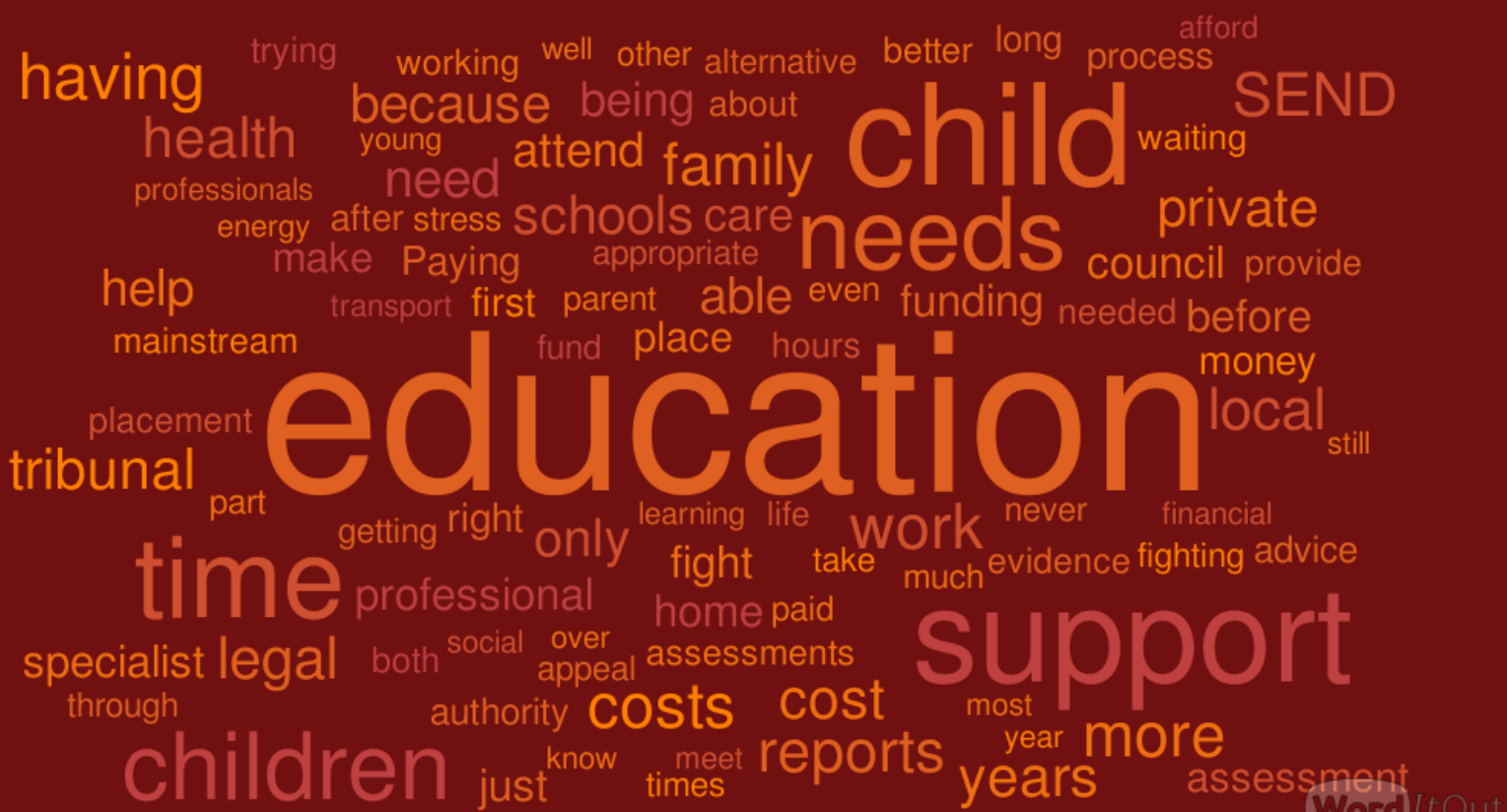




# Fighting for your SEND child: the hidden costs

Survey commissioned by Sky News

**REPORT**  
2024 Final



## SEND Hidden Costs survey for Sky News

### Project Outline

#### Project title:

**“Fighting for your SEND child: the hidden costs”**. Research for Sky News undertaken by the Support SEND Kids charity.

#### Project scope:

We were approached by Sky News to survey our Support SEND Kids community and discover if there was a hidden financial/time/career cost paid by parents of SEND children. The survey was aimed at uncovering the hidden costs that the lack of support from employers, schools, local authorities have on the working patterns of SEND parents.

#### Survey and distribution:

1 Feb 2024: Support SEND Kids mailing list, 1000+ members received a survey.

2 Feb 2024: A similar SurveyMonkey survey link was posted on Support SEND Kids socials: LinkedIn, Facebook, Instagram, X.

Note: surveys were created with different platforms to allow participation when we did/didn't have user emails. This resulted in minor differences shown in the raw data.

#### Project data:

Data in full is provided in the Appendix. This includes the free-text responses in full, including many illuminating quotes from parents, names are redacted. None of the questions on the survey were mandatory.

#### Survey deadline:

The survey ran for 6 weeks from 1 Feb – 14 March 2024.

#### Project lead:

Tamsin Ogilvie, User Experience lead, Support SEND Kids charity.  
Any questions please contact: [tamsin.ogilvie@supportsendkids.org](mailto:tamsin.ogilvie@supportsendkids.org)

## Results Summary

No questions were mandatory.

### 519 total participants

- 454 female (or identifying as female)
- 60 male (or identifying as male)
- 3 other
- 1 rather not say

### Does your SEND child have an EHCP?

- 412 child with EHCP
- 106 child without an EHCP

### Fighting to get the right EHCP provision:

- 213 had to give up work completely
- 172 reduced working hours
- 80 changed role at work
- 61 nothing changed

### Reason for changing working pattern:

- 125 lack of local authority help
- 81 lack of school support
- 36 lack of flexibility from employer
- 35 this doesn't apply to me
- 213 answered in detail (see results)

### Would extra support from: school, LA or employer make a difference?

- 398 Yes it would make difference
- 27 No it wouldn't help
- 219 answered in detail (see results)

### Changing work to fight for right EHCP provision:

- 185 this affected family finances immediately
- 103 this affects our family finances in the long term
- 86 I worry about money most of the time
- 23 we don't have money worries

Free legal guidance for parents is offered by our charity, Support SEND Kids, which can help with the EHCP process. Visit us here to learn more: [Support SEND Kids Q&A](#)

'Hidden Costs' are articulated clearly in this response:

**“Time, energy, access to information to equip ourselves to take on the LA. The emotional and mental cost of having to fight on behalf of our children for everything. Impact on all our other relationships, missed career progression opportunities, increased costs when we have to bridge the gap left in LA provision for our children out of school or in school part time. Paying for private reports, private professional support, funding provision that should be delivered through the EHCP but isn't.”**

## Survey Results

### Key findings

Impact of having an EHCP: 519 participants in total

412 child with EHCP

106 child who doesn't have an EHCP

**Summary findings:** Of respondents to the survey: 'Fighting for your SEND child: the hidden costs', 87% were women. Several of the 60 men who responded, referred to their wives giving up work or reducing hours. Of the female respondents only 11% said their working life was "unaffected" by having a SEND child.

Having an EHCP doesn't make much difference to the impact on working patterns. The EHCP doesn't remove the need for additional parental support. In general, many EHCPs focus on school adjustments, so only provide help during term time. The issue of inadequate holiday and after school care is significant in impacting working hours as parents need to step in to meet the gap. Children needing out of school help, whether or not this is provided by the EHCP, need parents to transport them.

In addition EHCPs have an annual review process which requires parental input on a regular basis, even if the EHCP is delivered in full. When the EHCP is inadequate, not delivered on, or not kept up to date, the child is still vulnerable to insufficient support and the load falls back onto the parent.

When a child can't attend school: parents are caring for children unable to attend school (37% of responses to: reasons for reducing hours or giving up work) most of this group don't have an EHCP and find the burden for home schooling falling on their shoulders.

**Fighting to get the right EHCP provision:**

- 213 had to give up work completely  
193 women / 20 men
- 172 reduced working hours  
156 women / 16 men
- 80 changed role at work  
69 women / 11 men
- 61 nothing changed  
50 women / 11 men

Of the total women who responded only 12% found their working life unchanged. With 40% (2 in 5 parents) having to completely give up work. The remaining 48% have had to compromise with reduced hours or by changing roles.

**Summary findings:** There is huge financial pressure on a vast number of SEND families. Waiting times of 2 to 4 years for NHS assessments have meant many families have turned to the private sector, where assessments can cost many thousands of pounds. In addition, some local authorities are not covering the full cost of support for children. Parents describe how they have to step in to pay for weekly physiotherapy year after year, online schooling, extra speech and language support, among other costs. One stating: “[we are] having to spend three times as much for a disabled child to learn a new skill”. “If they [local authority] adhered to the law, I would still have a well-paid career”.

Chasing the local authority to deliver on their statutory obligations or hold them to account when deadlines are endlessly missed, often means going to Tribunal. “[We paid for] Tribunal costs, twice. With barrister and expert witness support both tribunals cost in the region of £20,000. They were both won with the LA capitulating on the morning of the tribunal because they had no case”. This substantial cost is never repaid to families even when LAs lose their case (based on research from IPSEA is 90% of cases). “LAs save money by refusing support, they lose cases that go to tribunal over 90% of the time and never have to pay parents costs. It's a false economy, as we would rather spend our time and money on helping our children. If they receive the help they're entitled to, the majority [of SEND children] will be independent contributing members of society. Sadly the lack of early help fails our children, and the employment rates of SEND people are abysmal. It need not be this way!”

Some women say they ‘can't afford to give up work’ because of these costs, while many others have had no choice but must stop work and careers as their children are unable to

attend school. Many more have had to compromise work in order to provide wrap around care. Many respondents point out that there are after school clubs for neurotypical children but nothing offered to children with special needs. Having no after school help significantly reduces the working day for many women, as does a lack of provision during the school holidays.

Impact on parental mental health is significant, especially women who have had to give up jobs they love, respondents noted they had been teachers, nurses or keen to build a career. Having to take themselves out of the workplace is damaging to their mental health as well as to the UK's social services. *“How many caring and diligent teachers and nurses can the country afford to lose by not providing adequate childcare?”*

#### Reason for changing working pattern:

- 125 lack of local authority help  
118 women
- 81 lack of school support  
78 women
- 36 lack of flexibility from employer  
36 women
- 213 free-text answers – see separate results

Two main themes impact a parent's ability to work:

#### **1/ when care for the child has to be done by parents (in most cases by the Mother).**

This is when provision from school, Local Authority or other care team falls short. It affects the length of the working day, during term time and all days during school holidays. Due to lack of wrap around care, as mentioned earlier, neurotypical children are provided with after school clubs, neurodiverse, SEN or disabled children are left out. Children unable to attend school are at the extreme end of this scale, parents have to be on hand full time.

Examples include: *“I have had to give up a high paid career to look after my son. He's 11 so can't be at home alone. He's not been to school full time since year 1. There is no prospect of him attending school again. He is not able to cope with an independent PA as he does not trust adults in education due to school trauma. This is unlikely to change as neither the NHS nor the LA will provide treatment and as I can no longer work we cannot afford to go private. My time is spent trying to re-engage my son in education ... I am having to bear the costs of educating my son as he is no longer on a school roll and my son can't access the section 19 offer. There is also the mental toll which has affected all our family.”*

*“Our child currently lives in a hospital, 1.5 hours each way (on a good day) ... If we don't visit, they may not eat much, sadly.”*

As part of the work/carer decision are the costs associated with additional care during holidays or after school. *“Funds for outings during the school holidays and weekends. It's £100 per day for my brother to attend a workshop with other special needs kids. It's just not feasible to make that financial commitment weekly.”*

*“There were no suitable school places for my child, He was rejected from 15 schools, I have to be present for any tutor sessions it would have been helpful to be able to have had a care assistant during these sessions so that I could continue to work.”*

## **2/ Demands by school, LA, health professionals for parent to be available at short notice**

The other impact is made by demands from the school or local authority on the parent. The parent is assumed to be ready at a moment's notice to attend meetings, come into school to handle difficulties with their child or to attend Tribunal or other legal requirements.

*“[We need] School - to take the initiative to identify and put in place the correct interventions needed. Local Council - to not have unlawfully denied an EHC Needs Assessment, to not have unlawfully denied to issue an EHCP resulting in a 12 month battle to tribunal, to help parents to find a suitable school that can provide all the support required for our SEN child instead of refusing to assist because they have to be 'impartial'. Employer - I had to quit a conventional job and go freelance due to all the time off needed for meetings, organising professionals to assess my child, review reports, research, and putting together cases to fight the LA's many unlawful decisions. I also needed time off to find a suitable school for my child and then assist in the transition.”*

*“Needs of child were such that I needed to be on call whilst child was at school. She rarely made it through a whole day and I would be called to collect. Sometimes sent home due to lack of staff. Home schooling became best choice. She wouldn't accept anyone other than me. No energy or time for paid work or social life.”*

### **Extra support from: school, LA or employer**

311 Yes it would make difference

18 No it wouldn't help

(138 free-text answers – see separate results)

What SEND parents want is: *“recognition that as parents of children with SEND EVERYTHING is a battle, we already have a harder parenting job and we are exhausted and don't have the*



*time, energy or expertise to take on local authorities to advocate for our children and fight to get what they are entitled to by law, but if we don't, nothing happens and our children suffer."*

**Summary findings:** At its simplest, the need is "Money from the council/government. More experts available to support schools. They are stretched to breaking point." This is a systemic problem with one parent explaining: "We've battled with the LA to provide SaLT and OT within the EHCP.... but the NHS service is appalling. ... The staff turnover is very high. To force the LA to provide my son with the provision he needs as identified in the EHCP we'd need to ... take court action (a judicial review). But if the NHS is struggling to keep up with the demand then what's the point?"

**Changing work to fight for right EHCP provision:**

- 185 this affected family finances immediately  
173 women
- 103 this affects our family finances in the long term  
102 women
- 86 I worry about money most of the time  
82 women
- 23 we don't have money worries

Not surprisingly, changing working patterns, by reducing hours or changing roles or leaving employment entirely affects family income. Of the women in our survey who answered this question, 56% found their finances immediately impacted, causing them to worry about money most of the time.

There is a difficult time/cost analysis for parents in paying others for help with their child(ren). This can be in wrap around (respite) care, holiday care or educational support provided when the children can't attend school. In addition to taking time off work to attend appointments. The biggest impact is however in the "hours and hours of work on EHCP and associated research" where parents must choose whether to upskill themselves or pay for professional advice. "Part of my personal journey is that I self-financed and trained in SEND Law - as I could not afford a Barrister on top of all the private professional assessments etc".

Free legal guidance for parents is offered by charity, Support SEND Kids, which can help with the EHCP process.

33% of all responders requested more information about Support SEND Kids charity to help them navigate the EHCP process and the SEND legal landscape.

**Summary findings:** Parents find the legal process daunting *“EHCPs are a legal document and as parent-carers not trained in legal matters you don’t know if the EHCP is worth the paper it’s written on and you have to pay privately to get it checked.”* Going to Tribunal is challenging: *“[our LA] used barristers which was intimidating”*. A noticeable number of women called for *“Training for parents on law EHCP and disability”*. This is where charities like Support SEND Kids can provide vital free legal support.

# Appendix 1

Selected quotes by participants

## Bringing the parental experience to life

Some of many quotes by participants

1. If they [local authority] adhered to the law, I would still have a well paid career
2. Our child currently lives in a hospital, 1.5 hours each way (on a good day) at £14 a time all adds up. If we don't visit, they may not eat much, sadly.
3. LA constantly wastes tons of money by not having decision making in the first port of call, everything goes to panels of high level managers causing additional costs & wait times, way too many management layers, whenever you go to court, most LAs have Barristers on retainer.
4. LA's save money by refusing support, they lose cases that go to tribunal over 90% of the time and never have to pay parents costs. It's a false economy, as we would rather spend our time and money on helping our children. If they receive the help they're entitled to, the majority will be independent contributing members of society, sadly the lack of early help. Fails our children, and the employment rates of SEND people are abysmal. It need not be this way!
5. Having provision that meets the needs of relatively academic autistic children - many mainstream schools do not meet the needs of ASD students and the existing specialist provision is often aimed at less able students.
6. Time, energy, access to information to equip ourselves to take on the LA. The emotional and mental cost of having to fight on behalf of our children for everything. Impact on all our other relationships, missed career progression opportunities, increased costs when we have to bridge the gap left in LA provision for our children out of school or in school part time. Paying for private reports, private professional support, funding provision that should be delivered through the EHCP but isn't.
7. recognition that as parents of children with SEND EVERYTHING is a battle, we already have a harder parenting job and we are exhausted and don't have the time, energy or expertise to take on local authorities to advocate for our children and fight to get what they are entitled to by law, but if we don't, nothing happens and our children suffer.
8. Understanding that children with complex needs and/or obviously significant needs to be helped by providing the specialist input they need asap not waiting for them to fail or be excluded et cetera. The sooner we import the best chances the child has for independence in the future and not requiring long-term support.

