication assessment.

Currently on a 3 year waiting list for a first assessment for Global Development Day and Autism Spectrum Disorder for my non-verbal almost 4 year old, who is supposed to start school full time on September 2023 but has the development level of 18-24 months old.

The worst part is the endless waiting times for appointments - it took 18 months to get an autism assessment and we only got one then because someone cancelled at the last minute. Waiting times for children's mental health services are even worse.

As listed above, almost a third of parents reported delays with equipment and 1 in 5 reported delays with support devices or aids. NHS data¹⁵ confirms that children are worse off than adults when it comes to waiting times for wheelchairs. Figure 2 illustrates that the proportion of disabled children waiting beyond the 18 week target for their wheelchair is greater than for adults¹⁵.

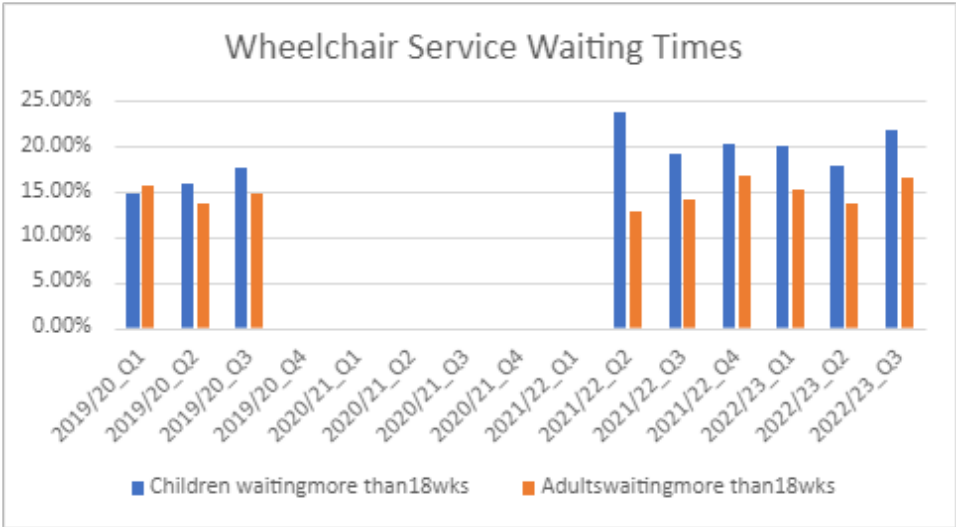


Figure 2 - Wheelchair Service Waiting Time - Adult and Child Comparison

3.2 Types of Delays

Parent Carers who were experiencing delays with health services were asked to indicate the types of delays they were experiencing, for example a new referral, a review, an assessment or provision of treatment or care. Predominantly, for the majority of services, Parent Carers indicated delays with reviews of their disabled child's care. Examples of delays with reviews are listed below:

- 54% Medicines Management
- 51% Ophthalmology / Orthoptics
- 46% Surgery
- 43% Diagnostics
- 38% Physiotherapy
- 34% GP services
- 33% Self-harm, self-injurious, high-risk behaviour
- 33% Talking therapies

Reviews are imperative to ensure that support still meets disabled children's changing needs. For example, disabled children may be prescribed more than one medication that needs to be adapted as they grow and develop. Reviews ensure multiple medications do not cause unnecessary side effects or that children are not taking unnecessary medication. However, more than half of parents reported delays with medicine management.

Similarly, more than half of parent carers reported delays for appointments for ophthalmology or orthoptic reviews. Reviews ensure healthy eyes and optimal sight so that children are able to learn and to lead a good quality of life. Reviews for services such as medicines management and orthoptic services are vital not just for a disabled child's quality of life but to ensure that they are safe as they go about their day-to-day activities.

For some disabled children, self-harm, self-injurious or high risk behaviour may be common due to their disability, but challenging behaviour, and in particular escalating challenges, are often a consequence of a reduced or inappropriate level of support. A third of parents reported delays to reviews for such support for their disabled children and the same proportion experienced delays for reviews with talking therapy services.

As discussed above, disabled children are not immune or protected from long NHS waiting times and backlogs. Parents were asked about the length of delays they were experiencing for the NHS services that they used. Parents experiencing services with delays beyond 12 months are highlighted below:

Table 2: Disabled children experiencing delays of 12 months or more with services

Service	Proportion reporting delays	Proportion reporting delays over 12 months
Hydrotherapy	26%	60%
Play Therapy	22%	60%
Talking Therapies	22%	57%
Self harm, self injurious, high-risk behaviour	22%	56%
Music Therapy	19%	50%
Speech and language	35%	45%
Support devices or aids	22%	41%
Occupational Therapy	38%	40%
Dental Services	28%	38%
Surgery	22%	38%
Equipment	29%	34%
Physiotherapy	25%	32%

Over 3 years waiting for CAMHS to diagnosis for ADHD, mental health and social interaction not addressed. No trauma support offered. Currently not attending school. Arrested over 10 times still not addressed. Now potential gang grooming due to being vulnerable.

Due to covid hydrotherapy stopped, now due to issues with the pool there's no hydrotherapy available

Since my daughter turned 18 the support is so bad and she is a full time Wheelchair user and also there is no Physio or OT and just services so bad

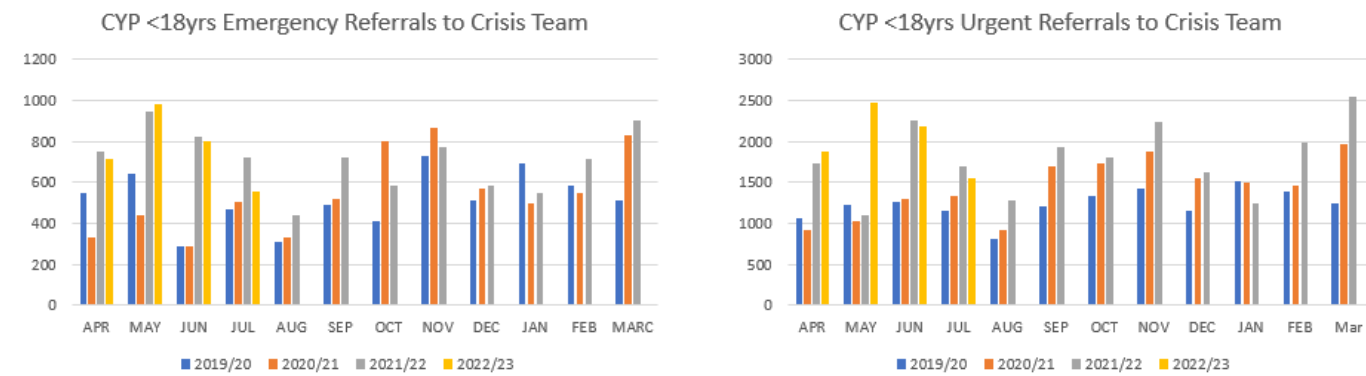
Awaiting SALT for 3 years for a non-verbal child!

Disabled children rely on a range of therapy services to ensure their bodies grow and develop as well as to alleviate pain and improve mobility, flexibility and gross and fine motor skills, aiding communication and meeting sensory needs. Our research during the pandemic 16-20 showed that disabled children were missing out on these vital services. Our latest survey demonstrates that there are long waits for disabled children to access the same services. In addition, more than half of disabled children that require support or advice for self-harming, self-injurious or high risk behaviour are waiting more than a year. Such levels of delay are not just a risk to a disabled child's quality of life, but a risk to life.

The impact of the pandemic on the wider mental health of the general population has been widely reported. There has been an increased demand for mental health services with long waiting times for young people referred for mental health support. Data available from NHS2I digital illustrates that in the first 4 months of this current financial year (2022-23) demand for mental health services remains on average 72% higher than pre-pandemic levels.

Mental health datasets clearly demonstrate a sustained increased level of emergency and urgent referrals for young people under 18 years of age. For the first four months of the current financial year (2022-23) emergency referrals remain 40% higher and urgent referrals remain 55% higher than pre-pandemic levels (Figure 3).

Figure 3: Emergency and Urgent Referrals to Mental Health Crisis Teams for young people under 18 years.



Another sign that the system is struggling to support young people is the number of bed days young people spend on adult wards. Data from NHS England²¹ illustrates that, for the first four months of the current financial year, the number of bed days that young people, aged 17, are on adult wards was 113% higher than the pre-pandemic average. In October 2022, the CQC warned that admission of all children under 18 years onto adult wards was 30% higher than the year before. More than a quarter of such admissions were due to no alternative child inpatient or outreach service being available²².

I feel that support in all areas for all 3 boys is severely lacking. Once disabled children become disabled adults (18) they are forgotten about. Mental health services are appalling long waiting lists and no real help available with long waiting lists.

We've been trying to get treatment from CAMHS for our child since the pandemic started 2.5yrs ago, causing him extreme anxiety and OCD. We are still waiting and have been told it will be "years" before he gets any help. There is basically no mental health service for children. It exists in name only.

Disabled children with greater or more specialised needs, due to physical disabilities, are also not protected from longer delays. National data for wheelchair services¹⁵ reveals that disabled children with high or specialist needs wait longer than their peers with lower or moderate need. This is not just the case for new referrals (Table 3) but also for disabled children already known to services (Table 4). As disabled children grow and develop, they require updated equipment but this is not appropriately planned for by services. Again, our pandemic research¹⁶⁻²⁰ has previously highlighted the reduced quality of life and detrimental impact on disabled children's bodies when equipment is not updated.

Table 3 - Proportion of children waiting longer than 18 weeks for a wheelchair – new referral

Time Period	Low level of need	Medium level of need	High level of need	Specialist need
2021/22 - quarter 2	11%	21%	26%	27%
2021/22 - quarter 3	15%	19%	23%	33%
2021/22 - quarter 4	21%	22%	28%	23%
2022/23 - quarter 1	23%	23%	29%	38%
2022/23 - quarter 2	17%	21%	25%	24%
2022/23 - quarter 3	15%	21%	26%	29%

Table 4 - Proportion of children waiting longer than 18 weeks for a wheelchair – re-referral

Time Period	Low level of need	Medium level of need	High level of need	Specialist need
2021/22 - quarter 2	9%	24%	25%	27%
2021/22 - quarter 3	15%	19%	25%	29%
2021/22 - quarter 4	12%	20%	28%	27%
2022/23 - quarter 1	9%	25%	36%	20%
2022/23 - quarter 2	11%	21%	26%	23%
2022/23 - quarter 3	20%	24%	30%	29%

3.3 Multiple Delays

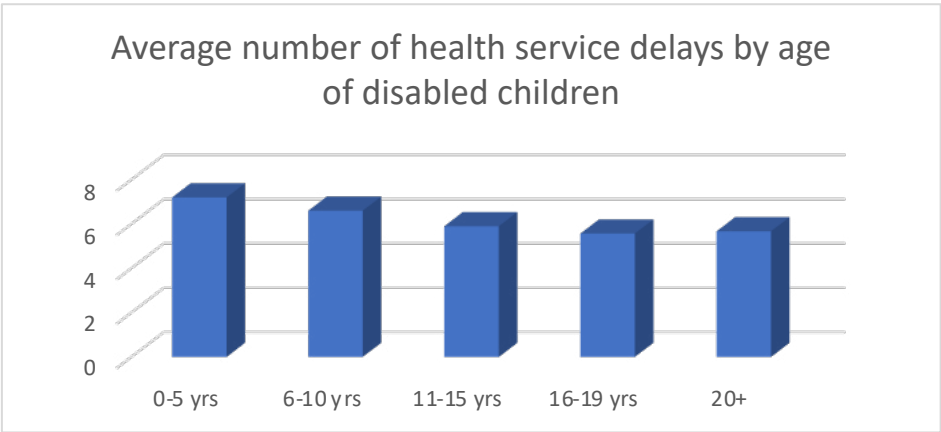
The NHS delays reported by parent carers for disabled children are alarming, particularly as many disabled children have multiple diagnoses and access multiple services. Parents taking part in this survey reported delays with multiple health services. On average, those experiencing delays experienced delays with six different types of health services, with 1 in 5 parents (18%) reporting delays with 10 or more services. Our analysis reveals further concerns when reviewing delays reported across various age groups. Figure 4 illustrates that the highest number of delays were experienced by parents with disabled children aged 0-5 years.