9. Tribunal costs, twice. With barrister and expert witness support both tribunals cost in the region of ~£20,000. They were both won with the LA capitulating on the morning of the tribunal because they had no case)
10. Honest processes that follow the law.
11. The local authority have the legal duty to provide free legal advice via impartial services...in Manchester that is the SENDIAS, it is not impartial and does not provide appropriate advice but merely gatekeeps
12. If you want legal advice you have to pay for it.... parents who have been through it are setting up companies charging parents for support that should be given free from LA
13. You can get legal aid to take the local authority to judicial review to fight unlawfulness such as not providing section 19 and 42 education or not sticking to EHCP deadlines etc.
14. However the amount of money allocated to JR by legal aid does not cover the cost of judicial review, therefore unless you are rich and can pay a specialist solicitor which there are not many of ...you can't afford 5k to take the council to court to enforce your legal rights.
15. Council know they are untouchable and just carry on not meeting their legal responsibility... they know we can't get legal aid or afford to pay private whilst living in crisis unemployed /lost your jobs due to schools demanding you collect your child /refuse to allow them return and remain out of education
16. Professionals see broken children and broken parents as the cause rather than collateral damage of incompetent council senior leaders and managers
17. Lack of Council staff who care or who are interested in the child rather than their budgets. Staff seem to be agency and outside the county largely so no local knowledge of schools or their area. It's been an appalling experience. Parents often pay for therapists and interventions due to long waitlists and lack of resource
18. Often EHCPs involve medical issues. Our medical bills are high. Last year we paid almost £40k.
19. School - to take the initiative to identify and put in place the correct interventions needed. Local Council - to not have unlawfully denied an EHC Needs Assessment, to not have unlawfully denied to issue an EHCP resulting in a 12 month battle to tribunal, to help parents to find a suitable school that can provide all the support required for our SEN child instead of refusing to assist because they have to be 'impartial'. Employer - I had to quit a conventional job and go freelance due to all the time off needed for meetings, organising professionals to assess my child, review reports, research, and putting together cases to fight the LA's many unlawful decisions. I also needed time off to find a suitable school for my child and then assist in the transition.
20. Costs of private assessments: Private EP Assessment & Report - £750  
Private SLT Assessment, Reports and DLD diagnosis - £1,500

- Private SLT weekly sessions for 3 years - £4,320  
Time off work over 4 years - £8,400 (approx)  
Luckily I didn't have to pay for legal advice but we were contemplating it.
21. Assistance in navigating the support and benefits systems that are in place
  22. The biggest hidden cost is parental mental health. My mental health really suffered due to the strain of trying to support my child and go through the hoops to get her the right support. I ended up in an acute mental health unit for two months because I had a breakdown. I still struggle with my mental health now and it has taken its toll on my family.
  23. Lack of understanding in the media, always targeting children not in school as naughty or parents as being neglectful means it has a negative effect on us as parents due to the lack of understanding.
  24. Funds for outings during the school holidays and weekends. It's £100 per day for my brother to attend a workshop with other special needs kids. It's just not feasible to make that financial commitment weekly.
  25. Parents do not get their costs back, even when they go on to win a Tribunal. If local authorities were obliged to pay costs when they lost cases, they would be less likely to pursue vexatious cases, or work on the basis that they might as well challenge cases because this means enough families will drop out. In our case, the legal costs amounted to about -£18,000 - it means that only families who can find these sums in the first place, and can write them off, have any reasonable hope of challenging local authorities who use taxpayers' money to fight them.
  26. To work EHCPs should be working documents that accurately reflect the child's needs and detail the support needed who will provide it and when. Most are badly written, and don't, meaning a battle with the LA to get them changed, this will mean getting legal advice, specialist reports and lengthy battles, stressful and costly, parents find themselves funding gaps as well.
  27. The cost is more about health than cash, spending your time dealing with so many forms, emails and calls etc takes you away from your work and family life, that makes you worried your not fulfilling your work commitments and not enjoying family life as there is always too much to do to fight the battles.
  28. Mental health, family relationships, maintaining a positive face to my child. Not letting him see the impact the system is having on us as he will internalise it if he thinks it's his fault. Having no time or energy for self care.
  29. Someone to oversee and coordinate everything involved in my child's care, including community paediatrician, consultant paediatrician, neurodisability team, teachers, SENDCos, specialists such as SALTS, OTs, psychologists as I am the one who currently needs to coordinate everything and ensure everyone is aware of the outcomes of appointments, meetings etc and ensure these are reflected in all reports, EHCP reviews etc.
  30. ...There are only 2 schools that would be appropriate and both are private specialist, if the LA won't fund the place she can't go, she also can't go to

- mainstream..so what happens then, we write her off at 11 into a specialist school that'd doesn't even do gcse's?
31. For the LA to honour the terms of the EHCP and not make us endlessly battle to secure each aspect of support for our young person.
  32. Better help from the local authority to understand not just the application process but the annual reviews and phase transfers. With step by step instructions! (so I don't get exhausted googling what I should be doing)
  33. Attending training courses for parents about EHCPs - this is so important to know your legal rights
  34. You spend endless amount of time making complaints to the Local Council to ensure provisions set out in the EHCPs are met. More often they tend to miss the statutory time frames to complete Annual Reviews, and issue and finalise EHCPs that you are left having to take it to the Local Government Social Care Ombudsman. Also, you have to dip into your savings to pay for independent reports and pay for representatives when you are taking your appeal to the tribunal. It is all a very draining process!
  35. Honest information about what my son was entitled to. I was unaware of any alternative provision being an option when my son became unable to attend school.
  36. Paying for childcare so I could attend meetings. Paying to attend webinars to educate myself on the process. Also the stress and endless worry and uncertainty.
  37. I have had to give up a high paid career to look after my son. He's 11 so can't be at home alone. He's not been to school full time since year 1. There is no prospect of him attending school again. He is not able to cope with an independent PA as he does not trust adults in education due to school trauma. This is unlikely to change as neither the NHS nor the LA will provide treatment and as I can no longer work we cannot afford to go private. My time is spent trying to re-engage my son in education with learning embedded were school trauma exists in respect of core subjects. I am having to bear the costs of educating my son as he is no longer on a school roll and my son can't access the section 19 offer. There is also the mental toll which has effected all our family as well as previous advocacy fees when we first started the journey.
  38. I have to give up lots of free/leisure time. I cant afford to give up work. I have to pay £3500 for an ASD/ADHD assessment before I can even ask for EHC needs assessment. The NHS waiting list is 4 years.
  39. There were no suitable school places for my child, He was rejected from 15 schools, I have to be present for any tutor sessions it would have been helpful to be able to have had a care assistant during these sessions so that I could continue to work or pursue my own personal goals ie mental health walks.
  40. Sticking to EHCPs, granting the child the accommodations recommended in expert OT, SLT, EP reports so that fewer EHCPs might be sought in the first place. Better

training for all sencos, all teachers and headteachers on the NORMAL behaviour of autistic children, such as stimming behaviours and failure to recognise social hierarchy and taking things literally is not deliberately rude. Working WITH and believing parents instead of being dismissive or defensive. Acting upon their thoughts that a child might be SEN or have additional SEN; I know it requires paperwork, but it's for the child and protects future mental health. More visuals in lessons. More written instructions for those with processing issues. Awareness of hyperlexia and how it is a learning style and cones with comprehension issues. If referrals have been made by a paediatrician who is an expert, schools should not be approached for a second opinion that overrides the expert's opinion that led to that referral. All diagnosed autistic kids should be assessed by an OT and SLT because hypermobility is common and needs accommodation and most autistics are Gestalt Language Processors even if they are verbal. BAN teachers from shouting at the pupils in primary schools. I've felt I have no other choice but to home educate now. I wish he could attend school but it's killed his love of learning and made him distrustful of adults.

41. I am a parent of two Secondary age children, both with a complex cocktail of hidden disabilities (G[redacted] aged 14 - ASD, ADHD, SpLD (Dyslexia) and DLD / S[redacted] aged 11 - ASD / ADHD and SpLD (Dyslexia)

I am an advocate for other parents who are trying to secure the necessary EHCP and school provision to meet needs. Helping them navigate the challenges of the 'System' and Tribunal / Judicial Review. (Part of my personal journey is that I self financed and trained in SEND Law - as I could not afford a Barrister on top of all the private professional assessments etc..)

I am also a Chair of Governors at their previous Main Stream Primary school (Giving me valuable insights into the 'Operational' and 'Strategic' approach and challenges in 'attempting' to provide SEND provision.

Without any shadow of doubt the biggest barrier to learning for a child or young person with SEN within mainstream provision is the LOCAL AUTHORITY (Not their disability or addition need!) Most LA's operate a playbook and systemic culture of 'Delay and Deny' playbook. They persistently operate outside the guidance of SEND Code of Practice and not meeting statutory duties and unlawful practices are common place across many LA's.

The biggest flaw in the system is that there is no consequential impact on an LA for being unlawful and/or not complying with statutory duties / guidance /legislation. At worst they will be listed in the Noddy Guide as a precedent of caselaw - but there is no fiscal consequence whatsoever, parents cannot recover



their costs, so the systemic playbook of maladministration is continually perpetuated.

42. Parents find the process exhausting, unfair, unreasonable - with LA's expecting them to fold and accept compromises that are loaded in their fiscal favour. I have parents who I have advocated for, who would go on record to expose the level of unlawful and 'dirty tactics' to actively try and get unsuspecting parents to 'say' something that would derail their entitlement to provision. (Things like trying to get the parents to say that a particular school is their 'Parental Preference' - when in fact it was the nearest or only school that could meet needs - persistently not recognising the fact that they MUST name the school, in the absence of any other appropriate provision - WHY? Simple they would not be responsible for transport if the school was named as a parental preference.
  
43. We have mountains of damning evidence, over multiple cases. Unlawful practices. Falsifying evidence. And fiscal maladministration that defies logic, and can only be put down to spiteful action from the LA case works and leadership teams (We have fiscal evidence that demonstrates that Hillingdon LA refused residential provision requested by parents, on the grounds that there was no specific specialist professional advice that there was a need for a residential placement - Myself and the parents provided detailed financial evidence that, whilst there was not professional advice for the residential placement, it would be in the interest of the public purse, as the combination of a residential placement with only 1 transport trip to and from the school each week, would lead to a saving of around ~£80,000 per year, in comparison to the daily transport costs. We also pointed out that the journey time was excessive, and far beyond the guidance for maximum travel times for a child of his age with SEN. The LA point blank refuses to provide the provision - and at the significant additional and necessary expense of TAX payers - The LA was failing in its duty of care, statutory duties, guidance, and not acting in the interests of the public purse... it beggars belief.. and the parents are more than happy to go on camera and triangulate the damning evidence of maladministration, malpractice and spiteful behaviour - where the child is the one that suffers the detrimental impact to their education and social / emotional wellbeing.

# Appendix 2

Results break down

SEND Hidden Costs survey results total								
<b>Combined results</b>								
Total participants	519	Mailerlite	94	SurveyMonkey	425			
<b>Q1</b>	<b>Does your SEND child have an EHCP?</b>		<b>Q1</b>	<b>Does your SEND child have an EHCP?</b>		<b>Does your SEND child have an EHCP? Answer yes, if any of your children have one.</b>		
Yes	412		Yes	83		Yes	329	
No	106		No	11		No	95	
<b>Q2</b>	<b>Are you male or female?</b>		<b>Q2</b>	<b>Are you male or female?</b>		<b>To understand if the impact of managing an EHCP affects parents differently, please tell us if you are male or female?</b>		
Female identifying	454		Female identifying	66		Female identifying	388	
Male identifying	60		Male identifying	26		Male identifying	34	
Other	3		Other	2		Other	2	
Rather not say	1		Rather not say			Rather not say	1	
<b>Q3</b>	<b>Fighting to get the right EHCP provision have you...</b>		<b>Q3</b>	<b>Fighting to get the right EHCP provision have you...</b>	women men	<b>Fighting to get the right EHCP provision have you...</b>	women men	
changed your role?	80		changed your role?	15	4	changed your role?	54	7
reduce your hours?	172		reduce your hours?	27	7	reduce your hours?	129	9
had to give up work completely?	213		had to give up work completely?	29	10	had to give up work completely?	164	10
nothing has changed	61		nothing has changed	10	3	nothing has changed	40	8
<b>Q4</b>	<b>Reasons for having to reduce hours or give up work...</b>		<b>Q4</b>	<b>Reasons for having to reduce hours or give up work...</b>	women men	<b>Reasons for having to reduce hours or give up work...</b>		
Lack of flexibility from employer?	36		Lack of flexibility from employer?	12		Lack of flexibility from employer?	24	
Lack of support from school?	81		Lack of support from school?	33	3	Lack of support from school?	45	
Lack of support from local council?	125		Lack of support from local council?	45	8	Lack of support from local council?	72	
Other	42		Other	42		This doesn't apply to me	35	
Free text responses	213					Answer in more detail (free-text responses)	213	
<b>Q5</b>	<b>What extra support from school, local council or employer would make a difference?</b>		<b>Q5</b>	<b>What extra support from school, local council or employer would make a difference?</b>	combined	<b>Would extra support from school, local council or employer make a difference?</b>		Men & women combined:
Add your answer here.... (free-text analysis shown separately)	219		Add your answer here.... (free-text analysis shown separately)		81	Yes	398	
yes	398					No	27	
no	27					Comments (free-text responses)	138	
<b>Q6</b>	<b>If you changed your working pattern, did it affect your finances...</b>		<b>Q6</b>	<b>If you changed your working pattern, did it affect your finances...</b>	women men	<b>If you changed your working pattern, did it affect your finances...</b>		
This affected family finances immediately	185		This affected family finances immediately	47	12	This affected family finances immediately	126	
This affects our family finances in the long term	103		This affects our family finances in the long term	47	1	This affects our family finances in the long term	55	
I worry about money most of the time	86		I worry about money most of the time	35	4	I worry about money most of the time	47	
We don't have money worries	23		We don't have money worries	4	2	We don't have money worries	17	
<b>Q7</b>	<b>Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?</b>		<b>Q7</b>	<b>Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?</b>	combined	<b>When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&amp;A site (supportsendkids.org) ...</b>		
Add your answer here.... (see free-text analysis)	78		Add your answer here.... (see free-text analysis)		78	Yes, I visited the site, it was helpful	30	
						Yes, I visited just to look around	30	
						Yes, but I didn't find the help I needed	30	
						No, I didn't know I could get help	160	
<b>Q8</b>	<b>When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&amp;A site (supportsendkids.org) ...</b>		<b>Q8</b>	<b>When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&amp;A site (supportsendkids.org) ...</b>	women men	<b>If you want to keep informed about this research, please enter your email. We will add you to our mailing list. You can unsubscribe at anytime.</b>		
Yes, I visited the site, it was helpful	59		Yes, I visited the site, it was helpful	21	8	Yes	68	
Yes, I visited just to look around	45		Yes, I visited just to look around	12	3	No/skipped	152	
Yes, but I didn't find the help I needed	39		Yes, but I didn't find the help I needed	8	1			
No, I didn't know I could get help	192		No, I didn't know I could get help	23	9			

## SEND Hidden Costs survey results raw data

### Mailerlite

Question	Answer
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f reduce your hours?
Reasons for having to reduce hours or give up work...	f Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f A send worker that answers your email quickly
If you changed your working pattern, did it affect your finances...	f I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f Emotionally draining Impact on family Frustrating just to get what your child is entitled to
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f Yes, I visited just to look around
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f had to give up work completely?
Reasons for having to reduce hours or give up work...	f Lack of support from local council?
Reasons for having to reduce hours or give up work...	f Other
Reasons for having to reduce hours or give up work...	f Lack of support from school?
What extra support from school, local council or employer would make a difference?	f EOTAS Recognising PDA as a disability instead of treating it as autism only Believing difficulties before by child burnt out This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f Parents often pay for therapists and interventions due to long waitlists and lack of resource
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f changed your role?
Reasons for having to reduce hours or give up work...	f Other
What extra support from school, local council or employer would make a difference?	f For council to meet deadlines of paperwork process. For EHCP case worker to be contactable by phone. I only have an email address and my emails are never answered.
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f Having to pay for legal advice and support to get what our child needs.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f No, I didn't know I could get help
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f changed your role?
Fighting to get the right EHCP provision have you...	f reduce your hours?
Reasons for having to reduce hours or give up work...	f Other
What extra support from school, local council or employer would make a difference?	f We have EOTAS so have to drive her everywhere. That being said, LA recently approved using the judge to pay for a TA to drive her some places
If you changed your working pattern, did it affect your finances...	f We don't have money worries
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f Often EHCPs involve medical issues. Our medical bills are high. Last year we paid almost 40k
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f Yes, I visited just to look around
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f reduce your hours?
Reasons for having to reduce hours or give up work...	f Lack of support from local council?
Reasons for having to reduce hours or give up work...	f Lack of support from school?
Reasons for having to reduce hours or give up work...	f Lack of flexibility from employer?
What extra support from school, local council or employer would make a difference?	f School - to take the initiative to identify and put in place the correct interventions needed. Local Council - to not have unlawfully denied an EHC Needs Assessment, to not have unlawfully denied to issue an EHCP resulting in a 12 month battle to tribunal, to help parents to find a suitable school that can provide all the support required for our SEN child instead of refusing to assist because they have to be 'impartial'. Employer - I had to quit a conventional job and go freelance due to all the time off needed for meetings, organising professionals to assess my child, review reports, research, and putting together cases to fight the LA's many unlawful decisions. I also needed time off to find a suitable school for my child and then assist in the transition.
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f Private EP Assessment & Report - ~£750 Private SLT Assessment, Reports and DLD diagnosis - ~£1,500 Private SLT weekly sessions for 3 years - ~£4,320 Time off work over 4 years - ~£8,400 (approx) Luckily I didn't have to pay for legal advice but we were contemplating it. Yes, I visited the site, it was helpful
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f Yes
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f reduce your hours?
Reasons for having to reduce hours or give up work...	f Other
What extra support from school, local council or employer would make a difference?	f Assistance in navigating the support and benefits systems that are in place
If you changed your working pattern, did it affect your finances...	f This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f It's the vast amount of time it takes to complete all the administrative tasks when managing the needs of a child with an EHCP
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f No, I didn't know I could get help
Does your SEND child have an EHCP?	f Yes
Are you male or female?	f Female identifying
Fighting to get the right EHCP provision have you...	f changed your role?
Fighting to get the right EHCP provision have you...	f reduce your hours?
Reasons for having to reduce hours or give up work...	f Lack of support from school?
Reasons for having to reduce hours or give up work...	f Lack of support from local council?
Reasons for having to reduce hours or give up work...	f Lack of flexibility from employer?

What extra support from school, local council or employer would make a difference?	f	If they adhered to the law, I would still have a well paid career
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Getting private specialist reports in order to appeal EHCP at tribunal. Also legal costs involved in getting professional representation
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Not having to spend every waking hour having to think about how to fight the local council
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I had to reduce my working hours for 7 years (the whole of primary school), plus pay the costs of tribunal, including solicitor and barrister in order to get the right placement (a special school) named in my child's ECHP. This nearly finished us off!
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	If the schools had put provision into place earlier, my daughter might not have suffered from school trauma. If the local authority had agreed to an EHCP earlier, she might have gotten support in school instead of us having to push for help. If the local authority had changed her placement sooner, I might not have had a nervous breakdown.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The biggest hidden cost is parental mental health. My mental health really suffered due to the strain of trying to support my child and go through the hoops to get her the right support. I ended up in an acute mental health unit for two months because I had a breakdown. I still struggle with my mental health now and it has taken its toll on my family.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
What extra support from school, local council or employer would make a difference?	f	Would have meant that my daughter would have access to an education that is suitable for her needs instead of the school/LA focusing on the wrong things such as attendance and reasons behind lack off attendance ignored.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Family pressure from older siblings being affected on a day to day basis with no support for them. Older siblings being questioned by school as to why younger sibling not in school. This impacted on our older child being negatively impacted and not supported with feelings around this. Lack of understanding in the media, always targeting children not in school as naughty or parents as being neglectful means it has a negative effect on us as parents due to the lack of understanding.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Funds for outings during the school holidays and weekends. It's ~£100 per day for my brother to attend a workshop with other special needs kids. It's just not feasible to make that financial commitment weekly.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	No
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
What extra support from school, local council or employer would make a difference?	f	Paying for school clubs that aren't ofsted registered, transport and appropriate holiday clubs/weekend activities. Emotional support in school and long term mentoring
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The emotional strain has been immense and had a hugely negative effect on the whole family. The hours of my life spent on fighting to get any support at all are hundreds of hours stolen from my children
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Making the process less adversarial, so that local authorities focus on the genuine needs of a child, rather than trying to save money as a first priority. More respite support.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Parents do not get their costs back, even when they go on to win a Tribunal. If local authorities were obliged to pay costs when they lost cases, they would be less likely to pursue vexatious cases, or work on the basis that they might as well challenge cases because this means enough families will drop out. In our case, the legal costs amounted to about ~£18,000 - it means that only families who can find these sums in the first place, and can write them off, have any reasonable hope of challenging local authorities who use taxpayers' money to fight them.