My child's key worker at nursery told me she is not doing one to one with her as much as she needs due to no funding for my daughter. We are on multiple waiting lists that are over 18 months wait, which will mean my daughter will be in reception and her developmental delays will become worse.

Early intervention is vital to ensure disabled children's needs are identified early and support is established within an adequate time frame, promoting positive outcomes for children and their families. Long and/or multiple delays risk disabled children falling behind their non-disabled peers and failing to meet their potential. Without appropriate support in place, parent carers of younger children are also less likely to be able to return to work or employment.

We can no longer attend a nursery setting due to the lack of support there, it's sent us into a regression

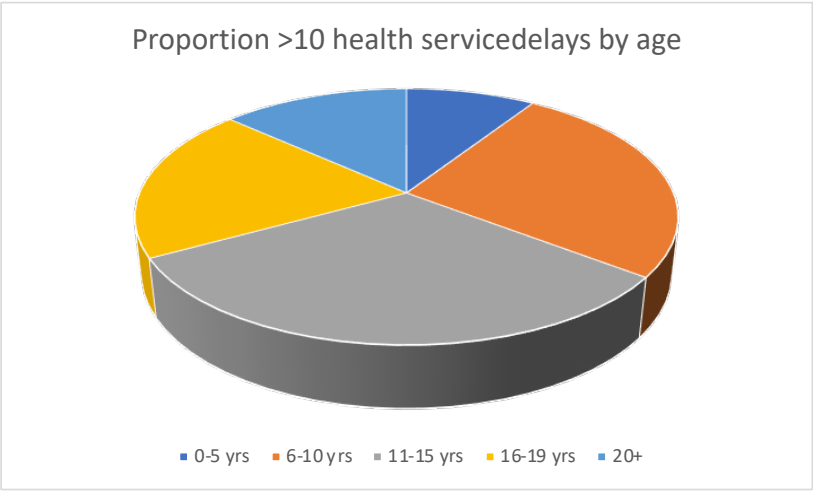
Figure 4 – Average number of health services delayed, reported by age group of disabled children



Further analysis of parent carers experiencing delays with more than 10 services (figure 5 below) illustrates that the age groups in compulsory education (6-10 yrs and 11-15 yrs) are more likely to be experiencing the highest number of delays with services. This risks their ability to make the most use of educational opportunities, due to unidentified and unmet health needs.

Service waiting times are very long, eg our community paediatrician orders blood tests six months in advance, for annual checks. Speech and language provision has been almost non-existent via school, they have no resource. Local services have waiting lists so long that each school can only refer one child (per term or year, I forget which) even though there are dozens of children in the school that would benefit from interventions.

Figure 5 – Proportion of disabled children experiencing delays with more than 10 health services by age group.



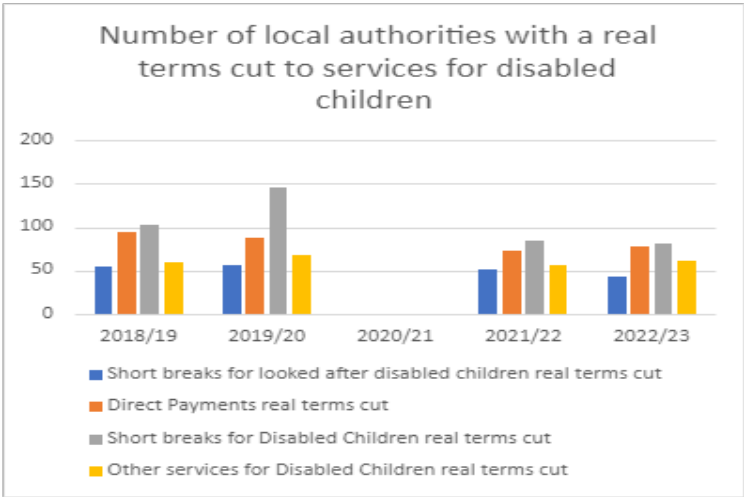
Multiple health delays have consequences on outcomes for disabled children, their parents and siblings. Many disabled children also require support from social care. The next section will discuss families’ current experiences of support from social care.

4. Social Care

An independent review of children’s social care published its report in May 2022², with the government implementation strategy published February 2023. It is important that the strategy includes a specific focus on disabled children and their families.

As part of the ‘Count Disabled Children In’²³ campaign, DCP analysed budgets specific to disabled children across each local authority. Our analysis of budgets revealed that, in this current financial year, 50% of local authorities have a real-terms cut in services for disabled children. 87% of local authorities plan to cut at least one of four services during the current financial year. Figures show that this occurs after successive cuts to budgets in previous years, with 97% of local authorities cutting one of the budgets for disabled children in 2019/20.

Figure 6 – Local Authority Cuts to disabled children’s budgets



As the chart above illustrates, over the last five years real term cuts to short breaks services and direct payments were the most common each year. Short breaks are vital for families, to reduce the impact of full-time caring roles and provide opportunities for disabled children and young people to take part in fulfilling activities.

Just over a third of parent carers taking part in our survey indicated that their disabled child received social care support related to their disability or condition. 34% had a social worker and 13% had a family support worker. However, accessing social care proved difficult for families with more than 1 in 4 families reporting that they had been refused a social work assessment on the grounds that their disabled child did not meet the threshold, despite being defined as children in need in the Children and Families Act, 2014²⁴.

Social care support is non-existent in my area, I was told I didn’t qualify for assessment, as I hadn’t attempted suicide or tried to put my son up for adoption.

Over the years, support has declined to an alarming rate. Our eldest child is entitled to 4 hours a week care but hasn’t accessed it since the pandemic due to no available support/care staff either from an agency or via personal contacts. His Child In Need plan was wildly out of date and we only received social care help after a series of complaints. We are not blaming the professionals, but each service seems to be running on empty. It’s a shocking state of affairs.

Parents experiencing delays to social care services were asked to identify the type of service and the type of delay. 70% of families experienced a delay in the provision of personal assistants due to the current workforce issues regarding availability of staff. The most common delays families reported are listed below in Table 5, with assessments for services the biggest barrier for parents with disabled children.

“Social care support is non-existent in my area, I was told I didn’t qualify for assessment, as I hadn’t attempted suicide or tried to put my son up for adoption.”

Table 5: Delays reported by parents for “assessment” of social care services

Social Care Service	Proportion of families experiencing delays for assessment
Domestic Household Tasks	50%
Personal Care	45%
Carers Assessment	43%
Travel to activities or day care	38%
Social Work assessment	35%
Support Outside of the home	35%
Short breaks	34%

My child is apparently too young (at 7) to be offered any short breaks/social care.

Respite care is lacking and never received all of our allocated time. Sometimes not having respite for months.

Delays reported above impact the ability of the disabled child or young person to move towards an independent life and limit their prospective life choices. Again, families are left filling the void where support from services should be, and this limits their opportunities for employment and increases the whole family’s isolation from friendships and activities.

In addition to delays with assessments listed above, families indicated a dual problem with equipment and adaptations within the home, with delays to both assessments and provision (Table 6).

Table 6: Delays reported by parents for equipment and adaptations within the home

Social Care Service	Proportion of families experiencing delays for assessment	Proportion of families experiencing delays for assessment
Equipment within the home	50%	40%
Adaptations to the home	45%	36%

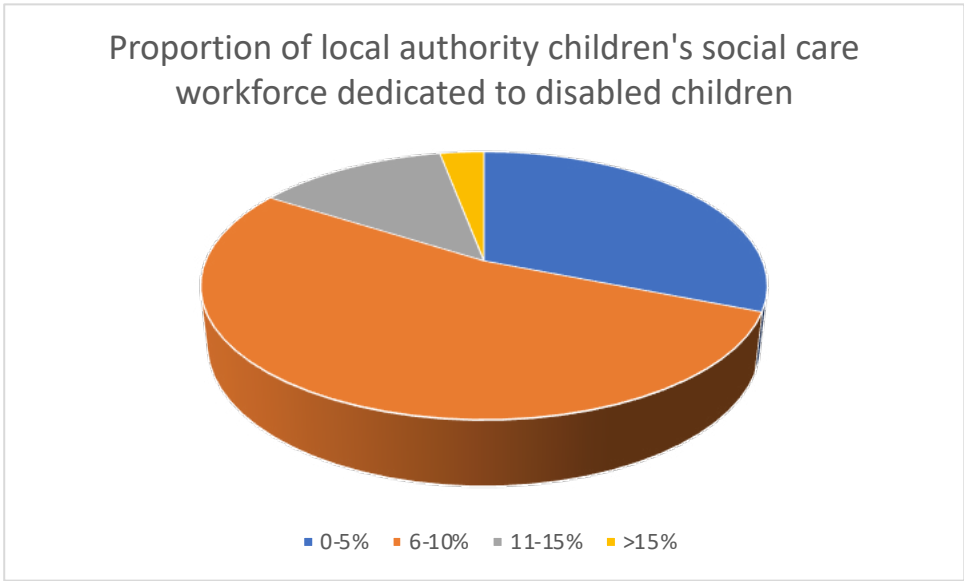
Due to the lack of provision available from local authorities, 36% of parent carers reported that they had to pay for social care services. Staff shortages and turnover means we have to keep providing the same information, chasing things up and waiting. It’s very stressful.

FOI requests concerning the social care workforce for disabled children were sent to all local authorities in England between October and November 2022. Responses were received from 53% of local authorities in England. Of those, just 52% were able to provide the number of disabled children on the local authority disabled children’s register. The Children’s Act 1989 places a duty of each local authority to “open and maintain a register of disabled children within their area”²⁵. However, the responses to our request suggest that a large proportion of all local authorities are not meeting this legal requirement.

We don’t currently have a register of disabled children in [name of Local Authority], although we do maintain a database of children and young people with Special Educational Needs (SEND) who have registered to access Short Breaks

Our analysis of workforce statistics obtained via freedom of information requests illustrates (figure 7) that 3 in 4 local authorities have dedicated 10% or less of the children’s social care workforce to disabled children.

Figure 7: Proportion of children’s social care workforce dedicated to disabled children



Results of our freedom of information requests reinforce the findings from parents that there is insufficient support for their disabled children from social care.

5. Education

Therefore, as demonstrated in the previous two sections (health & social care), before disabled children reach the classroom they rely on their needs being identified and understood, with appropriate support being established at the right time from health and social care.

In order for disabled children and young people to thrive at their education or training setting it is vital that they attend the most appropriate provider to meet their needs. However, a third (33%) of parent carers responding to our survey said that their disabled child is not currently attending the correct setting to meet their needs.

SEND organisations and professional bodies are calling for urgent action to address shortages in the specialist workforce that disabled children rely on, such as educational psychologists, speech and language therapists and teachers of the deaf²⁶. Combined factors have resulted in this urgent issue: insufficient numbers of specialists are being trained or retained, there is increased demand as well as more complex cases and COVID has exacerbated and extended pre-existing demands on waiting times to access specialist services.

At the appropriate setting, staff should be trained appropriately to meet the disabled child’s needs but a third of parents (34%) said that their child did not receive support at their settings from staff who were fully trained to understand and adapt provision accordingly.

Parent Carers identified the types of needs that were not met at their disabled child's setting, resulting in their child struggling whilst at their setting.

- 48% Therapy needs
- 47% Mental health needs
- 46% Communication needs
- 37% Equipment / Supportive device needs
- 33% Physical health needs
- 22% Medical needs

The list above highlights, as per findings in section 3, that the most common difficulty for families is that therapy, mental health and communication needs are not met at their children's education or training setting.

Even though my son has an EHCP he's been severely let down by the provision and that's supposed to be a legally binding document. He's in Yr2 and his school are still waiting for a ramp. A RAMP!!! A basic provision for his access.

I am incredibly lucky that my child now has an appropriate school placement (independent special school) however getting the placement took over 2 years and during this time my child received no support. He was on waiting lists for over 2 years and had to fight the LA to get SALT services, there was no CCG commission/contract for children with an Autism diagnosis!

My son has been waiting for a new speech therapist since April. This is still not in place despite my requests. Otherwise, he is supported at college between the TAs and his PA who goes in with him.