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	Appropriate school placement, after school and holiday provision.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The emotional toll of continually having to fight for everything, being gaslighted by the organisations that are supposed to be there to help and support you. Constant demonisation as somehow trying to obtain advantages for your child that they don't deserve/are not entitled to. Yes, I visited just to look around
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	I haven't worked for 14 years - a parenting decision to not work but would have restarted part time 4 years ago.  To work my child would have had to be able to attend a small school with 5/6 kids per class perhaps - and basically a completely different model.  Its hard to say what hat looks like because its hard to see what challenges are trauma induced. ( He is an 8 year old Autistic/ADHD boy) his experience of school was basically classed as "inclusive" because he had an ehcp / a TA etc  "inclusion" is basically the opposite - inclusive education happens when all around the child are trained to understand the connect of Neurodiversity and so the environments operate in a fair way with out neuronormative expectations. The basics aren't even out their in terms of useful ways to look at the system/society ( See Dr nick walker - neuroqueer - basic terms)  What would make a difference is nd friendly provision/ environments / more support for online connection and tech skills/interests/ education aligned with the concept of " Monotropism". And local activities supported by autistic led organisations. Our children have less opportunities to connect with their peers. Autistic/ADHD kids do better around those who think/act similarly - we don't need to pathologist just make more provsion that anyone can go to but happen to meet more nd needs and are environmentally considered.  Your first question asking if you have more than mon child with SEND may mean those with one child with send and an ehcp will think they shouldn't click ie only select if have 2 children with send. might have been Best just to ask - have any of your children got an ehcp as the first question.  It took me a couple of reads to check what you were asking.  This affects our family finances in the long term  This affected family finances immediately  I worry about money most of the time  I split with my ex husband 2019. Our divorce took 4 years. The cost was around -£200k; 150k was a litigation loan. The total lost to the family pot was around -£300k. If my child had been able to attend school; if I hadn't had to deal with LA; school; ex who created due to not understanding tribunal issues; or why LA would say one thing and do another - I ended up in family court accused of not meeting my Childs needs 3 times - despite that being completely inappropriate channel it inevitably compromised my right to family life; stress levels and ability to finalise my divorce etc. I had several episodes of burnout. I had never experienced that before.  Had the LA acted as they should then this wouldn't have been an opportunity to point the finger and assist in the delays they need due to lack of funding etc Yes, I visited the site, it was helpful
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	After school club
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Time and effort and checking that provision such as salt has been
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	for them to educate themselves in the law rather than local policy and then push back on the LA in support of the parent rather than fighting against them
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Yes it contributed ot the breakdown of the family unit.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
What extra support from school, local council or employer would make a difference?	f	Hybrid working / hours . After school , funding for specialist support, respite , ensuring school are providing the support they should , getting LA to write an EHCP properly so it actually means something and can be measured, professional support for children with severe anxiety ,holiday clubs
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	To work EHCPs should be working documents that accurately reflect the child's needs and detail the support needed who will provide it and when. Most are badly written, and don't, meaning a battle with the LA to get them changed, this will mean getting legal advice, specialist reports and lengthy battles, stressful and costly, parents find themselves funding gaps as well.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	More funding to increase more suitable settings from LA. LA staff to be more competent in their roles and be able to support parents as apposed to destroying them at a time that is already so stressful.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The cost is more about health than cash, spending your time dealing with so many forms , emails and calls etc takes you away from your work and family life , that makes you worried your not fulfilling your work commitments and not enjoying family life as there is always too much to do to fight the battles.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
What extra support from school, local council or employer would make a difference?	f	To fund what my son actually needs. Not what they think he. needs. And to stop trying to make us fit in to mainstream which cannot help him. It's not a fit and we have provided a great deal of evidence. Even the school says they cannot support him. As we have not come to an agreement on his EHCP we're in limbo and meanwhile we are paying for online schooling and other requirements. PLUS this is only after almost 2 years of him having time off to recover from school trauma.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Mental health, family relationships, maintaining a positive face to my child. Not letting him see the impact the system is having on us as he will internalise it if he thinks it's his fault. Having no time or energy for self care.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, but I didn't find the help I needed
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
What extra support from school, local council or employer would make a difference?	f	Someone to oversee and coordinate everything involved in my child's care, including community paediatrician, consultant paediatrician, neurodisability team, teachers, SENDCos, specialists such as SALTs, OTs, psychologists as I am the one who currently needs to coordinate everything and ensure everyone is aware of the outcomes of appointments, meetings etc and ensure these are reflected in all reports, EHCP reviews etc.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I am unable to return to the same career as I had before or seek career progression in the same way as I know I won't be able to juggle a more senior role with the needs of my child.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	Out of school care, before and after school clubs, holiday clubs that give 1-1 support, personal care, not overcrowded etc. Flexible working hours, working from home
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The time you spend and costs of paying for private reports as Council, NHS reports aren't detailed/specialised enough and take too long to be done etc
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Actually writing a decent EHCP, not removing provision from Section F which came from professionals, adhering to the law and legal timescales and funding the provision outlined in the EHCP.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Toll both mentally and physically on parents. Significant illness for both parents which could be attributed to the additional stress of fighting for EHCP provision when life is already stressful raising an SEN child.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Additional funding, travel passes for both parent carer and child.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Having to access support yourself, get seperate reports paid for. Before assessment.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes

Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	I don't know if there would have been any support that would have made a difference to me. I worked long hours in London, and this was just impossible. Wrap-around child care might have helped but I wanted to be there for my child - there were so many appointments and therapy sessions etc and I wanted to be there myself, not send a nanny or someone like that.
If you changed your working pattern, did it affect your finances...	f	We don't have money worries
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	We had to pay a lot for therapies and education that the LA wouldn't provide.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	<b>Yes</b>
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	Suitable child care to allow me to work
If you changed your working pattern, did it affect your finances...	f	Actually doing their job instead of failing my child repeatedly
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	This affected family finances immediately
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Cost of getting reports & assessments done as the LA fail to do them, cost of legal advice as those available for free are not independent & controlled by the LA
Does your SEND child have an EHCP?	f	Yes, I visited the site, it was helpful
Are you male or female?	f	<b>Yes</b>
Fighting to get the right EHCP provision have you...	f	Female identifying
Reasons for having to reduce hours or give up work...	f	had to give up work completely?
What extra support from school, local council or employer would make a difference?	f	Other
If you changed your working pattern, did it affect your finances...	f	It's not only about support in school, and EHCP is an education AND healthcare plan, school are doing a good job helping my autistic child in mainstream but she could be doing so much better if she had access to the healthcare side for anxiety, sensory therapy, perhaps mental health, speech and language..none of these things are available to her , they have to be fought for through her EHCP , which the LA argue she doesn't need and then we play ping pong between paediatrics and the LA and neither will support the need, while school are left to pick up the pieces of trying support a child's learning while the child has unmet healthcare needs.
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I worry about money most of the time
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	This affected family finances immediately
Does your SEND child have an EHCP?	f	Out daughter has an EHCP. We live in an area where our LA has applying for the government safety valve scheme. Their send budget is spiralling in debt over 50 million. To make matters worse they are proposing a 11 percent cut to all schools general budgets (affecting all children not just send). Then they are proposing to limit the number of EHCPs and stop funding private specialist school places . If a child needs extra support in school they need an EHCP, my daughter wouldn't be in mainstream without one and the extra 1:1 teaching Support. We now have to decide what secondary school she will go to and we have been told that she would not cope in mainstream, looking for a state specialist school in our area none are suitable, they are all for fairly low functioning autism. As our daughter can do most things with support, plays flute, sings in the choir, is a little behind academically but so are others in her class who don't have send. But she needs a small classroom and extra 1:1 support. There are only 2 schools that would be appropriate and both are private specialist, if the LA won't fund the place she can't go, she also can't go to mainstream..so what happens then, we write her off at 11 into a specialist school that'd doesn't even do gcse's?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	<b>Yes</b>
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	reduce your hours?
What extra support from school, local council or employer would make a difference?	f	Lack of support from local council?
If you changed your working pattern, did it affect your finances...	f	For the LA to honour the terms of the EHCP and not make us endlessly battle to secure each aspect of support for our young person.
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	This affected family finances immediately
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	This affects our family finances in the long term
Does your SEND child have an EHCP?	f	We pay for support and professional advice to help us to navigate the send minefield. It's never ending and wears us out but we want to help our young person in the longer term
Are you male or female?	f	Yes, I visited just to look around
Fighting to get the right EHCP provision have you...	f	<b>Yes</b>
Reasons for having to reduce hours or give up work...	f	Female identifying
What extra support from school, local council or employer would make a difference?	f	reduce your hours?
If you changed your working pattern, did it affect your finances...	f	Lack of support from school?
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Lack of support from local council?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Better communication and support network for parents and children , also more training for teachers in school with special needs children
Does your SEND child have an EHCP?	f	This affected family finances immediately
Are you male or female?	f	Parents having to pay for private diagnoses due to the long waiting list on the NHS and not enough education psychologist to go into schools to make their reports towards the EHCP
Fighting to get the right EHCP provision have you...	f	Yes, I visited the site, it was helpful
Reasons for having to reduce hours or give up work...	f	<b>Yes</b>
What extra support from school, local council or employer would make a difference?	f	Female identifying
If you changed your working pattern, did it affect your finances...	f	reduce your hours?
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Lack of support from school?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Lack of support from local council?
Does your SEND child have an EHCP?	f	Better interim provision for children who can't attend mainstream school but haven't yet found a place at the 'right' school. we were on a waiting list for a local authority tutor for months.
Are you male or female?	f	This affects our family finances in the long term
Fighting to get the right EHCP provision have you...	f	Better help from the local authority to understand not just the application process but the annual reviews and phase transfers. With step by step instructions! (so I don't get exhausted googling what I should be doing)
Reasons for having to reduce hours or give up work...	f	Yes, I visited the site, it was helpful
What extra support from school, local council or employer would make a difference?	f	<b>Yes</b>
If you changed your working pattern, did it affect your finances...	f	Female identifying
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	had to give up work completely?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Lack of flexibility from employer?
Does your SEND child have an EHCP?	f	<b>No</b>
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Does your SEND child have an EHCP?	f	Other
Are you male or female?	f	I couldn't work as my child was at home
Fighting to get the right EHCP provision have you...	f	This affected family finances immediately
Reasons for having to reduce hours or give up work...	f	This affects our family finances in the long term
Reasons for having to reduce hours or give up work...	f	Needing independent reports for speech and language as the LA refuse to fund them.
What extra support from school, local council or employer would make a difference?	f	Attending training courses for parents about EHCPs - this is so important to know your legal rights
If you changed your working pattern, did it affect your finances...	f	Yes, but I didn't find the help I needed
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	



Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	For years my child has tried to access school. LA have refused to fund reports before transfer to a specialist school and then refused to fund reports before transfer to an independent school. Child is no longer able to attend school due to school trauma. School parent blamed. LA finally conceded to do reports as part of re-assessment as EOTAS was requested. Reports now show parents were right. LA are currently 14 weeks late completing EHCP. The LA have wasted time consulting schools despite LA's EO saying EOTAS and are now delaying again as they are looking at tutors my son can't engage with.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	<b>I have had to give up a high paid career to look after my son. He's 11 so can't be at home alone. He's not been to school full time since year 1. There is no prospect of him attending school again. He is not able to cope with an independent PA as he does not trust adults in education due to school trauma. This is unlikely to change as neither the NHS nor the LA will provide treatment and as I can no longer work we cannot afford to go private. My time is spent trying to re-engage my son in education with learning embedded were school trauma exists in respect of core subjects. I am having to bear the costs of educating my son as he is no longer on a school roll and my son can't access the section 19 offer. There is also the mental toll which has effected all our family as well as previous advocacy fees when we first started the journey.</b>
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	No
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	After school clubs
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Cost of independent assessments and reports, cost of legal advice.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
What extra support from school, local council or employer would make a difference?	f	More flexible hours to allow me to attend meetings from employers and respite from the local council.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	You spend endless amount of time making complaints to the Local Council to ensure provisions set out in the EHCPs are met. More often they tend to miss the statutory time frames to complete Annual Reviews, and issue and finalise EHCPs that you are left having to take it to the Local Government Social Care Ombudsman. Also, you have to dip into your savings to pay for independent reports and pay for representatives when you are taking your appeal to the tribunal. It is all a very draining process!
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Honest information about what my son was entitled to. I was unaware of any alternative provision being an option when my son became unable to attend school. He was left with no education at all for a long time and only 1 -2 hours a week at other times. He has been out of school for four and a half years, during this time I have had to spend thousands on equipment, books, activities, online lessons etc.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Paying for childcare so I could attend meetings. Paying to attend webinars to educate myself on the process. Also the stress and endless worry and uncertainty.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Transport for my child
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Costs related to a private Educational Psychologist assessment and report, Occupational Therapist report and having to pay for attendance of EP as an expert witness when I took the council to tribunal to appeal the EHCP.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Proper coherent timely conversations with trained staff.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Lack of Council staff who care or who are interested in the child rather than their budgets. Staff seem to be agency and outside the county largely so no local knowledge of schools or their area. It's been an appalling experience.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?

What extra support from school, local council or employer would make a difference?	f	Its the basic support that is not accesable no chance of extra Basic rights are denied Human rights are denied If you have disabilities your discriminated against Professionals lack integrity empathy actual understanding of disabilities , inclusion, reasonable adjustments Private schools see a pricing pricec up 50k for ehcp but have no intention of delivering 50k of support, the ehcp us written so bad and the V10 financial agreements are exploited Individuals /Proffessionals see broken children and broken parents as the cause rather than collateral damage of incompetent council senior leaders and managers Non medical or mental health professionals record thier non qualified thoughts/without factual backup on their cptoms safeguarding systems as facts which is ludicrous unsupervised and unchallenged/accepted amongst education professionals as appropriate!
If you changed your working pattern, did it affect your finances... Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I could go on and on and on 7 years of abuse of mine and my 2 children's vulnerability and rights Putting child needs before budget I worry about money most of the time  The local authority have the legal duty to proved free legal advice via impartial services...in manchester that is the send ias, it is not impartial and does not provide appropriate advice but merely gatekeeps .  If you want legal advice you have to pay for it.... parents who havebeen through it are setting up companies charging parents for support that should be given free from LA  You can get legal aid to take the local authority to judicial review to fight unlawfulness such as not providing section 19 and 42 education or not sticking to ehcp deadlines etc.  However the amount of money allocated to JR by legal aid does not cover the cost of judicial review , therefore unless you are rich and can pay a specialist solicitor which there are not many of ...you cant afford 5k to take the council to court to enforce your legal rights.  Council know they are untouchable and just carry on not meeting thier legal responsibility... they know we can't get legal aid or afford to pay private whilst living in crisis unemployed /lost your jobs due to schools demanding you collect your child /refuse to allow them return and remain out of education Yes, but I didn't find the help I needed
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Other
If you changed your working pattern, did it affect your finances... Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I worry about money most of the time  I submitted evidence of my child needing physiotherapy provision has part of EHCP three years ago. Since then I have been fighting for it through tribunal and then judicial review. I have paid for my sons physiotherapy for 6 years and spent money on legal costs. This has meant my son has missed out on holidays and experiences that I just couldnt not afford. I have finally got Physiotherapy has part of EHCP but it's been a long time coming. No, I didn't know I could get help
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?	f	No
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference? If you changed your working pattern, did it affect your finances... If you changed your working pattern, did it affect your finances... Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I have to give up lots of free/leisure time. I cant afford to give up work. I have to pay ~£3500 for an ASD/ADHD assessment before I can even ask for EHC needs assessment. The NHS waiting list is 4 years. This affected family finances immediately  This affects our family finances in the long term  There is no support , schools can only do the minimum. We need early assessment and diagnosis. The stress and financial matters impact the whole family. The lack of diagnosis affects the child's SEMH as cause huge family strain Yes, but I didn't find the help I needed
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
What extra support from school, local council or employer would make a difference? If you changed your working pattern, did it affect your finances... If you changed your working pattern, did it affect your finances... If you changed your working pattern, did it affect your finances... Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	To not create hurdles that needs don't exist. Less paperwork to correct errors , la and sch do what they should and comply with law and not develop hurdles constantly ! Truthful la and sch would be a blessing! This affected family finances immediately  I worry about money most of the time  This affects our family finances in the long term  Reports At advise Not being able to work to irritate / review Constant complaining to lgsco etc to correct error Training for parents on law EHCP and disability of the child Constant appt attendance Cost of marriage and quality of family life Cost of isolation as not everyone understands Applying for services and resources takes time  Time to liase with school and professionals Time to research loop holes and move forward Exhausting Having to spend three times as much for a disabled child to learn a new skill
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?	f	No social care support Yes, but I didn't find the help I needed
Are you male or female?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference? If you changed your working pattern, did it affect your finances... Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Honest processes that follow the law.  This affects our family finances in the long term  Tribunal costs, twice. With barrister and expert witness support both tribunals cost in the region of ~£20,000. They were both won with the LA capitulating on the morning of the tribunal because they had no case) Yes, I visited the site, it was helpful
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?	f	No
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Listening to the parent from the offset of difficulties; my experience is that the LA only considers professional advice, by which time any difficulties have already escalated so much that child is at home and unable to go into school
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	In addition to lower income due to having to stop work, there are increased costs of having to fight for an EHCP, such as the implementation of support needs at home to support the child, increased home costs such as gas/electricity and food (where the child isn't able to attend the school setting), and extra costs to try and engage your child in activities that they might ordinarily be involved in with school, such as music tuition. There's also hidden (non financial) costs of fighting ehcp such as time, energy, and even family breakdown. Yes, I visited just to look around
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Together For Children (TFC), Sunderland's provider ,refused to return EHCP at phase transfer. Ended up having to go to Tribunal . The extra support I would like is for TFC to adhere to legal timeframes , respond to Tribunal orders and to advocate for the needs of my child.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	TFC had no school place for our child . We were forced to go to court and use solicitors to ensure some form of education. <b>TFC used barristers which was intimidating</b> , and a disparity of representation.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Other
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	To not make it difficult to put correct provision for SEND children in place. We end up spending a lot of time doing admin and battling to get professional input for education, health and social care.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Yes. We are forced to getting private professionals to do assessments and reports. LA professionals only reference the bare minimum and often skew reports so children don't get professional input they need written into ehcp's.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Understanding that children with complex needs and/or obviously significant needs to be helped by providing the specialist input they need asap not waiting for them to fail or be excluded et cetera. The sooner we import the best chances the child has for independence in the future and not requiring long-term support.
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
Does your SEND child have an EHCP?	f	No
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	changed your role?
What extra support from school, local council or employer would make a difference?	f	It would be helpful if the local council (LA) communicated more efficiently and in a timely manner as it appears the left hand doesn't know what the right hand is doing
If you changed your working pattern, did it affect your finances...	f	We don't have money worries
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	I have paid nearly –£6000 in the last year trying get my child an EHCP to ensure she gets the help and support she desperately needs so have had to fund private assessments as it takes too long on the NHS (her autism diagnosis took over 2 years to get through the NHS) and had to pay for an advocate to help with the EHCNa refusal appeal (as my mental health took a toll due to this process), only for the LA to concede. This was a gross disservice to my child who so clearly needs the support and has wasted 8 months. Just a side note, the LA also quoted the wrong law when refusing to carry out a needs assessment when first requested
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Other
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Are you male or female?	f	Male identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
What extra support from school, local council or employer would make a difference?	f	Faster decision making , understanding of Autism, professional staff ( local authority)
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	We have had to make huge sacrifices & leant on family to use a lawyer & still struggles
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, but I didn't find the help I needed
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	Flexible hours, no fear of losing my job when school call me in. The council could train more childminders to work with older children with SEN but my two children wanted to be at home after a tough day at school, not surrounded by more noise, ideally we needed support at home (ie an SEN nanny) but we couldn't afford this.
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?