Disabled children, as we have highlighted in previous sections, rely on multiple services within health and social care. This results in time away from education for appointments for therapies, assessments or surgery and for periods of poor

health associated with their disability. As a result, 1 in 4 parents said that their disabled children miss out on treats or activities as part of the pupil reward system or have been penalised for their attendance level. Too often the lack of attendance is due to the policy as opposed to a disability²⁷. The Children's Commissioner (2022) reported that disabled children with an EHCP plan have a higher chance of being severely absent as well as a higher overall absence rate and realistic goals for school attendance should be set at their education setting²⁸.

Due to a lack of appropriate support at a disabled child's educational setting, they may have a school place but be unable to attend full-time with their peers, placing them at further risk of isolation and lack of friendships.

Two of my children are currently on unlawful part-time timetables, the seclusion and isolation while in school is horrific. 3 of my 5 children who are in school are suffering terribly. I continue to fight this fight daily.

LA refused a needs assessment and online tutoring even though my son has been out of school since February. It's a constant fight to get education and support that he is entitled to.

Data from the Department for Education illustrates that across England 82.2% of children attending a pupil referrals unit have an EHCP or receive SEN support²⁹. Wider research established that, in some local authorities, all pupils attending pupil referral units had some sort of special educational need⁷. Pupil referral units are intended to be temporary measures rather than an alternative setting for disabled children to attend when needs cannot be met at their named educational provision.

The third most common educational setting reported by parents taking part in our survey was "no school place identified". For many, this was because the lack of support or an inappropriate placement meant that their needs could not be met at school or college.

Current EHCP names residential but since September 2021, my daughter has not attended college as no tracheostomy trained escort available, but me. I collapsed doing this, 5 hours per day, plus everything else. Current negotiations is EOTAS (education other than at school) and we are waiting for local authority tuition to get back to us. Head of health and head of education actually had their first meeting together on teams in august at 8am with me. After my request for a year that they work together

Cases such as the one described above emphasise the importance of timely appointments for reviews and assessments across health and social care, so that disabled children can attend education alongside their peers. The importance of joint working and integration across health, social care and education are discussed further in the next section.

6. Integration

It is clear that the level of support across health, social care and education is failing to meet the needs of disabled children, young people and their families. In addition, better integration between services is needed to improve the situation for disabled children and their families.

NICE guidelines for disabled children and young people with severe complex needs were published in March 2022³⁰. The guidance encourages education, health and social care services to work together and provide more co-ordinated support to children, young people and their family carers. Baseline assessments are provided by NICE to enable organisations to evaluate whether their practice is in line with recommendations.

In England, Integrated Care Boards were established in July 2022 with the aim of improved collaboration across services in order to improve the health of the population. Freedom of Information Requests were sent to all 42 Integrated Care Boards and 60% of ICBs responded to our request. Just one ICB

had completed the baseline assessment for their organisation. 58% of ICBs responding did not have a plan in place to undertake a baseline assessment.

NICE guidelines for disabled children and young people with severe complex needs encourage commissioners to better understand the needs of disabled children in their area and to commission services based on need rather than based on previous models of care. However, just 1 in 5 ICBs responding to our FOI request were able to report data held about the number of children and young people from their area attending provision outside of the Integrated Care System area. Similarly, as discussed earlier in this report, our FOI requests to local authorities across England identified that half of those that responded were unable to provide the number of disabled children on their register. Therefore, if the numbers are unknown to services, the challenge to understand their needs and commission accordingly appears ambitious from both the health and social care context.



7. Impact of lack of support on disabled children and their families

Parents taking part in our survey were asked to indicate the impact that the lack of support they may have experienced had on their disabled children, themselves and their other children over the last twelve months. Our pandemic research highlighted the detrimental effect that the lack of support had on families with disabled children. A number of the statements below were included in previous pandemic research. Although a direct comparison cannot be drawn from the previous work, due to there being a different group of respondents, statements below denoted with * suggest the impact on families to be greater in this survey than reported during the pandemic.

My son has been severely depressed for 29 months. He has taken an overdose, been out of school for over 2 years, 5 in total. He doesn't speak or leave his room.

After he took an overdose, crisis teams at the hospital said he needed an urgent medication review. CAMHS said he did not. We waited 9 weeks for that appointment. I could go on but I'm sure you're aware.

My son was funny, kind, smart, funny. He is now a shell and no one cares.

7.1 Impact on disabled children

The impact of reduced support on disabled children is listed below. The findings emphasise the ongoing detrimental impact that the lack of support has on disabled children and young people's day to day lives. Levels of isolation are high, with few friendships, leading to poor physical and mental health.

My disabled child's friends are actually his PA's. He doesn't understand the concept of friendship and doesn't have any friends apart from people that support him.

My children don't have friends round or sleepovers due to their complex needs dominating and dictating a very isolating existence for the whole family. The only social events we go to as a family are organised charity events in our local area.

The statements below indicate the impact that delays or reduced support has had on disabled children over the last 12 months.

- 73% My disabled child's health has been negatively affected*
- 73% my disabled child is more isolated
- 70% my disabled child is more anxious*
- 69% my disabled child's behaviour is more challenging due to stress, anxiety or pain
- 67% my disabled child is lonelier
- 58% my disabled child's disability or condition has deteriorated*
- 57% my disabled child has more problems sleeping
- 55% my disabled child has regressed*
- 45% my disabled child is showing signs of depression
- 41% my disabled child self-harms or takes part in self-injurious or high risk behaviour
- 39% my disabled child is experiencing more pain*

The main impact is isolation. Because there are no activities suitable for her to take part in (because the LA doesn't commission them), my daughter is dependent on school and family. She is safe and well, but she would love to have more friends and be helped to do fun things with her peers outside school.

7.2 Impact on Parents

As already highlighted, in the absence of support from services, parents of disabled children have to plug the gap. As demonstrated by the responses below, this does not come without consequence to the health of parents. The statements below indicate the impact that delays or reduced support has had on parent carers over the last 12 months.

- 87% My mental health has been negatively affected*
- 82% My physical health has been negatively affected*
- 64% I am unable to see my friends and family
- 55% I have sought formal support for my mental health
- 46% I have been prescribed anti-depressants

As the parent - I have no friends or support network - my child has 1 friend that she sees every day at school. It's incredibly sad & lonely for both of us.

No family. No friends. We don't go out, no social media, no groups, no nothing. We attend hospital and school only.

7.3 Impact on Siblings

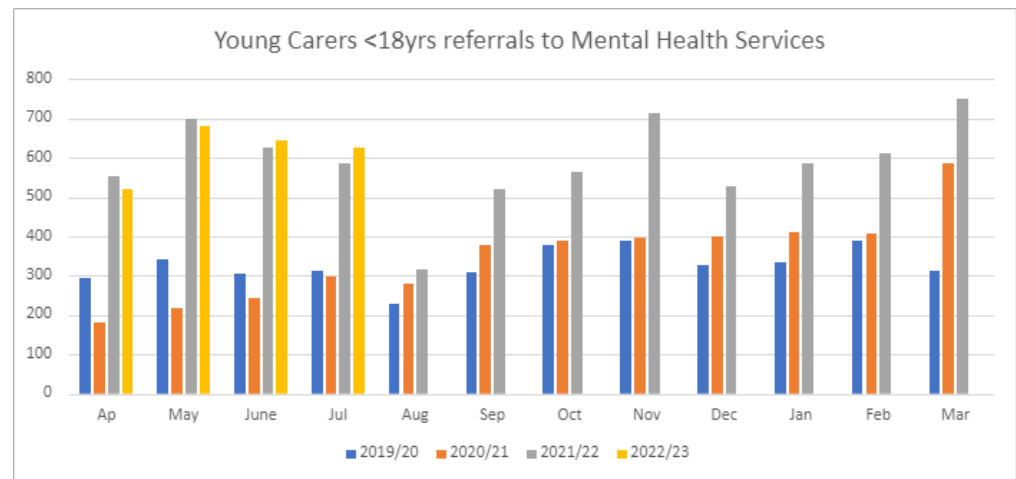
The detrimental impact on the wider family is clear from the findings below about the siblings of disabled children. The statements below indicate the impact that delays or reduced support has had on siblings over the last 12 months.

- 67% Is more isolated*
- 61% Is lonelier*
- 69% Is more anxious*
- 56% Confidence has deteriorated*

- 54% Has taken on more caring responsibility for their disabled sibling
- 52% Has more problems sleeping*
- 51% Is more downhearted*
- 48% Is unable to take part in hobbies or activities due to their caring role
- 44% Showing signs of depression*

The poor outcomes listed above, due to the lack of support available for siblings, are associated with poor mental health. Parents who seek support for the siblings of their disabled children are again impacted by NHS waiting lists and backlogs. As illustrated in figure 7, NHS mental health data for young carers illustrates that new referrals for those that require mental health support continue to increase.

Figure 8 –Young Carers referrals to mental health services – pre-pandemic comparison



The above findings highlight the impact that the lack of support has on disabled children and the wider family.

Relatives have never really understood my son's disability. He has friends but does not see them outside of his groups, or outside home. His grandad died during Covid that impacted him greatly. My mum is 86, so she can't take anything on. It's just us and his brother really.

We don't have friends, apart from my sister's friend who we see occasionally. My family live 110 miles away and due to the cost of living we get to see them once every 1-2 years. We are a very isolated and lonely family.

As a consequence of reduced support, families are caught in a vicious circle of developing physical and mental conditions and long delays within health and social care risk isolation for the whole family. This must be considered a risk factor for families facing the current combined cost of living and energy crisis, as discussed further in the next section.

8. Cost of living

73% of families taking part in our survey state that the cost of living crisis will have a significant impact on their disabled child. Reports from across the charity sector highlight the extremely challenging set of circumstances that families with disabled children face. Price rises across the board, particularly in relation to food and energy, have pushed families to their very limits and this is likely to worsen in the year ahead¹¹.

Even before the current cost of living crisis, 24% of parents with disabled children were spending more than £1000 per month on average. Almost 2 in 5 parents of disabled children have gone without food for themselves, 30% have gone without heating and more than half have gone without toys and equipment for their children³¹. 36% of parents and carers have pawned or sold possessions, 32% have borrowed money from family or friends for essential purchases and 1 in 4 have accessed a food bank⁴. 1 in 6 (16%) unpaid carers are in debt as a result of their caring role and their financial situation, increasing to 2 in 5 (40%) for unpaid carers in receipt of Carer's Allowance³².

The United Nations has called upon governments to increase benefits in line with inflation in order to avoid loss of life over the winter period 2022-23³³. The UK government has announced a recent uplift in benefits and extra energy payments for disabled households, which is most welcome. However, the uplift will not be

implemented until after the winter period, leaving families with disabled children extremely vulnerable. Wider research confirms that carers who have been caring for longer and those who provide more hours of care per week, such as parents of disabled children, are more likely to be struggling financially. People who have been caring for over 5 years are almost twice as likely to be struggling to afford the cost of food and be in debt than people who have been caring for less than 5 years³².

40% of families with disabled children have been forced to cut back on life-saving medical equipment for their disabled children, with 40% stating that this is making their child's condition worse³⁴. The combination of reduced support across education, health and social care, set within the context of the cost of living and energy crisis, risks leaving families with disabled children isolated and excluded from opportunities across wider society.

Responses to our survey show that parents who have a disabled child with an EHCP were more likely to be unable to work and to be experiencing poverty than those with SEN support or no support (no support refers to children with or without a diagnosis where formal support has not been identified). In addition, those that have had to give up work and are in poverty are consistently more likely to report negative impact, caused by the lack of support for their disabled child, for outcomes such as reporting that their disabled child has regressed or experienced self-harming behaviours, problems sleeping, deteriorating disability or condition and more pain.

The following section discusses in further detail patterns of social isolation experienced by disabled children, young people and their families, as reported in our survey.