YES so much to say,Ä¶When I was working my wages ended up being used to fund assessments and advocacy support which I needed for EHCP tribunals. Now that I'm not working I've been able to claim legal aid. The Government say that parents should be able to appeal by themselves and that the LA will assess my child. In reality the assessments are often biased towards what the LA can provide (not based on my child's needs) and they are very basic. We feel that to fully understand their needs (we have two children), we have to commission our own assessments. These are costly eg. an educational assessment –£1800, occupational therapy –£1600, speech and language Approx –£700. Then at the hearing the LA bring witnesses, so to make this fair we have to pay the professionals which costs Approx –£500 a day for each person (need all three). Sometimes a tribunal can run into two days so this is extra costs for us. If the LA concede within 5 days before the hearing we still have to pay the professionals. Each tribunal we've funded ourselves has cost an average of –£8,000.00. We've battled with the LA to provide SaLT and OT within the EHCP. We've been successful in having my sons need identified and added to the EHCP but the NHS service is appalling. The SaLT service provide hardly any of what they are supposed to. The staff turnover is very high. To force the LA to provide my son with the provision he needs as identified in the EHCP we'd need to pay a solicitor to send a letter before action to the LA (costs Approx –£500) to take court action (a judicial review). But if the NHS is struggling to keep up with the demand then what's the point?? The alternative would be the LA commissioning private SaLT's & OT's but they won't do this.

Currently there appears to be a tactic the LA is using whereby they know a parent will appeal but this benefits the LA because the hearings are taking 12 months to be heard, and in this time they don't have to provide anything to the child. They are saving money. They then concede a week before the hearing date. To date we have needed to appeal my sons EHCP 5 times and my daughters twice. I've had to pay for a few private psychological sessions for my son because CAMHS are so bad (he needs more help but I can't afford). I used to work full time as a nanny, I did this for 28 years. Then when my children started school the school would call me in several times a week to take my son home for a shower because he struggled with bowel incontinence. Same for my daughter but because she struggled with stomach ache due to anxiety (about school). So I switched to working nights as a maternity nanny. This worked for a few years but only because I didn't sleep all day!!! My hair began falling out due to the stress. In terms of the hidden mental health costs ,Ä¶(although not sure if this is what you're asking about) the schools were failing my children but when I pushed them and tried to hold them accountable they would use language such as, 'Ä¶mum is anxious', 'Ä¶mum is overprotective'. They blamed me for my children's deterioration of their mental health, (not dad), I have seen social service documents which mention a meeting between the two schools (each child's) and social services which states that the school want to refer me to safeguarding. We were appealing the Yes, I visited just to look around

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

Reasons for having to reduce hours or give up work...

f

What extra support from school, local council or employer would make a difference?

f

If you changed your working pattern, did it affect your finances...

f

If you changed your working pattern, did it affect your finances...

f

If you changed your working pattern, did it affect your finances...

f

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?

f

The EHCP process takes too long to assess for increases needed in funding provision levels. Direct payments and personal budgets could help somewhat but again the process is very lengthy to assess and is not awarded in a timely manner if required. Yes, I visited the site, it was helpful

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

Reasons for having to reduce hours or give up work...

f

Does your SEND child have an EHCP?

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

What extra support from school, local council or employer would make a difference?

f

If you changed your working pattern, did it affect your finances...

f

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?

f

energy cost - its exhausting  
telephone calls  
time - form filling  
petrol appointments  
No, I didn't know I could get help

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Reasons for having to reduce hours or give up work...

f

Reasons for having to reduce hours or give up work...

f

What extra support from school, local council or employer would make a difference?

f

If you changed your working pattern, did it affect your finances...

f

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?

f

The fear of Fil (fabricated and induced illness) being used to silence families

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

Does your SEND child have an EHCP?

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

Reasons for having to reduce hours or give up work...

f

What extra support from school, local council or employer would make a difference?

f

If you changed your working pattern, did it affect your finances...

f

If you changed your working pattern, did it affect your finances...

f

If you changed your working pattern, did it affect your finances...

f

Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?

f

for my first child I had to pay thousands, over –£5000 for a lawyer upfront. for my second child I tried to do it myself but it cost me time and my health and i am only half way through. i fear i may have to go back to the lawyer but it is so expensive and time is a factor. Yes, but I didn't find the help I needed

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Fighting to get the right EHCP provision have you...

f

Reasons for having to reduce hours or give up work...

f

Reasons for having to reduce hours or give up work...

f

What extra support from school, local council or employer would make a difference?

f

If you changed your working pattern, did it affect your finances...

f

If you changed your working pattern, did it affect your finances...

f

When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ... Does your SEND child have an EHCP?

f

f

f

Are you male or female?

f

Yes  
Female identifying

Fighting to get the right EHCP provision have you...	f	nothing has changed
Reasons for having to reduce hours or give up work...	f	Other
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of flexibility from employer?
What extra support from school, local council or employer would make a difference?	f	For them to actually do the job properly. They take their time to do anything. That's all of them.
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, but I didn't find the help I needed
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
What extra support from school, local council or employer would make a difference?	f	Money from the council/government. More experts available to support schools. They are stretched to breaking point. My employer has been flexible.
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	My son was a CME (child missing education) for almost three weeks when we moved from one area to another. It was stressful and time consuming and I have no idea what we would have done if we couldn't work from home. In the end we got a formal apology from Surrey Council because of their admin vacancies and training. This is the tip of the iceberg. Systemic underfunding of schools and councils is the issue.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	reduce your hours?
Fighting to get the right EHCP provision have you...	f	changed your role?
Reasons for having to reduce hours or give up work...	f	Lack of support from school?
Reasons for having to reduce hours or give up work...	f	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	f	*- Funding for alternative provision for the time my children have been out of school/unable to attend school - more provision and better availability of provision for children not able to attend school including those on reduced timetables/part time attendance - more specialist alternative provision available for children and young people with SEND, not just sending them to a PRU
If you changed your working pattern, did it affect your finances...	f	- better expertise and provision in schools to prevent our SEND children falling out of school in the first place due to schools being unable to meet their SEN - therapeutic support for children with school related trauma - therapeutic support for children who have missed education to re-engage with education/school - recognition that as parents of children with SEND EVERYTHING is a battle, we already have a harder parenting job and we are exhausted and don't have the time, energy or expertise to take on local authorities to advocate for our children and fight to get what they are entitled to by law, but if we don't, nothing happens and our children suffer.
If you changed your working pattern, did it affect your finances...	f	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	Time, energy, access to information to equip ourselves to take on the LA. The emotional and mental cost of having to fight on behalf of our children for everything. Impact on all our other relationships, missed career progression opportunities, increased costs when we have to bridge the gap left in LA provision for our children out of school or in school part time. Paying for private reports, private professional support, funding provision that should be delivered through the EHCP but isn't.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	nothing has changed
What extra support from school, local council or employer would make a difference?	f	Having provision that meets the needs of relatively academic autistic children - many mainstream schools do not meet the needs of ASD students and the existing specialist provision is often aimed at less able students. A personal budget would be the best way for post 16.
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	If you don't get transport for the provision that best meets your child's needs it can be costly in terms of time and money to get them there.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	Yes, I visited just to look around
Does your SEND child have an EHCP?	f	Yes
Are you male or female?	f	Female identifying
Fighting to get the right EHCP provision have you...	f	changed your role?
Fighting to get the right EHCP provision have you...	f	had to give up work completely?
Reasons for having to reduce hours or give up work...	f	Other
What extra support from school, local council or employer would make a difference?	f	If they could assess my child when they are supposed to, and not push back and deny that my child needs support even when they haven't actually bothered to check. Then I wouldn't have to successfully appeal to the SEND Tribunal twice! LA's save money by refusing support, they lose cases that go to tribunal over 90% of the time and never have to pay parents costs. It's a false economy, as we would rather spend our time and money on helping our children. If they receive the help they're entitled to, the majority will be independent contributing members of society, sadly the lack of early help
If you changed your working pattern, did it affect your finances...	f	Fails our children, and the employment rates of SEND people are abysmal. It need not be this way!
If you changed your working pattern, did it affect your finances...	f	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	f	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	f	The stress of navigating the system is extraordinary and LA's should be audited on their conduct towards parents and schools and held to account for their failures that are reflected in their loss rate at tribunal
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	f	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	nothing has changed
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	We can do this stuff ourselves. However, a decent Senco /Coordinator is worthwhile. strong leadership within SEN setting, council are generally well meaning but too stretched - networks of parents who have been through it before
If you changed your working pattern, did it affect your finances...	m	We don't have money worries
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	it requires time and commitment and a lot of thought - if you put a time cost on those (and for some SEN parents these things are in v short supply) then yes, i guess its costly
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited just to look around
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	It was different for me as when I first gave up work it was because after my year of maternity my son was still on oxygen and immuno compromised and it was during covid and I had to care for him full time. There are no alternative options for this.
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	EHCP's are a legal document and as parents carers not trained in legal matters you don't know if the EHCP is worth the paper it's written on and you have to pay privately to get it checked. People have to get legal help when refused to Assess
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying

Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	Sleep support, suitable facilities & amenities which are accessible in non-term times, help with additional costs as we cannot work, a Universal Income would help greatly.
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Yes, the LA constantly wastes tons of money by not having decision making in the first port of call, everything goes to panels of high level managers causing additional costs & wait times, way too many management layers, whenever you go to court, most LAs have Barristers on retainer. No, I didn't know I could get help
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Reasons for having to reduce hours or give up work...	m	Other
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
What extra support from school, local council or employer would make a difference?	m	No appropriate school place - better provision of school places with an understanding of autistic young people
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Impact on what we can do socially which supports mental health, having to pay for professional support privately which is expensive
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Lack of flexibility from employer?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
What extra support from school, local council or employer would make a difference?	m	Unfortunately we are a low income household. So information about free or low costing activities that are stable for child like mine. The local council Don't unstand anything about sends child.
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Losing out on family time is a hidden cost Your mental health is a hidden cost
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	Listening and believing us parent carers for a start
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Our child currently lives in a hospital, 1.5 hours each way (on a good day) at -£14 a time all adds up.. if we don't visit, they may not eat much, sadly.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	changed your role?
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Other
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	I am a parent of two Secondary age children, both with a complex cocktail of hidden disabilities (George aged 14 - ASD, ADHD, SpLD (Dyslexia) and DLD / Sophie aged 11 - ASD / ADHD and SpLD (Dyslexia)
		I am an advocate for other parents who are trying to secure the necessary EHCP and school provision to meet needs. Helping them navigate the challenges of the 'System' and Tribunal / Judicial Review. (Part of my personal journey is that I self financed and trained in SEND Law - as I could not afford a Barrister on top of all the private professional assessments etc..)
		I am also a Chair of Governors at their previous Main Stream Primary school (Giving me valuable insights into the 'Operational' and 'Strategic' approach and challenges in 'attempting' to provide SEND provision.
		Without any shadow of doubt the biggest barrier to learning for a child or young person with SEN within mainstream provision is the LOCAL AUTHORITY (Not their disability or addition need!) Most LA's operate a playbook and systemic culture of 'Delay and Deny' playbook. They persistently operate outside the guidance of SEND Code of Practice and not meeting statutory duties and unlawful practices are common place across many LA's.
		The biggest flaw in the system is that there is no consequential impact on an LA for being unlawful and/or not complying with statutory duties / guidance / legislation. At worst they will be listed in the Noddy Guide as a precedent of caselaw - but there is no fiscal consequence whatsoever, parents cannot recover their costs, so the systemic playbook of maladministration is continually perpetuated.
		Parents find the process exhausting, unfair, unreasonable - with LA's expecting them to fold and accept compromises that are loaded in their fiscal favour. I have parents who I have advocated for, who would go on record to expose the level of unlawful and 'dirty tactics' to actively try and get unsuspecting parents to 'say' something that would derail their entitlement to provision. (Things like trying to get the parents to say that a particular school is their 'Parental Preference' - when in fact it was the nearest or only school that could meet needs - persistently not recognising the fact that they MUST name the school, in the absence of any other appropriate provision - WHY? Simple they would not be responsible for transport if the school was named as a parental preference.
		We have mountains of damning evidence, over multiple cases. Unlawful practices. Falsifying evidence. And fiscal maladministration that defies logic, and can only be put down to spiteful action from the LA case works and leadership teams (We have fiscal evidence that demonstrates that Hillingdon LA refused residential provision This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	We personally spent nearly -£40,000 (so-far) as the journey is never over!
		But with perseverance we are ensuring our children get the education they are entitled to. Having the right provision is transformational - our Son has made incredible progress in the right setting with the rigs support, and is now on target to attain his GCSE's and potential higher educational prospects (Something that was just not achievable before fighting all the way to tribunal to secure this placement.) The irony is that now with this intervention he will be able to contribute in his adult life - pay taxes - and not be an ongoing draw on the system... the polar opposite he will pay back is education - it'll just take a bit longer than a mainstream education.
		It is a case of a penny wise pound stupid short sighted approach by the LA
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful

Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	changed your role?
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	In our case the local council was the problem - very adversarial - and they had the legal resources and funds to fight, whereas we had to fight our own case, unfunded.
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	The local authority insisted on independent tests, which we had to source and fund (costing c. -£3,000). Their own tests were weak and biased and lacking in expert knowledge. Ours were highly specialised and ultimately 'won' the case (nobody 'wins' - one is just getting what is right and appropriate and legally correct.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	m	No
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	Respite care
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Help with travel costs
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited just to look around
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	changed your role?
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	Less admin and reducing the need to attend tribunal to receive an education for send young person in appropriate setting
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Tribunal and professionals charges to attend and submit evidence
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	There were no suitable school places for my child . He was rejected from 15 schools, I have to be present for any tutor sessions it would have been helpful to be able to have had a care assistant during these sessions so that I could continue to work, or pursue my own personal goals ie mental health walks
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Paying for legal advice
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Paying for support and education while the LA creates delays
Does your SEND child have an EHCP?	m	I paid for 6k work of therapy because the LA made errors which I was not able to be compensated for because i used my right to appeal
Are you male or female?	m	No, I didn't know I could get help
Fighting to get the right EHCP provision have you...	m	No, I didn't know I could get help
Reasons for having to reduce hours or give up work...	m	No, I didn't know I could get help
What extra support from school, local council or employer would make a difference?	m	No
If you changed your working pattern, did it affect your finances...	m	Male identifying
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	had to give up work completely?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Lack of support from school?
Does your SEND child have an EHCP?	m	Sticking to EHCPs, granting the child the accommodations recommended in expert OT, SLT, EP reports so that fewer EHCPs might be sought in the first place. Better training for all sencos, all teachers and headteachers on the NORMAL behaviour of autistic children, such as stimming behaviours and failure to recognise social hierarchy and taking things literally is not deliberately rude. Working WITH and believing parents instead of being dismissive or defensive. Acting upon their thoughts that a child might be SEN or have additional SEN; I know it requires paperwork, but it's for the child and protects future mental health. More visuals in lessons. More written instructions for those with processing issues. Awareness of hyperlexia and how it is a learning style and cones with comprehension issues. If referrals have been made by a paediatrician who is an expert, schools should not be approached for a second opinion that overrides the expert's opinion that led to that referral. All diagnosed autistic kids should be assessed by an OT and SLT because hypermobility is common and needs accommodation and most autistics are Gestalt Language Processors even if they are verbal. BAN teachers from shouting at the pupils in primary schools. I've felt I have no other choice but to home educate now. I wish he could attend school but it's killed his love of learning and made him distrustful of adults.
Are you male or female?	m	I worry about money most of the time
Fighting to get the right EHCP provision have you...	m	Financial costs in feeling like you have to prove need. For example, we paid for a private SLT assessment when school rejected the referral. Turns out my son has a high arched palate and speech impediment, but the school still ignored the report. I can't afford an educational psychologist; that's another referral the paediatrician made but the school said wasn't needed so my son was never assessed, despite having a spiky learning profile thanks to having both hyperlexia (gifted) and autism (disability). Non-financial costs of fighting for an EHCP include strain on relationships, time, energy and decreasing mental health due to stress and strain.
Reasons for having to reduce hours or give up work...	m	No, I didn't know I could get help
Reasons for having to reduce hours or give up work...	m	No, I didn't know I could get help
What extra support from school, local council or employer would make a difference?	m	Yes
If you changed your working pattern, did it affect your finances...	m	Male identifying
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	changed your role?
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	reduce your hours?
Does your SEND child have an EHCP?	m	Lack of support from school?
Are you male or female?	m	Lack of support from local council?
Fighting to get the right EHCP provision have you...	m	This affected family finances immediately
Reasons for having to reduce hours or give up work...	m	EHCP doesn't cover the needs properly and the process is antagonistic for parents
Reasons for having to reduce hours or give up work...	m	No, I didn't know I could get help
What extra support from school, local council or employer would make a difference?	m	Yes
If you changed your working pattern, did it affect your finances...	m	Male identifying
If you changed your working pattern, did it affect your finances...	m	Male identifying
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	had to give up work completely?
Does your SEND child have an EHCP?	m	Other
Are you male or female?	m	Lack of support from school?
Fighting to get the right EHCP provision have you...	m	Lack of support from local council?
Reasons for having to reduce hours or give up work...	m	Lots
Reasons for having to reduce hours or give up work...	m	Child unable to attend
What extra support from school, local council or employer would make a difference?	m	I worry about money most of the time
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying

Fighting to get the right EHCP provision have you...	m	nothing has changed
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	Awareness is key and it is awareness and knowledge which is lacking in both school and local authority SEND departments. It "flies in the face" of part 3 of the CAFA 2014 in which "views, wishes and feelings" of either parents/carers or young people need to be acknowledged and listened to. Keep it legal, always. We don't have money worries
If you changed your working pattern, did it affect your finances...	m	
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	The cost is often emotional and affects the family unit and mental health and well being. Stress, uncertainty and fear of the unknown are mentally draining.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited just to look around
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	My child is out of the education system. We have been neglected by our LA in terms of receiving an alternative education and the LA has broken the law experientially
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	I am a 24/7 full time carer with little family support. We have had to pay thousands privately for professional reports and the cost of being at home and not being able to work means we are more disadvantaged. You can't measure the cost that this has had on our mental health. There are far more layers of cost other than money in our situation
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
What extra support from school, local council or employer would make a difference?	m	Funding for respite / childcare - there is no appropriate childcare that can meet my child's complex needs, as they need 1:1 care.
If you changed your working pattern, did it affect your finances...	m	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Financial support for carers is minimal, it's a joke. Social care, education all bicker and try to say that it's someone else's job to pay, but when that all fails they resort to good old fashioned parent blaming. I'm a qualified teacher, and I'll likely never set foot in a classroom again because of my children's needs.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	No, I didn't know I could get help
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	changed your role?
Reasons for having to reduce hours or give up work...	m	Other
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	The local authority failed to comply with there statutory legal requirements. The school failed to have proper specialist support in place. Where were the properly trained specialist staff.
If you changed your working pattern, did it affect your finances...	m	I worry about money most of the time
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Mental health of family. This whole process was driven by the parents fighting for there legal rights for support. Precious family time was lost. Parents exhausted as they do the job of a solicitor to fight for there children.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, but I didn't find the help I needed
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	had to give up work completely?
Reasons for having to reduce hours or give up work...	m	Lack of support from school?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	The right school being available. The head being inclusive and not getting rid of all the SEN children. The local authority realising what was going on earlier..
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	Paying for private OT to make sure provision is correct. Paying for SEND advocacy
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	reduce your hours?
Reasons for having to reduce hours or give up work...	m	Other
What extra support from school, local council or employer would make a difference?	m	None
If you changed your working pattern, did it affect your finances...	m	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	No
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	nothing has changed
Does your SEND child have an EHCP?	m	Yes
Are you male or female?	m	Male identifying
Fighting to get the right EHCP provision have you...	m	changed your role?
Reasons for having to reduce hours or give up work...	m	Lack of flexibility from employer?
Reasons for having to reduce hours or give up work...	m	Lack of support from local council?
What extra support from school, local council or employer would make a difference?	m	Flexible amd WFM will make Hugh difference from work.
	m	School holidays support from council is really needed.
	m	Shorten the waiting list for diagnosis and treatment from NHS. E.g. I am waiting from last one year tk get ADHA assessment and treatment from Harrow CAMHS This affected family finances immediately
If you changed your working pattern, did it affect your finances...	m	Not financial cost however, it takes lots of fight with council to get things on EHCP plan.
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	m	No, I didn't know I could get help
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	m	Yes
Does your SEND child have an EHCP?	o	Other
Are you male or female?	o	reduce your hours?
Fighting to get the right EHCP provision have you...	o	Lack of support from school?
Reasons for having to reduce hours or give up work...	o	Lack of support from local council?
Reasons for having to reduce hours or give up work...	o	Earlier intervention. Keeping to legal timeframes. Providing what is in the EHCP. The whole process isn't fit for purpose
What extra support from school, local council or employer would make a difference?	o	This affects our family finances in the long term
If you changed your working pattern, did it affect your finances...	o	This affected family finances immediately
If you changed your working pattern, did it affect your finances...	o	This affected family finances immediately
Is there anything else, about the hidden costs of fighting for an EHCP, you would like to add?	o	Privately funding alternative provision as child out of school with little support. Privately funding therapy due to long waiting lists. Privately funding neurodivergent assessments as also long waiting lists,, 3 years currently in our area. 2 years for mental health support with CAMHS. Driving to alternative provision. Repairs and replacement of things broken during child's emotional dysregulation episodes. Resources and equipment, for learning, arts and craft supplies, sensory toys and equipment. All probably well exceeding ten thousand pounds.
When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ...	o	Yes, I visited the site, it was helpful
Does your SEND child have an EHCP?	o	No
Are you male or female?	o	Other



# SEND Hidden Costs survey results data

SurveyMonkey

Does your SEND child have an EHCP? Answer yes, if any of your children have one.	To understand if the impact of managing an EHCP affects parents differently, please tell us if you are male or female?	Fighting to get the right EHCP provision have you...	If you changed your working pattern, did it affect your finances...	Reasons for having to reduce hours or give up work...	free text responses	Would extra support from school, local council or employer make a difference?	free text responses	When looking for help with my EHCP, I know I can get free legal guidance from the Support SEND Kids Q&A site ( <a href="https://supportsendkids.org/">https://supportsendkids.org/</a> )
Yes	Male identifying	had to give up work completely?		Answer in more detail	Child's needs too complex to be met by schools or child care providers	Yes	Services needed to meet complex needs.	
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	I can't work more than 3 days due to the need to be around to support my daughters	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	- Having to support SEND child during the day as not able to attend school - Having to attend meetings re school attendance & for SEN assessments, diagnosis, etc - The huge amount of time that goes into research, paperwork, emails required to fight for AP & EHCP	Yes	If the process was better explained, organised, straightforward, less of a fight, etc etc	Yes, I visited the site, it was helpful
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	1st child no school place for years bounced from school to school finally at a school where he left at 9 and was back at 2. Second child extreme school trauma due to being dragged into school couldn't attend for 4 years until he got an EHCP and specialist placement. Even then his anxiety was so high that he could only attend an hour a day for 4 years. Currently getting tutors at home 2 hours a week so I cannot work.	Yes	If the schools had not "broken" my children (their words not mine "they have to break before we will help them") by tormenting them and physically dragging them into and round the school and also subjecting them to psychological abuse (google flattening the grass) then my boys could have gone to mainstream school full time so I could keep my job. Both boys spent years out of school waiting for ehcp's or school places	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Above all	Yes	First if we feel my child is happy and safe then I can think about my career and job placement according and adjustable to my family life.	No, I didn't know I could get help
No	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All 3 bullets above apply to me.	Yes	Yes, in terms of funding for an assessment, counsellors, and from employer more sympathetic flexible working hours.	Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All if the above	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All of the above	Yes		No, I didn't know I could get help
Yes	Male identifying	changed your role?	This affected family finances immediately	Answer in more detail	All of the above	Yes	Obviously	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	All of the above applies, you don't get help and people just don't understand what it's like being Sen parent. No help from anyone or anywhere...	Yes	A big difference, it would help us parents focus on our children not the crap system. We won't have to fight.	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	All of the above!	Yes	If the school had listened to me in the first place they could have support in place sooner and my son may not have ended up in burnout and missing three years of school!	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	All of the above. Ended up home educating to make sure my child's mental health was ok.	Yes	Yeh it would have but there wasn't any. All support is to "tick boxes" so it appears they are supporting but the reality is they can't support us.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All of the top three answers. Council unwilling to support as school unwilling to support. I was denied flexible working and discriminated against by my employer which had a negative impact on finding roles, also no working hours to suite care needs in any role.	Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All of them	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	all the above	No	the LA are against helping SEN children as they are seen as a burden on the public purse. The school do not support as they cannot afford to put things into place within their settlement to ensure everyone is kept safe and happy	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	All three of the above, sadly	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	Although I've not had to change my work hours or job I am constantly fighting to keep up and manage working 37hrs a week while looking after children	Yes		Yes, I visited just to look around
Yes	Male identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	And from school.	Yes	Not now our son reached crisis. But if they helped when he was younger we may have saved him from this.	Yes, I visited just to look around
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Appointments for my child and constantly chasing services.	Yes		No, I didn't know I could get help
No	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	As soon as I had a child with SEND I had to reduce my hours. Now she is at school age this impacts wrap around care and the support she needs. If I don't work, she has me. If I do work then I can't get the leave I need to look after her outside of school hours.	Yes	Absolutely!! The wrap around side of things is hard for those with SEND. Getting support in school is difficult when waiting for a diagnosis. If your child has a TA then they are sharing them with other kids who are still waiting for an EHCP. It's not fair.	Yes, I visited the site, it was helpful
No	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Both lack of support from school and council. Both equally useless	Yes	We have been forgotten about many times. We keep having to remind school and council that we've had no access to an education for our daughter for over a year. They have provided nothing. We have no EP support either as school can't afford it. School won't apply for high needs funding to get support we need. It's chicken and egg. Both are equally unhelpful bar the odd wonderful staff member (who can't sway decisions of new school head).	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	By the time an ehcp had been issued my child's anxiety was so bad they were unable to attend a school setting	Yes	Better support for educational settings and better mentor services would help	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Cannot afford specialist child care for SEN child during holidays. Need constant time off for meetings, appointments and care needs.	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Caring for child out of school	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Change of role so I could be around more to support my child before and after school rather than relying on wrap around care and to be able to take him to extra curricular activities not provided by his school.	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	Child couldn't attend school. LA refused to assess for EHCP and EOTAS which has slowed the process of getting provision.	Yes	With earlier provision from LA and adaptations at school by son may have still been able to attend or receive alternative provision at home which would have meant I wouldn't have to change my work hours and be based at home.	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	Child is homeschooled. I haven't worked since child was 1around 18months old.	No		No, I didn't know I could get help

No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Child needs support and it takes hours to provide that and then getting help is a full time job	Yes	Don't make everything so difficult to access. Change school attendance rules to recognise mental health as well as physical help. Invest in services to support mental health. Have specialist provision for autistic kids to reduce the anxiety	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	Child not in school so have to work from home.	Yes	Looking for a residential placement but having to go to tribunal to get it.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Child out of school	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Child out of school whilst appealing school placement.	Yes	Local council just need to do the right thing first time round, not kicking the can down the road making parents appeal. Shocking system. How it operates the way it does is beyond belief	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	We don't have money worries	Answer in more detail	Child stopped being able to attend unsuitable named mainstream school and is waiting for specialist placement.	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Child too anxious to attend mainstream school, so while waiting for EHCP and a different school placement, one of us had to be at home to look after her.		That's tricky. Extra financial support would obviously help, but both school and local authority were supportive-mainstream just wasn't the right environment for our child. The pressure we felt as parents to 'get her in' was coming from wider society/government.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Child too sick, can't go to work as need to stay at home with them even if they get an EHCP it would need to be delivered at home	Yes	My child could get an education.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Child unable to attend mainstream and no sen school found yet	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Child unable to attend school due to anxiety and pain caused by the anxiety. Many hospital appts, an hour's drive and an hour in length each time. Still told we can't apply for an ehcp	Yes	Child should have had eotas. Still on waiting list for autism diagnosis. Had to pay for tutors myself as a sole parent, on reduced income. Cost over £3000 for one year.	No, I didn't know I could get help
No		had to give up work completely?	This affected family finances immediately	Answer in more detail	Child unable to attend school due to unmet needs	Yes	We have been given no mental health support or support around not attending school or any alternative educational provisions	No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Child unable to attend school so needed daily care	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	Child was unable to be settled with any other caregiver- employer was great but it was totally unsustainable and I had to give up a really great job as a result. My earnings are now 1/5 my husband's so going forward all the impact will have to continue to be on my career.	Yes	My employer is pretty supportive but there's only so much they can do - I have to work some of the time. I should not have to spend huge chunks of work time chasing council, following up, watching ipsea/sendias webinars etc, so employer can't take that strain. EHCP should be a given not a fight. Yes I see in q7 the free legal guidance, thank you, but this is the point - I am putting so much time and effort into finding legal guidance, reading council policy (oh it's just policy it's not the law which is great because it doesn't follow the law), keeping up with my child's documents, have to go to a parenting class in summer term in case it's me parenting wrong... what is left for me?	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Child's deterioration resulted in poor mental health for us as parents	Yes	You are already drowning before help is offered. It's a fight for everything.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Child's needs not met at 2 special schools over a period of 3 years. Growing anxiety and challenging behaviour has led to major trauma for sen child and led to suspensions, part time timetable, isolation from peers at breaks and lunch and ultimately permanent exclusion. She is so scared of school that we can't see her coping in a classroom environment without a great deal of time to heal and appropriate support / interventions. Lack of support from school leaders, governors and LA have made us as a family feel alone, isolated, frustrated and unheard. After permanent exclusion, our child has been at home for over 3 months. Mum has had to reduce working part time from 3 days to 1 day with little notice and having to pay childcare for the 1 day at work. We are around £1000 worse off every month and worried about our current financial commitments such as mortgage, bills etc. We are having to heat our home more as child is at home during the day which has increased our bills and we can no longer afford occupational therapy costs so our child is missing out on vital therapy. Her siblings will miss out on extra curricular opportunities which we will no longer access support. Adjustments to get her in school or to appointments. Impact on mental health	Yes	The LA need to be contactable, open and transparent. They are not. It feels like the system is against us, playing games with parents of sen children, trying all tactics to cut costs and get out of providing the education that every child has a right to. Tactics such as not being contactable by phone, not answering emails, no one being accountable, not properly updating EHCPs to reflect need for fear of having to fund the required provision set out therein, delaying providing information, consulting totally inappropriate schools as a next step to somehow show they are doing something when actually they are doing nothing. Furthermore, the funding crisis is putting financial pressure on schools who in turn are also having to manage reduced staffing and larger class sizes meaning they can often no longer fully meet the needs of sen children and more and more are dropping out of the system and schools become part of the problem. Families are either being forced into giving up the fight and home schooling (perfect for the LA as they no longer need to fund their education) or those who continue to fight are jumping through hoop after pointless hoop trying to advocate for our child. It often feels like we are shouting into a huge void of nothing. It's exhausting, humiliating and wrong. And all the time, we have an often complex child at home who we need the mental strength to care for- our child is secondary school age, has reached puberty, is 71kg but still needs help to get dressed, with washing, toileting and needs constant attention to keep her Flexibility from employers, paid time off for caring roles. Protection from disciplinary action. More flexible working.	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Constantly been called by police, school, missing persons, social worker I worked in Accounts doing payroll & VAT & my work was suffering from constant distraction & interruptions.	No		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Couldn't get affordable childcare because of son's needs. Couldn't get a flexible enough job to enable me to meet the transport. Before and after school clubs would not take him. No childcare available for holidays or sick days. Too many appointments to take him to.	Yes	Flexibility to work at home. Carers leave when needed. Working hours to suit life.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Couldn't do the job and put in all the hours to complete the ehcp as well. It would have been like working 2 full time jobs.	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Couldn't manage behaviours and attend school/appointments/training/support groups etc for 2 children with suspected (now diagnosed) disabilities and still work. Worst was when I had 10 appointments in 9 consecutive working days	Yes	Had to apply for both EHCPs myself - primary school for daughter supportive but said we were more likely to success with a parental application. Secondary school for son unsupportive of his needs and tried to delay me. With a lot of work and effort for both awarded at first application. Not compatible with also working. Two lots of DLA (MRC, LRM) + Carers Allowance and small amount of Tax Credits still less than previous salary.	No, I didn't know I could get help

Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Council refused to assess for ehcp initially so had to appeal - council backed down- then issued a plan for mainstream which couldn't meet need (against advice of own educational psychologist) so had to appeal again. This delayed specialist help from age 2 to 4. I gave up work and taught child myself with help private autism specialists during this period. My child regressed and lost all speech at age 2 and many other skills that clearly needed help beyond what a mainstream nursery place could offer. I felt I had no choice than to step in. Child was distressed and self harming with no means communication. I also went into debt to pay for private help and legal advice.	Yes	My child had very obvious high level needs. very quickly diagnosed with autism after regression but council gatekept specialist help trying to delay this until school age for budget reasons. Early intervention is most successful before age 5 so this time was lost and meant child had required much more specialist (and expensive) help throughout rest time in school. I've never been able work fulltime since, never been able to apply for promotion and my pension is less than half what it would have been. I will retire into poverty despite working and caring over 130 hours a week. Even when my child had more help won at tribunal the council denied transport so this prevented me working too.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	Daughter having issues at school meant I was always there for 1 readin or another. Can't travel independently so have to drop off and pick up. Attend appointments linked to EHCP	Yes		No, I didn't know I could get help
No	Other	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	Delay in getting ehcp means child's needs haven't been met for over a year. They now have autistic burnout and anxiety, which has led to suspensions and he now can't attend school at all. There is no alternative provision for primary age children in my area, homeschooling is the only option. As a single parent, I'm now having to give up work to care for him 24/7.	Yes		Yes, I visited just to look around
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	During the EHCP assessment process my child's mainstream placement broke down and we were left without any school placement for an extended period.	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Emotional drain trying to work hard and also support child with ehcp and the rest of the family.	Yes	After school support and transport would have made a huge difference	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Even in specialist provision my daughter struggled to attend school. I'm currently her 1:1 at home while school sets work. I can only work 4 hours a week now max and on a zero hours contract. We've had to move house (downsizing) to make this work.	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Fighting for a SEN school place. People deciding have never met my child or been to the school	Yes	Need help changing school not obstacles put in our way!	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Fighting for support that should just be out in place automatically	Yes	Follow the send code of practice and meet the needs of the child	No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Financially cannot afford for Arthur to be able to attend nursery more than 2 days per week	Yes	If Arthur either had more free hours or the price wasn't so high, I'd be able to offer the agency more availability	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	Full time Carer. Used to work in IT, can no longer sustain full time employment due to Caring responsibilities.	No	School/LA shift into parent blame to save money. It's literally in their job role to help (according to the SEN Reforms in 2014), but that doesn't happen, lack of teachers, training, money etc.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	Had a mental health breakdown due to the stress of trying to work whilst caring for my child who developed severe mental health issues due to lack of understanding and support in secondary school	Yes	When your child is not supported in school they start to feel unsafe and lose trust in the system. If they are then bombarded with negative behaviour points for every thing they get wrong they start to feel like a failure who can never get anything right. This then can lead to attendance issues as they are fearful of being in an environment that is hostile to them and where they fail every day and are misunderstood. Once attendance issues arise then the relationship often breaks down between family and school and the stress is unbelievable. I desperately wanted my child to go to school but being at school broke him and he had a total mental health breakdown in year 8. If schools cared less about zero tolerance behaviour policies and attendance data and looked instead at each child individually and were creative and flexible in dealing with their needs then so many of these issues would go away without an EHCP. The rigidity in schools around behaviour attendance and curriculum is creating stress and anxiety. Developing trusting relationships would be my priority for all schools. Having trained family support workers in every school whose job it is to work with struggling families. Having a pastoral hub in every school where kids can go if they get overwhelmed. Routinely analysing poor behaviour to identify where it arises, when it arises, which lessons, which teachers so that patterns can be understood and acted upon. Behaviour is communication and often poor behaviour in certain environments or certain subjects can be a	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Had to become a sen lawyer to get my children what they need to thrive	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Had to fight to get our daughter in to a specialist school. Her mainstream school were shocking and our daughter was unable to attend for nearly 12 months. Had to take LA to tribunal to fight for independent specialist school. LA conceded 6 weeks prior to tribunal. I had to give up work completely due to daughter's needs not being met.	Yes		Yes, I visited just to look around

Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Had to give up my career as a Bank manager in London within a year of my eldest son being born. We didn't realise at the time that he is autistic, we just knew he was unable to be cared for by anyone but myself and sometimes my husband (his Dad). He was unable to sleep for more than 90mins at a time and we were all completely sleep deprived by the end of that first year. My basic salary with the bank was £40k and including my non-contributory Pension plus bonuses my package was worth £60k per year. My husband decided that as I was breastfeeding our son, I should stay home with him and my husband got to keep his career. That was 16yrs ago and whilst I love my son more than anything, I am unfortunately very bitter about the loss of my career as I've never been able to go back to work full time. I managed to have some part time jobs over the years but inevitably had to either give up work or change my work patterns as my son struggled to cope with having to attend mainstream schools without any support. It's been nothing but an uphill battle to get a formal diagnosis for him, to finally get an EHCP for him during year 9 (I had to do it myself as SENDCO'S kept telling me not to bother	Yes	Schools - teachers urgently need training on autism, ADHD, OCD, dyslexia /dysgraphia /dyacalculia etc etc from neurodiverse professionals (there are hundreds on LinkedIn alone) Local authorities - as above! And please stop making the EHCP process so incredibly convoluted - it should be there for those children with complex needs, not neurodiverse children who just need some support and understanding at school level, in order to succeed at school Employers need training in neurodiversity! The ignorance I have encountered amongst some colleagues had been hurtful and astounding in equal measure. My son (and every other person) deserves to have a place in society and be able to contribute meaningfully	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Hard to do work as you your child needs needs someone with them .	Yes	If employees are more flexible in doing certain hours. I do 0 hours contract to work around my child.	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	This affects our family finances in the long term	Answer in more detail	Have not been able to work as all placements to date have failed and my son has spent most of 10 years of education at home. The last four and a half years he has been at home with me and constantly fighting different departments to the point I would have been prosecuted due to the failures of all LA departments. Not had any personal budget or financial assistance to ensure I can provide an education	Yes	Never had a full school year placement and there are no schools that have been able to meet need. Council needs to address lack of schools in our area	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Having child at home due to failure of provision meant me having to stay home. The lack of support was across medical, school and LA but the LA is by far the worst culprit	Yes	LA doing their job, following the law, responding to emails etc. also, an effective CAMHS system would have potentially saved us an entire year	Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Having to find out the legal frame work myself to ensure ehcp was legally binding. Schools and local authority lie to reduce cost. So I have to research everything myself. I have no trust in the education system. I blindly trusted them before, not anymore.	Yes	A in depth information book would be helpful so parents know what is important and legal.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	I am needed to collect child from school earlier and currently she's only in school 1 hour per day. Not been FT since Sept 22. We don't have other childcare support so I've had no choice but to reduce hours and work in an evening when my husband is home. It is extremely hard	Yes	Having the correct support as listed in her EHCP would help. School not having to admit tribunal children so classes are to full and noisy. Actually providing the provision listed would be a help.	No, I didn't know I could get help
No	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	I changed career as I needed to be able to support my son. Primary school just deflected responsibility to secondary level. I was actually laughed at by a senco at primary for Asking for an ehcp. I applied for ehcp at secondary but had it refused because he was academically capable (but only if supported) doing GCSE's this year and I am doing a lot of work to support him so he gets 4's.	Yes	School only recently have a decent senco. Everyone before him at all school levels were seemingly unqualified and unaware and acting on behalf of the school not the child. LA male It so hard to even get an Ed. Psych in a class room for observation. Any help will be better than the no help so have no idea what would be needed at this stage	Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	I could not carry out my role due to lack of support/sleep/respice	Yes	I could have continued in my role .. however la took us to tribunal 5 times AnD the high court to save money .. we won each time	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	I could not entertain working whilst my daughter was at school and once I pulled her out I still couldn't as I needed to be home. Even post year 11, trying to find the right continued education means I still cannot work. It's impossible. Now I have such a large gap in work. History it will be even harder to even think about trying to get back into any work, my career is over too.	No	It made things worse. What support? Often the wrong support was offered to my daughter.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	I could not work full time and look after my son. My employers have been very understanding of my situation. I had a choice of full time or three days so I now do three days. I am a teacher.	No		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	I did not give up work but I did change careers and left a 15 year career due to lack of understanding	Yes	My new employer is fully supportive of my situation and it honestly changes everything, his support at school and wrap around is also amazing, but this has taken time and effort to achieve	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	I did volunteer work which helped get me work experience I know can't do that and can't do my law degree due to caring for 5 disabled children and getting no support despite 4 judicial reviews	Yes	The Sen team have repeatedly failed to engage they have failed to follow their own legal response to the pap letters	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	I gave up work as my send child was not in full time education despite being entitled to it. He was doing just 1 hour a day when I gave up work in October 2022. Now in March 2024, he is STILL on a PTT. Minimal support from the school, LA are useless! Sendiass have been very useful and I now attend parent carer coffee mornings.	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I had accepted a permanent post in Scotland, and my child's needs worsened in the months before we relocated from southern England. A CAMHS referral was escalated to neuropsychiatry and school supported our parental application for an EHCP.	Yes	My former employer (and the sector as a whole) makes no allowances for the needs of parent/carers, with compulsory meetings and trainings repeatedly held outside of hours for which childcare is possible. A long hours working culture is considered essential, and the only part-time roles are zero hours contracts.	Yes, I visited just to look around

Yes	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	I had to change my working pattern, but that wasn't an option above so I answered that I reduced my hours, because it's very difficult to juggle, every day is a very delicate balance because there is no such thing as SEND wraparound care. We are just refused it, it's not for us it's for neurotypical children. I am unable to progress my career because of worrying about how my life would work if I changed anything.	Yes	Just provision of wraparound care would help, even unfunded, would be a huge support. To have someone else help us take care of our children and make our lives work, have some respite, would reduce chronic levels of stress. We, and our children, are denied access to basic services that are fully available to neuro typical children	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?		Answer in more detail	I had to change roles initially because the job I was in was not flexible enough and lacked understanding. I moved to a new role on reduced hours which saw me working full time 37 hours a week, down to just 15 hours a week which was a huge drop in take home pay. I did this for 6 months but had to leave because I needed to care for my son as well as prepare for tribunal, and try and sort alternate provision/ some sort of education for my son.	Yes	If school had supported from the first instance, instead of postponing meetings, it would have meant my son may have stood a chance of returning to school. But due to the delay and then lack of support, he was out of school for 4 months and then we stood no chance of him returning because he had lost trust in the school and he had experienced school trauma. The LA in 15 months of not attending school, have provided my son with 2 x 30 minute online lessons both of which were unsuitable and inaccessible for a 6 year old. No teaching was done, and it was essentially a powerpoint with multiple choice questions. There was a chat box which he could type in to if he needed help but his typing skills and spelling at the time was not sufficient enough. We have only just got gaming mentoring sessions which my son started this week, 15 months after his last day in school!!	No, I didn't know I could get help
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I had to look after my child full time at home	Yes	Better full time provision whilst waiting for EHCP	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I have 2 children with an EHCP. One in school and one that, despite having a school place, is unable to attend due to extreme anxiety related to school based trauma. He is 12, and no alternative education provision has been put in place for the 8 months since the school told the LA they are unable to meet his needs and that an EOTAS provision is required. Despite the EHCP annual review being completed 8 months ago, the LA are yet to make a decision. Which is clearly in breach of the law. I complained to the LA 7 months ago. I have received no response yet. I complained to the LGO, who won't investigate until the LA complete their complaints process. The LA gets to act with impunity, there appears to be no gate keeper for the SEN law. Ultimately I had to stop work to provide the education my child needs at home. The admin involved in all the chasing is daily, it's stressful. All because the LA hasn't made a decision if they will fund an alternative provision. I have now complained to our MP. The only other option is funding a solicitor to take the matter to judicial review. Not surprisingly we don't have the money to do this, not the time to independently	Yes	Yes and no. If the LA agreed the EOTAS request, and the personal budget, then the provision would be being paid for, rather than us trying to fund as much as we can out of our reduced budget. I would have an increased capacity to go to work, but it would still be limited as I am the full time carer for our 12 y/o, and that's not going to change in the short term.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	I have changed role so I work less hours. This means I can do school runs and support my child when they get home from school. I also work term time only so I can look after my child during school holidays. There is little provision for SEN children and it would be difficult to find childcare for him during school holidays.	Yes	My employer is flexible to an extent, however it is a worry having to ask for time off to attend appointments and school meetings. There should be greater accommodation for parents of sen children at work due to the demands of looking after a child with sen and the mental stress and burnout. There should also be more provision from the la	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I have to be at home while both children receive home tutoring provided by temporary alternative provision.	Yes	Carers allowance for ND children specifically in these circumstances	Yes, I visited the site, it was helpful
Yes	Male identifying	nothing has changed	This affects our family finances in the long term	Answer in more detail	I haven't had to reduce my total hours but I do take time out for the various appointments, work from home more, and make up out of hours. I had to fight for the flexibility which can affect my ability to be available when I am needed. I am a lawyer and I would say this could have a potential long term effect on finances which will always be impossible to measure.	Yes	Obviously LA but really the issue lies with central government which has put the LAs in a bind. Nursery is generally very supportive but we have observed that the principal has been more supportive of others than us and we think this is because she regards us as more privileged - but we are not as privileged as she thinks and in any event this should not be at issue, everyone with a SEND child needs support .	Yes, I visited the site, it was helpful
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	I myself as a single mum don't work due to mental health issues	Yes	My son was permanently excluded from high school he now attends a PRU unit which we do not approve of because there's is no help with ALN they just brush us under the carpet	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I needed to be at home full-time with my child	Yes	If the LA had given a place at a specialist school 3 years ago when we asked our child might not have gone into total autistic burnout	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I ran my own business and the demands of the business couldn't be met whilst also feeling like I was doing the best for my children	Yes	The thing that would make the biggest difference is if f more people were aware of the realities of living with additional Needs. The prejudice and misconceptions people with SEN face are the biggest challenge	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	I reduced my hours at work and just work one day a week, but my partner is the main earner.	Yes	Definitely, even if it was just something as simple as them providing nappies and wife for my send child while at school!	No, I didn't know I could get help
Yes	Male identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	I suspect that I will need to stop working as my child gets older	Yes	More wrap around care my child - currently have to start work at 5am to ensure I'm managing to cope with workloads	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	We don't have money worries	Answer in more detail	I was a stay at home parent but I was unable to get a job due to having to be at home to support my children to get what they needed	Yes	Sadly they work against parents and make it far harder	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	I was a teacher (HoD) when my daughter started to struggle in school. No flexibility to even go 90% part time in that role so had to leave and take part time teaching job elsewhere. Then even less hours when we were at the point of needing EHCP and daughter was unable to attend school at all.	Yes	Being allowed to go 75% part time would have made life easier before the EHCP. I'd still have had to leave when my daughter really started to struggle with attendance. School having better SEN support without an EHCP would have helped - less parent blaming, less assuming child is fine when they say they are not.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I was a teacher and my son was put on a reduced timetable so I was unable to work.	Yes	More financial support/ flexible working options	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	I was and still am on a career break.	Yes	Advice regarding the ehcp process, that parents can apply, appeal, mediate. Non of this was given, i had to do my own research. I was told that the school had to gather evidence before they could apply for an ehcp, I discovered this wasnt true and applied myself. Sendias were not helpful at all, staff didnt have the knowledge.	Yes, but I didn't find the help I needed

Yes	Female identifying	had to give up work completely?		Answer in more detail	I was constantly called into school as my daughter refused to go to classes after lunch. This made it impossible to continue working.	Yes	The school were unable to cope with my daughter's behaviour, better training for the staff would have helped. Although our children are both adopted through the LA we have been unable to secure appropriate support despite fighting for many years.	Yes, I visited the site, it was helpful
No	Female identifying	nothing has changed	I worry about money most of the time	Answer in more detail	I was looking at going in to work after my baby but now can not	Yes	We need transport from our local council	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I was never able to go back to work - no suitable childcare was ever available, and then no school could meet need.	Yes	It's hard to imagine being able to go back to work now, after 15 years, and when I'm still needed all the time by my child. But I imagine that extra support in a timely way, years ago, might well have made a difference.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I was on a placement that would lead to full time role, constant phone calls from school and difficulties finding after suitable school care led to me leaving and not taking job offer.	Yes	I think suitable childcare for SEND children is hard to find.	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	I was training to be a nurse and could not continue with university commitments due to child's needs	Yes	If our local authority didn't have an unlawful disabled children's social care policy - I'm sure we could have benefitted for respite/PA hours.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I was unable to manage to all the paperwork, appointments and keep on top of doing my job well.	Yes	If the local council acted within the law then I wouldn't have had to give up my job.	Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	I went self-employed before we knew about my daughters needs. However the support she needed to gain her ehcp and the support she needs now she's in mainstream secondary means I can't work the full hours I have done in the past which directly impacts my billable hours	Yes	Suitable childcare, more resource in the schools	No, I didn't know I could get help
No	Female identifying	nothing has changed	This affects our family finances in the long term	Answer in more detail	I work part time to support my child/ren. It's so time consuming to deal with all the send issues.	Yes	My employer is good at allowing time off for appointment but I do feel a burden.	No, I didn't know I could get help
No	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	I've had to flex my hours considerably to be able to attend meetings with numerous agencies	Yes		Yes, I visited the site, it was helpful
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	I'm a widow and my child's disability means it is unpredictable when I can get him in to school so can't start early.	No		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	I'm had an autistic teen plus a toddler and baby. Teen struggled throughout school and had a breakdown after that. Youngest also autistic. Utterly impossible to do my job with this going on, especially as it was a high stress job with expectations you stayed after shift to finish off. It wasn't doable.	Yes	No support/fighting the system, having to prove your kid is suffering and declining time after time takes up all your waking hours. There's no time to work	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	I've spent 10 years fighting for my son and it's all consuming on top of working	Yes	If LAs followed the law and were held accountable if they don't then things would improve and they'd stop gatekeeping funding by delaying timescales and avoiding provision children need.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	In a special school for ASD children but been on a reduced time table of 2 hours a day for a year.	No	I'm self employed Childminder no work no pay.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	In wales the system is horrific we have no choice to give up everything	Yes	Problem is they never have helped not all schools are bad but they are afraid to speak up against the nhs and LA	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	It got to the point where my daughter could no longer attend school due to EBSA and trauma brought on by being in the school environment where her needs weren't being met and where the environment was too triggering for her sensory differences. After years of being gaslit by the school, my daughter had no trusted adult there and saw school as a very unsafe place to be. In the end, her anxiety was crippling her, she had suicidal ideation and tried to self harm. All by the age of 8. I kept being dismissed and told she was fine in school. I was even accused of being melodramatic, overly anxious myself and having FII. The school wouldn't support an EHC needs application, so I didn't myself. My daughter has been waiting 2 years for ASD/ADHD assessment and we've been waiting 40 weeks for EHC needs assessment to conclude (agreed to assess 40 weeks ago). I've since deregistered and we are home educating as my daughter couldn't bear to be in a state of limbo any longer. We are trying to progress the EHCP process in the meantime. My eldest daughter has an EHCP but her school didn't implement most of the provision. She was also gaslit and suffered greatly being in a mainstream	Yes	The Council and schools need to uphold their legal requirements. SEND law is actually pretty robust but there is no accountability when the law is ignored. Quicker access to diagnostic assessment, EHC needs assessment would help. But the whole education system needs to radically change in order to be built upon a culture of inclusion and acceptance of SEND and difference, rather than relying on unrealistic expectations that all children can fit into the coercive, rigid and discriminatory system currently on offer.	Yes, I visited just to look around
No	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	It takes a lot of time to chase professionals, take child to appointments often at inconvenient times	Yes	More resources to support needs. More 1:1 staff.	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	This affected family finances immediately	Answer in more detail	It was a temp adjustment	Yes	More flexibility means can still do a full time job as single parent of a SEND child	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	It was all 3 as well as no support for mental health/eating disorder	Yes	Out of education for 3 years waiting for a specialist placement	No, I didn't know I could get help

Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	It's a mix of lack of support from school, from community and lack of availability of respite. It's not only that. My care hours run through the day and night. I am utterly exhausted. My eldest is now 15 and has always needed day and night care. My husband is often up around 5am, whilst I take the other side, and stay up until about 2am, but kiddo often can't relax to sleep properly until about 4/5... we also have 2 other 'complex needs' children. When are we supposed to eat, sleep and use the bathroom, never mind work?! Amazingly hubby does work, but has had to give up going into the office and works from home. His hours get distributed all the time, even with myself having given up work right from the start with child 1 (high needs right from the start).	Yes	Yes it would, but it feels like for us, it's too late now. My eldest has an ehcp. As his needs grew higher and he needed more support, I had to go to tribunal to secure it (we won). It took about 6 months of him not attending a setting to make the decision that some drastic changes were essential for his well being and then a year and a half of fighting for it, before winning at tribunal. My other 2 children slipped right through the radar. Neither were recognised as having particularly higher needs than their peers and we were constantly told, for 5!! Years that they would 'catch up', that they 'were fine in school' etc. Well fast forward to yr 6 when one hit breaking point (child 2 of mine to go down that route due to lacking school support) stop attending school and in yr 7, at a new school, get recognised as needing a Camhs assessment and more school support right from the beginning. Unfortunately she'd been turned down 4 times by cahms already, due to not scoring high enough from the papers sent to school. She was turned down a 5th time. We went private with both girls, to a highly recognised child psychiatrist who also works for Camhs. Both children now have full ASD/ADH diagnosis and after further assessments, one was found to have significant learning disabilities, scoring less than 2%, in fact less than 1% on some tests and with what was described in her paperwork as having a 'very low IQ'. How on earth could this child have slipped through the system for 7 years?! We have deregistered both younger children. Their real academic levels are	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	It's hard to find a job in school hours only and our son needs full time care	Yes	More employers could offer flexi time or school hours	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of action/dismissal/neglect by range of 'professionals' (school, mental health & local council) meant I had to give up a senior management role to push not only for action for my eldest who had hit crisis almost a year prior, was struggling to access school (being repeatedly let down by inconsistent care and lack of action) but also to pursue a diagnosis for, by then, 2 of my 3 children. Faced also with need to research and identify alternative schools for one who'd just started secondary and 2 other children who would be transitioning from primary. Received no guidance whatsoever and attempts to access help continuously thwarted/thrown out.	Yes	Collaborative approach to problem solving rather than blame; open and honest and consistent dialogue, listening culture, advice on what's genuinely in the best interest of the child ... serious mental health issues and family stress (and higher costs for all parties concerned) might have been avoided .. i trusted advice was in interest of child, not budget driven, and I was expected to be the expert on services/solutions yet dismissed as any sort of expert on my child/children.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of alternative support as no family support available	Yes	More options for respite, more funding for activities that can be done as a family with other send families with no judgement.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Lack of appropriate education leading to me needing to leave work on several occasions to support my son at school.	Yes	The right education in the first instance would have prevented my son displaying behaviours that the school felt they could not support	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of everything! School and council support as well as understanding from others about my child's needs.	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of flexibility from employer A school provision which is over 25km away one way (for a four year old!) Cost of private reports, tribunal	Yes	Not needing to fight for every single step, would certainly be helpful	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Lack of local council planning s lack of Flexibility from employers (multiple) Upfront on applications about home schooling Promise remote work which in reality is 3/4 days in the office 1/2 at home Think the LA put the file on a basement desk & forget about you EHCP wasn't updated from 2016 to 2022	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of professional support in all areas of school, LA and health care, the system is designed to drown you in refusals to use any money to provide just what your child needs	Yes	But the problem often lies in funding, staffing and having a robust EHCP of which our LA will not give	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	Lack of sleep	Yes	Maybe more term time jobs more jobs that fit around your child's school hours	No, I didn't know I could get help
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of suitable childcare.	Yes	With suitable childcare I would not have had to give up work.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Lack of support - carer support which was safe, we had 18 different careers in the space of two weeks so I called it a day on agency staff.	Yes		Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of support from (in order of struggles) School CAMHS Council inclusion team Social worker/children's services SEN dept at council	Yes	We had no support with school trauma, no support with suicidal preteen, no support with family at crisis, needing to use food banks, grants from charities, loans from family just to get by. I felt suicidal.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from all areas - Mental health, education, things being done at snails pace no urgency in anything. Attending meetings for nothing to change causing further issues.	Yes	Yes certainly would make a difference when a child goes into crisis they don't have time to be stuck waiting for services. Quicker actions could probably make the a lot of difference to the end results and could avoid unnecessary further problems and distress.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Lack of support from all even more so when have more then one child fighting for	Yes	Doing things on time and more flexibility in the work place	Yes, but I didn't find the help I needed
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from all services, social services, local authority, SEND operations and school cannot meet needs and calling me in up to 3 times a day, everyday.	Yes	If they were more equipped and understanding and could offer more respite and the right things in place at school it would be easier. We are just a number to their systems and another box to tick off their lists	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from any service, school does what they can. They could do more if they had more staff or funding	Yes	Waiting lists for support are long, and when support is offered its either a short fix, if child can't engage rejected to start all over again	No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	Lack of support from anyone. Have to continue to work as single parent with only my income or have to lose house. Have to wfh and care because EHCP hasn't been granted. No social care support granted even though child has ebsa. Every single thing we have (diagnosis) has been through huge battles and still no support from councils or school.	Yes	Offering a bespoke package as per EHCP, setting or package would take the unrelenting pressure off just me. I would be able to leave my house. I would be able to have funding towards special needs/care/education rather than being on myself and breathing space for myself so I don't feel like I'm drowning 97% of the time with my own stress related health issues.	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from both school and LA.	Yes	I would be able to work, instead we were forced into EHE and no chance of ever keeping a job at present, til EHCP is fit for purpose.	Yes, but I didn't find the help I needed

Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Lack of support from both school and the local authorities/council. My children has struggled massively with school attendance due to needs to being met.	Yes	If the appropriate support was there continuously then my child would be able to enjoy school and gain a full education.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Lack of support from council and lack of support from school	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Lack of support from everybody, school, council, CAMHS. All totally ignoring policies, withholding information, just awful	Yes	If they actually followed any of their policies, this would be a good start.	Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from local council - extra time required to fight to get an EHCP. Lack if support from CAMHS - discharged immediately following referral for anxiety and self-harm as, apparently the school nurse deals with that and not them. This led to emotional based school avoidance. We are paying for private therapy instead of getting any support through CAMHS.	Yes	I would not have had to leave my job. We would not have to pay for private therapy. I would like to point out that the school have been excellent in their support.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from school and council	Yes	He would have hours he deserved instead of 2 a week, then he's bored and vulnerable when he goes out and gets into trouble	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Lack of support from school and employer	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	Lack of support from school, I now hybrid work and home educate which is very difficult	Yes	If school or the council had the faintest idea on how to care for SEND children, my child probably would have been able to return to school. The support is non-existent	Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support from school, local authority and CAHMS	Yes	I fought for years for support for my children and received nothing but threats of fines and to be told 'I was putting my child's learning in jeopardy despite the fact no one would help us access support, or even give learning to be sent home!	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	Lack of support from school, nhs, local council. I have an adult child, never supported adequately if at all. They had a statement. Now homeless.	Yes	My child would have less MH issues & not be homeless if they'd been supported.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support in schools, council,	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of support when things went wrong in school, and then lack of support from NHS and from anywhere really. Council deeply unsupportive on all levels.	Yes	Any kind of support at all from the school would have made a massive difference. They don't take safeguarding seriously, complaints were completely ignored about the same member of staff for several years, who carried on bullying children. Any efforts that we made to get adjustments got nowhere, and despite the trauma, the council insist our kid would be "fine in mainstream". We now home educate and get no support at all, we pay for it all ourselves, both in lost income and in private physiotherapy and private tuition.	Yes, I visited just to look around
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Lack of support with everyone	Yes	Be more understanding help with finances housing needs	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of support, provision and education on managing my son's disability. The system is harder to navigate than the disability itself.	Yes	It's the make or break of our children's survival. The LA's don't want to fund it, they're incredibly short sighted and unkind	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of systemic and familial support for my sons EOTAS. I cannot work consistently as I have no-one to help get my son to and from provision. Often my son struggles to get there and it's not at mainstream school times.	Yes	Fluidity in employment is essential. Understanding that there are endless appointments and reams of paperwork, endless fighting and researching. I lost my job because supporting my son became a full time role.	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Lack of time	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lack of time as a single parent of two children, to drive through the EHCNA application process and maintain my mental health.	Yes	The LA should not make the hurdle to get an EHCNA so difficult. Most of the time these are driven by a parent with limited resources (already parenting a sen child, or more) who is not getting their needs met - meaning disruption to home life, impact on the family dynamic, impacts on parents.	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Lincoln county council do not recognise the high level of need. They continually sign post to universal services which my daughter cannot access due to level of need. Despite risk due to requiring 100 percent supervision they will not support	Yes	Cannot access any setting in school holidays Social worker does not see this as an unmet need, therefore won't increase in read care package and currently receive basic care package which doesn't even cover personal care. LCC the learning and disability team have failed our daughter. She has a severe and profound disability and at first assessment the social worker stated we were looking for a babysitting service and closed the case	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Local Authority refused specialist placement despite mainstream school repeatedly stating they can't meet needs i.e., they don't have Teaching Assistants for 1-2-1 support so child not given access to school/education, therefore parents had to.	Yes	We don't need extra support, we just need the appropriate education that children are entitled to under law.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Local council, inflexible nursery provision, inflexible employers. All appointments during the working day - system seems to assume "mum" doesn't work. All the stress meant my head just wasn't in the game at work	Yes	Actually being any suitable educational provision, and being supported rather than blamed.	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My child came out of (their 3rd) primary school in October 2021. Since that date, they have been provided with zero education nor specialist educational provision, despite having had an EHCP since July 2022 and us having secured a full EOTAS package at Tribunal in April 2023. As such, they are at home 24/7 so I have to be as well.	Yes	If my child received the provision set out in Section F of their EHCP (as the LA legally has to ensure, as per s42 Children & Families Act 2014), they would be receiving a full time education of 29.5 hours a week and I would be able to return to work	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	My child had no schooling, she was thrown out. Therefore I could not work as she needed constant care.	Yes	Access to schooling that meets needs would be a start. An employer that doesn't threaten with disciplinary every time you have to fetch your suspended child. Schooling that is more than 1 hour a day.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	My child has a reduced timetable and school refusal	Yes	Zero support given had to get private assessments and apply for EHCP myself	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My child has never coped full time in school	No	I can't manage my life in the few hours he is at school, let alone work	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	My child is unable to go to school. Some support has been offered but it is not adequate and some interventions only available if my child attends for a full day. She is unable to attend for a full day due to unmet needs and anxiety.	Yes	My child doesn't feel safe in school, isn't coping with school. She is autistic suffers with anxiety and low self esteem. If the school could offer more emotional support and therapy this would make a difference.	Yes, I visited the site, it was helpful



No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	My child who is autistic and has adhd, was refused an EHCP in July. Support that school were funding was pulled due to them not being able to afford, all of his support was pulled in his September and then he could no longer face going to school in November he has been off school since.	Yes	Had my child had the support he needed he would still be in school. I would have more income and we both would have had better mental health. It's affected all of our family, more than I could ever imagine.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	My council ie send officer has been awful with support & Communication	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	My hours were impossible to manage. I now have a new job hybrid working and flexi time	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed		Answer in more detail	My husband and I are fortunate that we both work from home and our hours are flexible. In addition we are both qualified solicitors. Our answer would no doubt be different if that were not the case as advocating for your child is extremely time-consuming and stressful. Our EHCP process was fairly straight-forward. However, I believe that was for the following reasons: 1 - our son was struggling to the point where he was close to being excluded. The NHS wait at the time (2019) for an ASD/ADHD assessment was 18 months - 2 years (I believe post Covid it's more like 4 years). We were able to pay for a private assessment (a 13 month wait at the time) for c.£2,400 (same provider is now charging over £4000). Getting the diagnosis gets you on the right path and allowed him to be prescribed melatonin which meant he could sleep (the prescription of melatonin is a whole other complicated issue which is applied unfairly but can make an enormous difference to a child's wellbeing sleep being so fundamental - again the children with parents who can advocate for them effectively and pay for private diagnosis are most likely to benefit). 2 - as degree educated professionals we were able to affectively	Yes	From the outset the process is designed to put the parent on the back foot. It's an extremely stressful process.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My job- a teacher meant lots of extra workload outside work plus my own health deteriorated due to the trauma of meeting my child's needs. The ehcp process in particular nearly caused my a mental breakdown.	Yes	Accept and put in place reasonable adjustments without being begged and checked up on. Maintain support. Make multiple reasonable adjustments as needed not just what can be done free of charge. Train ALL staff and advocate for our child when we are not there. Think ahead, plan and be consistent.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	My partner has had to stop work completely. I am stretched as sharing child care and trying to fight the system to get us support	Yes	We have an EHCP but school do not have the LSA support staff to be able to implement provision. But they wont admit that as they will lose the funding. Result is being unable to attend and no contact from school or LA regarding this.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My son could only manage 1-2 hours a day at different times due to subjects... Constantly on assess, see, do review for 4 years. I could manage to keep my job whilst taking him to and from school as I didn't know what I would be available for from one week to the next.	Yes	If they had done his needs assessment 4 years ago when I initially requested it	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	My son has been mainly out of education through either school anxiety and our local education not finding a school for 5 years. Then when a SEND school was fund it took years for him to be able to attend every day as the trust had gone. He also has OCD so when he needed the toilet I had to drive to his school and bring him home to use the toilet and drive him back . 40 min journey each way. I have to be here to support and provide for his needs even though 19 years old	Yes	If there was early diagnosis, support and understanding a lot more children would not have school anxiety due to there needs not being met.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	My son has had no school placement for 18 months.	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	My son has no school placement available, he's been home since September and is likely to not have a placement until September 24	No	I have left my job	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	My son has various days where he's not able to attend school due to his mental health	Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My son is still waiting for his ehcp and only attends 30 minutes of school hours a day this is on a basis of him not being with any other children as he cannot cope with it but we are still waiting to get a ehcp also and fighting for a space at a send school which he cannot get into without his ehcp and I cannot get him a ehcp yet as the local authority want enough time frames evidence ... my son is in year 2 and has not done a full day since the start of year 2 his needs have been present since before nursery but lack of support meant a longer fight for acknowledgment and help for him	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My son was left without a school space for 4 years and unable to be home alone. When tutors were provided I was expected to be home, when a direct payment package was provided I had to manage it and supervise it and drive him everywhere. When he refused to leave home I couldn't take him to a meeting. I lost £715pm in benefits changing to UC after a move and had to sell my car to afford rent because I couldn't work or leave him alone to be able to afford both.	Yes	They could ensure childrens rights are protected rather than expecting parents to individually reinvent the wheel when their child is failed. They could stop traumatising and restraining children. Or even make their guidance statutory and hold abusive staff to account. They could stop fighting with parents, ignoring them when valid questions are asked and actually provide an education to children instead of spending all of their efforts avoiding it.	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My son was no longer able to attend school and it has taken 2 years to get him in the correct setting	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	My son was unable to attend school. Nothing they could do & no SEN school places for him.	Yes	They could have funded some time at an Independent Alternative Provision. We self-funded this.	No, I didn't know I could get help

Yes	Female identifying	nothing has changed	We don't have money worries	Answer in more detail	My workplace is understanding and allows me to flexible work	Yes	Ehcp is very confusing process I don't understand half of it the annual review changes the time of year each year! Local authority never responds and don't know who to ask for help if I need it.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Needing time off for appointments with the school, lots of telephone calls in working hours for advice and information including calling SENDIASS and charities, no out of school support	Yes	We were lucky in that our school were very supportive and had years of documentation to prove the need for an EHCP however it is really difficult having to take so much time off work for meetings and complete all the forms and forms etc	No, I didn't know I could get help
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Needs of child were such that I needed to be on call whilst child was at school. She rarely made it through a whole day and I would be called to collect. Sometimes sent home dye to lack of staff. Home schooling became best choice. She wouldn't accept anyone other than me. No energy or time for paid work or social life	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	No after school or holiday support for SEND children	Yes	After school and holiday support would allow us to earn more. Why can't parents of SEND children get on the Board of directors in companies??? Because they cannot work to their full potential!	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	No appropriate help from healthcare or education / council. Professionals don't believe or think ASD kids are not worthy or should expect to have nothing as this is their disability / problem My child developed very severe depression and anxiety and became suicidal as a result of school ptsd	Yes	But for now it's just too late , my PDA child has withdrawn from society and living for 5 years now . We have fought long and hard for nothing but indifference . Parents shouldn't have to use legal system to get basic education and healthcare . We are the families left pushed in the gutter. Many education council officials lie and treat parents like rubbish on the floor . I have remained dignified and calm throughout the process but I now have nothing left to give .	No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	No childcare facilities for children & young people with disabilities	Yes	If social care were not denying statutory assessments to disabled children & young people, there would be more access to respite, etc	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	No childcare for child with complex disabilities	Yes	Might have enabled me to stay in work	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	No education provided By La for child who was out of education for over a year I retrained as a TA changed careers and jobs to less hours in order to be able to be at home more and to be qualified to teach my own child I also funded from my own pocket SALT and OT provision too	Yes	The LA Providing an education as they have duty too and not fighting cases at tribunal that they know they are going to loose which wates everyone's time. More resourced orovisionunits for children who just can't cope in mainstream environments who need a smaller calming environment to aid them	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	No longer able to attend any educational placements, traumatised by 2 failed special schools	No	Too late, already traumatised, parents not believed, child distress ignored by both special schools, will never return, needs full time care and parent to facilitate all support	Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	No school can support my child's needs so the are home every day and I have to be there to support tuition provided by the council.	Yes	Council could provide someone to support my child so I could work more.	Yes, I visited just to look around
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	No support	Yes	More information, the waiting times are so so frustrating no communication	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	No support to care for children.	Yes	My children would have remained in school, I would not have had to give up work.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	No support was offered through school, said she was fine when she very much wasn't. Had to give up my business and work, remove her from school which was destroying her mental health. Pay privately for autism & sensory assessments & fight at tribunal for EHCP & specialist school placement. So much time wasted & both daughter & my health has deteriorated.	Yes	Listen to and believe parents who know their child best. Allow for diagnosis from parents referrals. At the moment school has to write a report in support of referral. Teachers have little to no specialist training on SEND, how on earth can they be adequate for being the authority on if a child has SEND or not? Full & comprehensive SEND training should be rolled out for all professionals that work directly with children. LA's should have an independent body carrying out EHCP assessments. How can an LA who's sole interest is to save their budgets, carry out a fair process? They turn down extortionate rates of EHCP applications which are overturned at a high cost at tribunal, all to delay the expense for another year's budget. All the while a vulnerable child is not getting the support they require, leading to a deterioration in their health, wellbeing & education.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	No wrap around care and shorter days than a mainstream school	Yes	The provision for wrap around care or more short breaks during holidays	Yes, but I didn't find the help I needed
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	No wraparound or holiday care they can access whatsoever	Yes	I work flexibly and part time already - disabled children should have equal access to wraparound and holiday care	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Not catering for sons needs and not understanding, therefore due to his send I have needed to reduce my hours from work to ensure I can try and help cater for my son as much as possible me	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Nothing was ever offered to us. School couldn't meet needs and no other school was available. It's being 18months	Yes	Even part time education would of being better than nothing.	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Our child was in school 1-2 hours a day, so someone has to be off work with him	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Permanent exclusion from school as they are not meeting need and also LA not finding a school. Year 1 child out of school for 2 months	Yes	Any provisions or tutoring for our son would support. Working reduced hours now, with a mortgage, bills and another child at school to support too	Yes, I visited the site, it was helpful
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Reduced timetable at school then could not attend meant I had to look after him in schools hours.	Yes	If he had a suitable school I'd be able to continue with the career I've worked hard for.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	School & local authority were slow to provide help, limited options, I am now fighting annual review!	Yes	Quicker response from council to actually meet their deadlines.	Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	School and council	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	School complete waste of space it's their way ir the highway	Yes	More educated staff	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	School did not recognize my child's difficulties before transitioning to high school	Yes	Schools hide children's needs as they don't have funds to help them	No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	school does not adhere to the EHCP. I had to battle to get the EHCP in the first place	Yes	Constantly battling for the basics outlined in EHCP	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	School not implementing professionals recommendations and need to apply for EhCP myself meant I couldnt deal with mental charge etc. Had to learn all SEN terms in English too, a new world, terminology etc.	Yes	Before anything else, to be believed and implement what professional reports recommended	Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	School reduced child's hours.	Yes		No, I didn't know I could get help