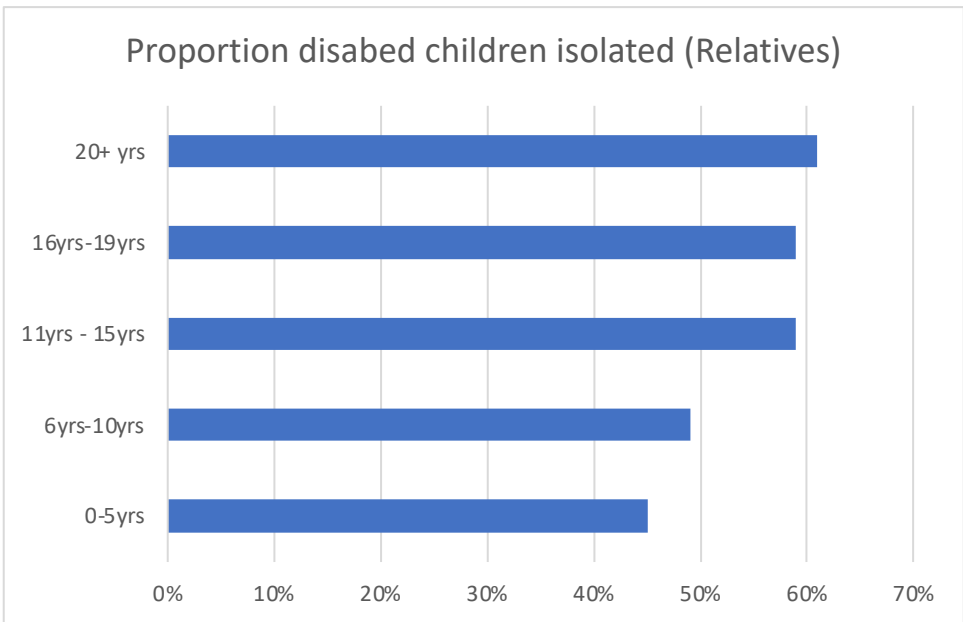


9. Social Isolation and Support into Adulthood

Further analysis of social isolation figures reveals two key areas to consider regarding the impact of a lack of support over the lifetime of disabled children and young people. Parents tell us about how the isolation increases with age, as figure 7 below demonstrates. Disabled children and young people are more likely to become more isolated as they get older, with the proportion of those not seeing relatives outside the household greatest in the 20+ age group.

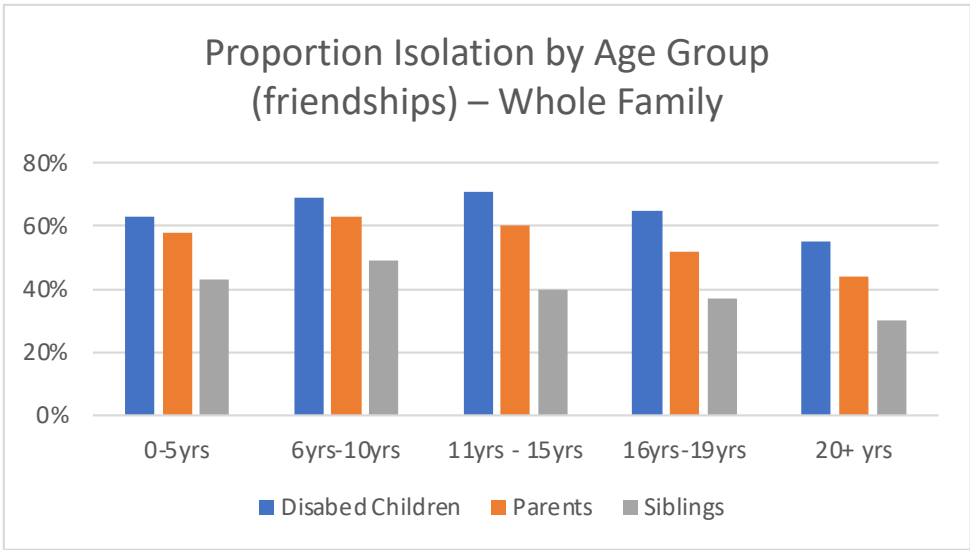
Social isolation and no appropriate respite, all provision seems to stop at aged 18 yet EHCP supposed to end at 25. The EHCP is worth nothing

Figure 9 – level of isolation of disabled children and young people from relatives outside the household within the last month by age group.



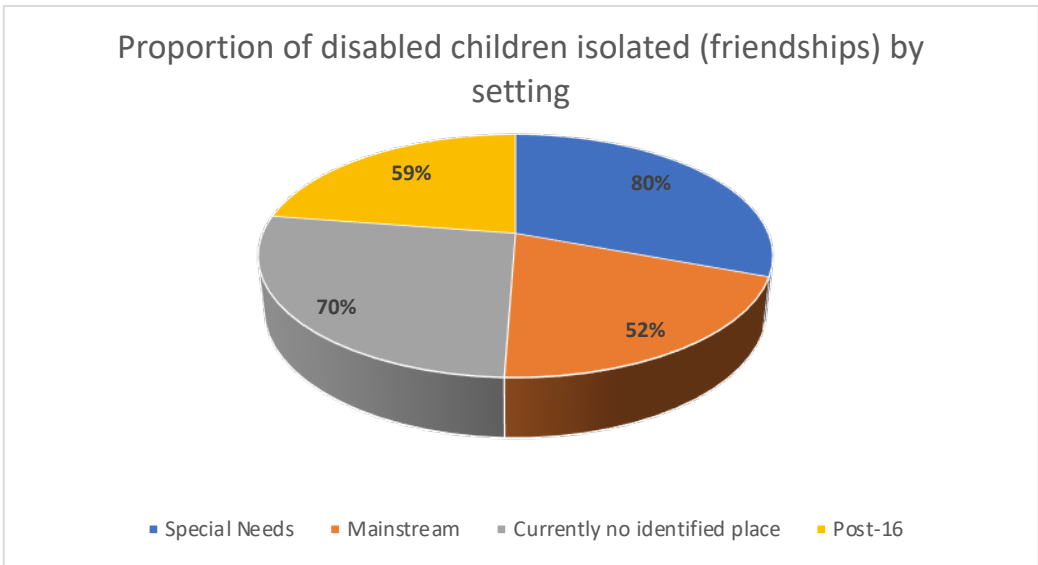
Support is vital to ensure disabled children and young people can fulfil their potential but also to ensure that young people remain safe. However, half of parent carers are concerned that their disabled child or young person is vulnerable to being exploited or coerced into behaviours or relationships that may put them at risk emotionally and physically. 1 in 4 parents are concerned that their disabled child could be at risk of becoming involved in anti-social or criminal behaviour. The role formal support plays, not just in the day to day short-term at school or in training but in view of the long-term benefits for young adults moving into adulthood, must be recognised by authorities.