Yes	Male identifying	nothing has changed	I worry about money most of the time	Answer in more detail	School refused to change daughters nappies and said no teacher would do it, has to constantly pick child up from school no speech and language intervention.	Yes	Because they are not bothered about SEND children. Make EHCP fit for purpose instead of making up lies.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	School SENCO told me that in our county "we don't actually have EHCP's" and "there's no more money left in our pot for <child's name>" unbelievable but true.	Yes	They make us fight constantly for crumbs. If we fight 'too much' we are vaguely threatened with potential claims of munchausens etc.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	School Stopped doing part time timetable for school refuses as it affects their attendance figures	Yes	Any support from ANYONE would make a difference. When your child is given a diagnosis you are handed a brief letter A4 sheer of paper with a few website addresses on for support, which is unbelievable given your child has just been told they have a lifelong disability	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Son has been out of school 13 months. Still on roll at school. School are not able to meet his needs.	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Son has been unable to attend a school for the last 4 years	Yes	The right support and respite. Support	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Son has no school placement	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Son has not been able to attend school in a year. Local Authority rejected his ehcp and now on our way to second tribunal. Its been emotionally hard and couldn't cope doing so much	Yes	If we were listened to when it first started going wrong all of this could be avoided. We have spent thousands fighting for support, private assessments and appeals.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	Son was expelled in one school, aged 4 & then the 2nd school couldn't keep him safe. Now in his first educational setting (started just as he turned 9 years old in May 2023). Had his first full week in education the last week of the 2022/2023 summer term.	Yes	Local council or government as I couldn't have worked as he didn't have an educational setting.	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Spending so much time learning what rights I have and what I can advocate for them, as well as time on call when he won't speak to school staff/ can't attend and I have to have him home.	Yes	Budgets tend to go to the more obviously suffering and while I accept that it's hard to see my son mask at school as they can't/don't understand him which affects his mental health considerably.	Yes, I visited just to look around
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Stress	Yes	We have had the opposite of help. A lot of being ignored, resistance, lots of convoluted processes without taking our own additional needs into consideration	No, I didn't know I could get help
No	Male identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Struggle with wrap around care	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	The amount of time required to correct mistakes made by local authorities is almost a part time job on it's own sometimes. The more support you try and get the more appointments you end up with as well	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	The constant meetings, emails and phone calls meant that I couldn't work at a "normal" job. I now work with other parent carers which affords me more flexibility and more understanding because we are all in the same boat. The LA want you to work full time but also to be available at the drop of a hat for any meetings they decide is necessary	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Answer in more detail	The constant need to be ready to enter into battle is exhausting. The sheer amount of admin on top of actually looking after our children is huge. In entering into the tribunal process I quickly realised I would get no answers from the LA until the hearing - as it turned out they withdrew their objection to the provision (recommended by leading experts) at the final point possible in proceedings. We never found out what there case was - we can only assume it was purely trying to save money. I fear that the local authority will choose to go down this route again at the next transition point.	Yes	We need case workers who actually want and are allowed to provide support that will enable young people to reach their potential.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	The draft EHCP that was created was woefully inadequate and not specific enough to mean anything. I had to do my own research and create an entirely new version to ensure that the plan reflected my child's needs.	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	The intensity of hospital appointments and illnesses and sleep issues meant that having any kind of senior corporate role, even with a flexible employer, was impossible.	Yes	Access to respite care, clubs during holidays, anything!!! We get nothing. We can't even get incontinence wear which we have to pay for privately at £100 a month.	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	The L.A. delayed assessment, delayed their decision to issue, and is now delaying actually issuing the EHCP. In this period of time I am now full time carer to my child who has no educational provision, she is at home full time with me. I used to run my own business but cannot work at all. We applied for EHCP over a year ago, but one has still not been issued. Even when an EHCP is finally issued, my child is now so traumatised that she will not be able to return to a school environment.	Yes	The 'extra support' that is needed is mainly them following the law and timescales. And explaining what their jargon and processes actually mean! If they did this, many problems would have been avoided. There is also crack that children like mine fall into - too complex for Early Help support, but not complex enough for Children's Disability Services, so we have no support there either.	Yes, I visited just to look around
No	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	The process of accessing care is exhausting and is difficult to manage on top of caring for a child/children with SEN needs and disabilities.	Yes	It's so difficult to find the time to do the admin and the energy to get what your child needs. You cannot get help without an EHCP and it is so hard to attain an EHCP. We've been told by professionals that our child's need should justify one but they are so hard to get. School has flat out told us the council will not see our child as needing one and they won't support it due to lack of resources.	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	The school doesn't have sufficient funding to open on Friday afternoons and I do not have anyone qualified to take care of my SEND child.	Yes	The local authority needs to review their funding to ensure the school is funded properly as so many SEND children are missing out on vital provision and experienced staff at his SEND school are leaving due to lack of pay. This has been ongoing for the past 4 years with no sign of being corrected.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Answer in more detail	The stress of having to take time off to care for my daughter, stress of having to fight the LA made me sick. I had to give up my job. I'm now beyond broken, a shell of the person I used to be.	Yes	La make it so difficult to get help, mainstream schools are very reluctant to go down the EHCP route. You have to go it alone. There is so little support. Even the best employers get frustrated when you have to call off work again and again.	No, I didn't know I could get help

No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	There are few of any postions that offer flexibility to fit in with carers allowance. As a single parent alone it's a case of security	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	There are no afterschool provisions and childminders won't take him as they don't have the ratio	Yes	School is 9-3 I can only work during these times. Make wrap around provision available to ALL children	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	There is no wraparound childcare support for SEN children. This means I am only available to work from 9.30 till 2pm weekdays. I had to give up my nursing career as no nursing employer can accommodate these hours, which has affected my pension as well as our immediate family finances.	Yes	Term time contracts that fit round school hours, and access to childcare would enable me to work.	No, I didn't know I could get help
Yes	Male identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Time needed to take LA to Tribunal / now 3 times. Each time is long and drawn out and needs near full-time effort to coordinate all parties involved in our case, including lawyers and independent therapists.	Yes	It's all about money for the LA. We need to fund our Social Care budgets much better if we are to provide properly for the needs of our young people with additional SEND needs.	No, I didn't know I could get help
Yes	Male identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Time overhead	Yes		Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Total lack of help from LA, and the school were horrific. Their main concern was full time attendance at all costs no matter the impact on my child. He is no longer able to attend and I removed him to home educate.	Yes	My sons difficulties started being unmanageable for him in September 2022. Since then I have battled constantly to get support and still have nothing but a now useless EHCP. There is simply nothing.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Answer in more detail	Two children with EHCPs and no suitable school placement, meaning we have to care for them at home as well as advocate for and coordinate their SEN provision.	Yes	My employer was very supportive, but it still got to the stage where I was unable to continue in my professional management role, as I just couldn't commit the time. I am now self-employed, doing teaching and consultancy work, but cannot take on as much work as I would like, so money is always a worry! It would be so much more helpful if the council would do their job - helping to research suitable placements, arranging funding in a timely way etc. Instead, it falls to us to organise these things, and to chase the local authority every step of the way.	No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Answer in more detail	Unable to meet my child's care needs with the DLA	Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	Wasn't originally sign posted to any help, have struggled for years trying to work full time. It's taken until very recently for someone to advise we could be eligible for DLA which would help so much. I have struggled for 8 years to bring in money whilst looking after 3 send children	Yes	If my health visitor had listened to me when I first expressed my concern with my eldest who's now 8 she would already have a EHCP and support. But unfortunately everyone has passed the concerns to the next teacher.	Yes, I visited the site, it was helpful
Yes	Female identifying	changed your role?	I worry about money most of the time	Answer in more detail	We are having to home school our daughter while awaiting a tribunal, I therefore have to now work from home and this has resulted in me not getting valuable work experience to try and further my career	Yes	I would not have had to give up my role at a hospital	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Answer in more detail	We ended up with no suitable school place for our child so one of us had to stay at home.	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	We have the support of grandparents for childcare and are able to afford a lawyer which has meant that we have not yet had to dramatically change our work circumstances. However, our son is four and we are at the beginning of our journey so our work long term and finances are a concern.	Yes	We are paying privately for the therapies my son requires that are not currently being provided.	Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Won't accept him in after school clubs unlawful suspensions	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	We don't have money worries	Answer in more detail	Won't even come out and assess my child	Yes	I need someone to come and see my child in school... I have now also had to pay someone to help me as it all got too stressful for me alone !!	Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Working full time on a high powered demanding job as a single was impossible. Sleepless nights, fighting for correct services and schooling is constant.	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Answer in more detail	Working full time with a child with additional needs is exhausting so reduced hours to look after my own mental health	Yes	Holiday clubs for older children with SEN After school clubs at SEN settings.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Answer in more detail	Zero support from the council, constantly fighting for what my son needs. School have agreed he needs one to one TA or they can't meet his needs and council refusing to fund it.	Yes	To just be given what my son is entitled to would mean he's safe at school.	Yes, but I didn't find the help I needed
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Answer in more detail	Zero wrap around care for disabled kids and teens	Yes	Available and suitable child care and school holiday support	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?		Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	This affects our family finances in the long term	This doesn't apply to me		Yes	My son has been without education for almost an entire year. There are no provisions to support him during our application for his EHCP. Our local school have no understanding of SEN needs and for the first three months of his school attendance didn't even realise he had a diagnosis as no formal transfer had been put in place. After personally fighting all year for his EHCP we were placed in a school that isn't right for my son.	Yes, but I didn't find the help I needed
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me		Yes	Many schools are not supportive and LA'S will lie and break the law on a regular basis. Many family do not know enough to be able to fight them. My work was/is extremely supportive.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?		Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of support from school?		Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?		Yes	Putting alternative provision in place sooner. Listening to parents concerns. Understanding EBSA. Stop parent blaming.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	This doesn't apply to me		No		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?		Yes	Having to chase people. Constant meetings. Constant trying to phone people so they'd get thing done	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of support from local council?		Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of support from local council?		Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?		Yes		No, I didn't know I could get help

Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes	Would like advice on what I can do from professionals and people to listen to the problems we face rather than trying to give parents classes or blame something else other than the real problem	No, I didn't know I could get help
No	Female identifying	changed your role?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes	An EHCP would mean my son would be supported in school and I wouldn't have to pay external agencies	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	Flexible hours for child and myself Use different methods of teaching, making it person centered. Have staff in the LA, we have had no communication or support which has resulted in complaints	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes	I struggled to wfh with my Sen child, no option to work back in the office & couldn't take any more time off for appointments	No, I didn't know I could get help
No	Female identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of flexibility from employer?	No		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of flexibility from employer?	No		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	No		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?		Lack of support from local council?	No	Everything is such a fight and takes too long. I had no choice but to resign.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	No		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	No		Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	This doesn't apply to me	No		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	No		No, I didn't know I could get help
No	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	No		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	No		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	No	My wife has been impacted by all the work required by managing the EHCP but I have been able to keep my job and continue as usual.	No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affects our family finances in the long term	This doesn't apply to me	No		No, I didn't know I could get help
No	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	No		
No	I'd rather not say	nothing has changed	We don't have money worries	This doesn't apply to me	No		No, I didn't know I could get help
No	Male identifying	nothing has changed	We don't have money worries	This doesn't apply to me	No		No, I didn't know I could get help
Yes	Female identifying	changed your role?	I worry about money most of the time	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Lack of flexibility from employer?	Yes	Having to fight firstly for what is written in law for our children is ultimately the unjust topic here but to be working in a school - supporting other people's children with SEND and having your own head teacher/ employer in the very local authority you're trying to obtain correct support from being inflexible and unaccommodating when you're having to fight the very system your working in to support your own child? Where is the conscience in that... therefore I had to leave the industry- reduce my hours so I can better support my children ... my story isn't isolated I know ...	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	This affected family finances immediately	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes	I kept missing important appointments for my child	Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of flexibility from employer?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of flexibility from employer?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	We don't have money worries	Lack of flexibility from employer?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of flexibility from employer?	Yes	Just to know that my son with ASD, non verbal can get a place at a Sen school! The stress involved in trying to secure him a place is unbelievable.	Yes, I visited the site, it was helpful
Yes	Female identifying	changed your role?	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help

Yes	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes	Would give my child the 1:1 or access to a specialist school as mainstream education isn't the right choice for my ASD child.	No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	Respite, after school clubs for high care need SEND children	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	Children/Young people and families should not be left on long waiting lists with INACTION often for years, left to descend into chaos.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	There definitely needs to be more support for parent caregivers it's impossible to work .	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	My son has not been to school since last April when he turned 5. The council are refusing to give him a mainstream setting.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from local council?	Yes	The school has done everything they can to support but, without specialist advice into our daughter's specific situation, we are struggling to support her anxiety, behaviours and attendance.	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	nothing has changed	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes	More communication from the local authority in the fight for a SEN provision	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes	By providing suitable school placements, adequate alternative provision and social care support	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes	More fundings, 1:1 full time instead of half a day.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes	I would like to be supported by the council for not recognising my send family they say, theres services to help you but those services are against you and that needs to stop!.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	changed your role?	This affects our family finances in the long term	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
No	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
No	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed

Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from local council?	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	Listening to parents views Supporting children into the right provision.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	The LA just don't listen. In doing so they create a bigger problem for all parties, increasing needs and cost.	Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, I visited just to look around
No	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes	Having to chase local authorities to make sure all provision in the plan is delivered through education, health and social care. Having to do this and all the administrative tasks is a full time job in itself, it's left me with 2 long term health conditions and depressed, not a good way to live in a caring role that again isn't supported.	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
No	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
No	Female identifying	changed your role?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
No	Female identifying	changed your role?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Female identifying	changed your role?	This affected family finances immediately	Lack of support from school?	Yes	In fairness I was an emotional wreck cos school kept writing safeguarding referrals accusing me of FII	No, I didn't know I could get help	
No	Female identifying	changed your role?	This affects our family finances in the long term	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes	An understanding that SEND is real. It's a real thing. It happens. As a parents you don't want to be on this journey but here we are. Believe us. We know our children best.	No, I didn't know I could get help
No	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes	I'm self employed but no childcare setting local to me can support my daughter so I've had to stop working	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	Lack of support from school?	Yes	I have to be on hand throughout the school day to answer texts or phone calls to help my daughter navigate situations at school	No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
No	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	I worry about money most of the time	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	Yes		No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from school?	Yes	Perhaps if schools made it less of a battle, but also central government needs to recognise that Covid massively increased the number of children struggling	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes	School were refusing to train staff in the communication techniques that my son needs for his severe speech disorder. As such they cannot fully support him but refuse to say that they are not able to meet his needs. This training for them is free by the way. As a result he isn't in school. We sent a complaint to the local authority as we have tried to find a resolution with school, but they have threatened to prosecute us for non attendance instead.	Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from school?	Yes		Yes, I visited just to look around
No	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from school?	Yes		Yes, I visited just to look around

Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from school?	Yes		Yes, I visited just to look around
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of support from school?	Yes		Yes, I visited just to look around
No	Female identifying	nothing has changed	I worry about money most of the time	Lack of support from school?	Yes		Yes, I visited just to look around
No	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affects our family finances immediately	Lack of support from school?	Yes		Yes, I visited just to look around
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from school?	Yes		Yes, I visited just to look around
Yes	Female identifying	changed your role?	I worry about money most of the time	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
No	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	changed your role?	This affected family finances immediately	This doesn't apply to me	Yes		No, I didn't know I could get help
Yes	Female identifying	changed your role?	This affects our family finances in the long term	This doesn't apply to me	Yes	Not constantly threatening to suspended or exclude him. Actually implementing the provision in the EHCP	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?	This affected family finances immediately	This doesn't apply to me	Yes	Any actual support would be amazing. Try living on Carers allowance. Unable to work full time due to son being in and out of provision, medical appointments etc .	No, I didn't know I could get help
Yes	Female identifying	had to give up work completely?		This doesn't apply to me	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes		No, I didn't know I could get help
Yes	Female identifying	nothing has changed	This affects our family finances in the long term	This doesn't apply to me	Yes	It would be good to have some courses for parents with a SEND child at our local school	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes		No, I didn't know I could get help
No	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes	Autism outreach referral made but long waiting list. School can only do so much without funding.	No, I didn't know I could get help
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes	Local council has provided some support but we are having to finance some of our child's education ourselves (mainstream independent secondary school with EHCP). We didn't have the energy to fight for this through the legal route so accepted that we would pay for the school fees and the council pays the top up fees. This will put us under quite some financial strain but having reviewed the options open to us, we felt that the school we chose would best meet our child's needs.	No, I didn't know I could get help
No	Female identifying	nothing has changed		This doesn't apply to me	Yes	Not having to fight for the smallest support and having to jump through hoops to get anything put in place. Once a child has a diagnosis then they should be signposted and offered a needs assessment rather than leaving it too late to offer intervention or granting and EHCP at all.	No, I didn't know I could get help
Yes	Female identifying	nothing has changed		This doesn't apply to me	Yes	The delays for EP's are too long, delays to getting a draft and then final are too long leaning we spend hours chasing up people and often get no reply to our calls/ emails.	No, I didn't know I could get help
Yes	Female identifying	reduced your hours?	This affects our family finances in the long term	This doesn't apply to me	Yes	Better access to specialised support and clubs.	No, I didn't know I could get help
No	Female identifying	changed your role?	I worry about money most of the time	This doesn't apply to me	Yes	Key worker who has an in-depth understanding of our case, to help the time line speed up, and to stop us repeat the same info over and over again	Yes, but I didn't find the help I needed
No	Female identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes		Yes, but I didn't find the help I needed
Yes	Female identifying	changed your role?	I worry about money most of the time	This doesn't apply to me	Yes	I have had to increase my hours at work and take on a more senior role to help pay for the support my child needs as the EHCP as issued didn't include the support he was assessed as requiring in private reports. My child gets higher rate DLA and is awake a lot at night, so looking after them is intense. We are appealing the EHCP and have so far paid over £15,000 for private reports and legal advice. Taking on the extra hours is exhausting in the context of our child's needs and I cry every day.	Yes, I visited the site, it was helpful
No	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	reduced your hours?	This affected family finances immediately	This doesn't apply to me	Yes		Yes, I visited the site, it was helpful
Yes	Female identifying	nothing has changed			Yes	I haven't given up work but it's because my employer have been extremely flexible. I can work remotely and have worked from the back of my car etc	No, I didn't know I could get help
No	Female identifying				Yes	Clearer referral pathways for diagnosis and treatment both from the public and private sector. Realistic information on waiting times and the limitations of what services can provide. More information on accessing evidence based treatments	No, I didn't know I could get help
Yes	Female identifying	nothing has changed			Yes		Yes, but I didn't find the help I needed
No	Female identifying	nothing has changed			Yes		Yes, I visited just to look around
No	Male identifying	changed your role?	This affects our family finances in the long term	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
No	Male identifying	had to give up work completely?	I worry about money most of the time	Lack of flexibility from employer?	Yes		No, I didn't know I could get help
Yes	Male identifying	changed your role?	This affects our family finances in the long term	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Male identifying	had to give up work completely?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
No	Male identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Male identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		No, I didn't know I could get help
Yes	Male identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes	Within the first 2 years of my child having an EHCP we were in constant battle with school as they ignored EHCP. This was in a mainstream secondary academy.	Yes, but I didn't find the help I needed
Yes	Male identifying	changed your role?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited just to look around



Yes	Male identifying	reduced your hours?	I worry about money most of the time	Lack of support from local council?	Yes	Clear guidance on available support is non-existent in the local EHC framework it would be great to know what support can my child and family get and how	Yes, I visited the site, it was helpful
Yes	Male identifying	reduced your hours?	This affected family finances immediately	Lack of support from local council?	Yes		Yes, I visited the site, it was helpful
Yes	Male identifying	changed your role?	This affects our family finances in the long term	Lack of support from school?	Yes	Very slow transition to school for children. Still after a September start we are on staggered times. Makes work very difficult at times.	No, I didn't know I could get help
Yes	Male identifying	had to give up work completely?	This affected family finances immediately	Lack of support from school?	Yes		Yes, I visited the site, it was helpful
Yes	Male identifying	reduced your hours?	This affects our family finances in the long term	Lack of support from school?	Yes	It would have made a huge difference if my child could have gone to a small school, when he struggled in the huge mainstream environment. Trying to find the right provision for him took him out of education for over a year.	Yes, I visited the site, it was helpful
Yes	Male identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes		No, I didn't know I could get help
Yes	Male identifying	nothing has changed	I worry about money most of the time	This doesn't apply to me	Yes		No, I didn't know I could get help
Yes	Male identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes		No, I didn't know I could get help
No	Male identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes	more support from the school would help, but they have no money, and have said as much. the wave of SEND children seems to have totally surprised many institutions, and they are simply not equipped with skills or money to meet needs.	No, I didn't know I could get help
Yes	Male identifying	nothing has changed	We don't have money worries	This doesn't apply to me	Yes	We are fortunate in that my partner had not returned to work yet after our youngest started school. She had intended to by now but has yet been able to. Again we are fortunate that it is not a financial necessity for us, but she wants to and the impact on her mental health from not being able to is huge. Additional support from the LA rather than it being a year long fight would have been huge.	Yes, I visited the site, it was helpful
Yes	Female identifying	had to give up work completely?	This affects our family finances in the long term	Lack of flexibility from employer?		The right school setting that could meet need would	No, I didn't know I could get help