Figure 10 – level of isolation from friendships experienced by disabled children, siblings and their parents by age group in the last month.



The level of isolation from friendships is greatest for parents and their disabled children and young people in the 11-15 years age group and the 6 - 10 years age group. Therefore, the age group of compulsory education is the period in disabled children's lives when they feel the most isolated. Wider research has highlighted the role education settings play in facilitating social contact and friendships for disabled children and young people, especially when considering challenges to accessing hobbies and activities in the wider community⁷. In addition, figure 9 illustrates that disabled children attending a special needs school are more likely to be isolated (80%) than their mainstream peers (52%).

Figure 11 – Proportion of disabled children isolated by setting



The high levels of social isolation identified within our latest survey are a result of poor levels of support and lack of integration across health, social care and education. Without intervention, isolated disabled children and young people will become isolated adults, marginalised from wider society.

My child has suffered extremely low self-esteem & self worth, threatened suicide at 10 years because of lack of recognition of FASD (Foetal alcohol spectrum disorder) even though my child was previously cared for. My child’s social problems resulted in agoraphobia, isolation & depression. It is a continuing battle to gain correct qualified provision

Isolation, has now become more insular and unwilling to go out now. It is a struggle to get him out of the house.

Good transitional support into adulthood from across services is vital to ensure disabled children and young people reach their potential. However, our previous research into transitional age groups found that 75% of families reported problems transitioning into adult healthcare services and a third reported problems transitioning into adult social care. Far from achieving independence, two thirds of parents indicated that they expected their child to continue to live in the family home and to be supported by benefits. A third of disabled young people were not expected to continue in post-16 education due to a lack of suitable provision. In fact, more than half of disabled children do not have a transitional plan in place³⁵.

Reforms to the SEND and social care system must ensure disabled children and their families’ needs are met with a comprehensive support system that prepares disabled children for adulthood and reduces the risk of isolation across the life-course. In order for that to be a reality, local authorities and providers need to meet their current legal duties and to be held to account for doing so. The following section provides more clarity around the lack of accountability across systems that support disabled children.

10. Accountability

As previously mentioned, the Children Act 1989²⁵ requires local authorities to open and maintain a register of disabled children within their area. However, FOI responses from local authorities in October & November 2022 found that 43% were unable to provide this figure. Our FOI requests, discussed in section 6, highlight that just 1 in 5 of Integrated Care Boards responding to our requests were able to provide a number of disabled children receiving support outside of their area, despite having the responsibility of commissioning appropriate services for children with complex needs. Disabled children need to be a priority across statutory authorities.

Legislation states that local authorities should complete assessments for Education, Health and Care Plans within 20 weeks. However, data since 2017 reveals that just 15% of local authorities have met this target for all EHCPs. Table 7 illustrates that, on average across England, around 6 in 10 EHCP assessments have been completed within the statutory framework over the last five years.

Table 7 – Timescales for local authority EHCP assessments 2017 - 2021

Year	Average Proportion of EHCP assessment completed within 20 weeks
2017	67%
2018	63%
2019	66%
2020	66%
2021	65%

The current system supporting disabled children and their families must be improved to ensure that services and statutory bodies are accountable for adhering to legislation and requirements set out in law.

Further analysis of local authority level data illustrates that 1 in 5 local authorities are consistently below (meaning 4 or 5 out of 5 years) the already poor national average of completion rates listed in Table 6. For some local authorities, just 1 in 10 EHCPs may be completed within the statutory timescale of 20 weeks. Analysis of workforce and vacancy data reveals that 1 in 3 local authorities consistently (meaning 4 or 5 out of 5 years) report children’s social work vacancies above the national average.

Lack of support for families, either through delayed timescales or limited staff numbers, contributes to a failure to meet the needs of disabled children and their families. Delays in identification of needs and, therefore, lack of appropriate support for disabled children and young people mean that they are at serious risk from falling out of the education system, failing to reach their potential, becoming isolated in later life and marginalised in society.

Disabled young people with educational health and care plans or special educational needs support are more likely to not be in education, training or employment (NEET) than their non-disabled peers. Again, further analysis of four years of data at local authority level concerning disabled young people who are NEET illustrated that 1 in 3 local authorities are below the national average for all four years³⁶.

Latest Ofsted data³⁷ shows that, since visits started six years ago³⁸, more than 2 in 3 local authorities inspected by Ofsted had significant weaknesses in their SEND support for disabled children and young people. Therefore, it is clear that parents’ experiences reported within our survey are unfortunately not rare.

“My child’s social problems resulted in agoraphobia, isolation & depression. It is a continuing battle to gain correct qualified provision”

11. Conclusion

Disabled children and young people deserve a support system that enables them to flourish at whatever stage of their life they are at. However, they are currently facing excessive delays across multiple services. It is common for huge periods of disabled children's lives to be spent waiting either for an identification of their needs through assessment before appropriate support can be provided or for that provision to be implemented for both themselves and their families. The needs of disabled children and their families should be prioritised across all government departments and the public sector. The current landscape provides opportunities to improve the experiences of disabled children and their families.

The Department for Education, working closely with the Department for Health and Social Care, must ensure that reforms to special needs and disability do not make it harder for parents to get the support their children need.

The Department for Health and Social Care and NHS (England) must ensure all Integrated Care Systems have clear plans for eliminating the backlogs in assessments and therapies/treatments for disabled children. As recommended in the Independent Review, the Department for Education should ask the Law Commission to review the legal framework for disabled children's social care, and this should be used to clarify and improve access to support.

Future reforms to Children's Social Care must include a specific focus on disabled children in the proposed 'Family Help' arrangements, building on lessons from the Short Breaks Innovation Fund, and must increase the focus on disability within children's social work training. Government should provide financial support to families with disabled children during the current cost of living crisis, including a social energy tariff.

The government has the opportunity to improve outcomes for disabled children through the SEND green paper, social care review, disability action plan and cost of living initiatives.

Improved support within a truly integrated support system would ensure the path for disabled children to reach their potential and lead fulfilling lives becomes a practical reality.

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The Disabled Children's Partnership (DCP) is a growing coalition of more than 100 charities who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families. We are administered by Royal Mencap Society (registered company in England and Wales no. 00550457; registered charity numbers are 222377 in England and Wales, and SC041079 in Scotland).

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