

# Report of experiences of parents with special-needs children across Cambridgeshire.

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**Brief overview:** A survey was carried out in Cambridgeshire to understand the experiences of parents of special-needs children/adults in the area. The intent of this is to raise awareness of these experiences and create positive change in Children's and Adults' services.

Our experience and the data collected from 106 parents highlights a deeply flawed and exhausting process, particularly within the education and social care systems. Key themes emerged showing widespread issues with transparency, poor communication, support, misuse of child protection/safeguarding, and use of coercive control. The mental and emotional toll on parents is significant, with many experiencing extreme stress, anxiety, and burnout. The system's ineffectiveness, coupled with fears of retaliation potentially affecting parents and children, leaves parents feeling powerless and victimised.

The complaints system appears completely flawed, used as a defensive tool to protect authorities rather than aiding parents and being an instrument for systematic improvement.

There is a clear need for systemic reform prioritizing transparency, adequate funding, co-production, and accessible support services. To truly support families and children with learning disabilities, the system must shift from a bureaucratic focus to one that genuinely prioritises the well-being and needs of those it serves.

It is understood that there are financial pressures on the LA and ICB, however it is not understood how this justifies spending money from the public purse in hiring social care staff and expensive legal representation to vilify parents and avoid providing the care needed by the most vulnerable in society.

## Acknowledgements

Thank you to the 106 parents that took the time to fill in the survey, enabling the report to be produced. Thank you to my dear friends Clare Lucignoli and Dr Alison Bishop for pushing me to put the survey out and encouraging me to write the report, and thank you to my husband and daughter, David and Serena for all your thoughts, unwavering support, and editing skills. I want to thank each of those friends and family members that held our hands over the last few years and supported us when we needed it most – I am not sure Rohan and I would be here today without each one of you. Above all, thank you Rohan for being my constant source of inspiration.

## Introduction

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*“Frankly I'm too scared to give this information.”*

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The purpose of the survey was to understand the experiences of parents of special-needs children/adults in Cambridgeshire, raise awareness, and use this information to create positive change in Children’s and Adults’ services.

This survey was live for a four-week period in September/October 2024, with 106 responses collected from parents. All data has been anonymised for GDPR purposes. The responses are mainly from parents of 0-25yrs old children, with a few parents of children older than this. For simplicity we use the term children, as the survey was completed by the parents.

Many of the charts are lifted straight from the google survey; others have been created based on the response to help analyse more qualitative data. We wanted to understand what the common experiences are across this group, in particular of using education services, social care/ LA (Cambridgeshire County Council), ICB (Cambridgeshire & Peterborough Integrated Care Board) and their complaints systems, and how it compares to our personal experiences. Each qualitative question received 4-5 pages of responses so I have included some anonymised direct quotes from respondents throughout the report in *blue italics*. These direct quotes may contain spelling and grammatical errors, I wanted to share these authentically – omitting just personal data, as they represent the themes found throughout the survey.

I wanted to bring to the reader’s attention, that many parents contacted me about my credentials before filling in this survey. They asked how their data was going to be used as they were afraid of being identified and consequently targeted by service providers. No one filled the form in until I was able to reassure them of their anonymity.

I was also very tentative about putting the survey out and writing this report due to poor past experiences with LA/ ICB. I was initially afraid this could be used in a negative way against our family. I do, however, consider it is more important to raise awareness, and trust the services will take this information with my good intentions in mind.

## Section 1 – Information about parents

A number of questions were asked to ascertain who the respondents were, and their demographic information. **89% of responders identified as being female and 11% male.**

Equality Do you consider yourself to have a protected characteristic under the Equalities Act?  
105 responses

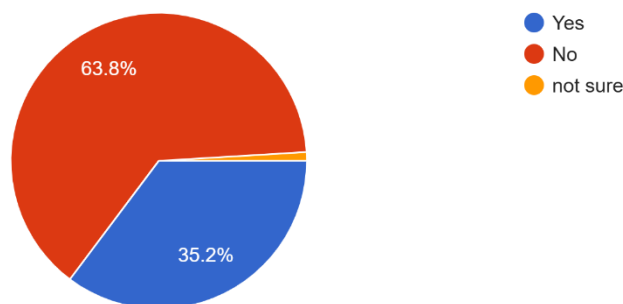


Fig. 1 – Pie Chart displaying proportion of people with protected characteristics under Equality act.

Fig. 1 shows 35% (37/105) respondents believe they have protected characteristics under the Equalities Act. Many examples are given by parents of authorities/professionals not making reasonable adjustments, from simple requests to enlarge fonts for the partially sighted, to parents' and children's needs not being asked about or considered in the process.

**Respondents report that systems involved in their child's assessments felt inaccessible, overwhelming, ambiguous, they felt belittled or ignored, and many mentioned feeling bullied and threatened by the process.**

*"I've never been asked by any professional if I have a protected characteristic."*

*"The whole process is ambiguous and difficult to follow. Our SEN Caseworker only ever communicated via email, it was impossible to reach her by phone. We were given misinformation and sometimes lied to."*

*"We were belittled overridden at every stage"*

*"No adjustments made at all. Just used for their gain"*

*"I have felt very alone and overwhelmed every step of the way"*

*"As a parent I was ignored regarding my child. I was informed we know better however I am the one living with the child and trying to help them."*

*"Care planning, such as it is, has been very sporadic and only at our instigation. Our needs as carers have been disregarded in our daughter's care planning - our increasing disabilities are not taken into account in her care planning by rule and policy"*

## Respondents were asked if supporting their child has negatively impacted their health?

Fig. 2 shows **84% (87/104 respondents) say yes.**

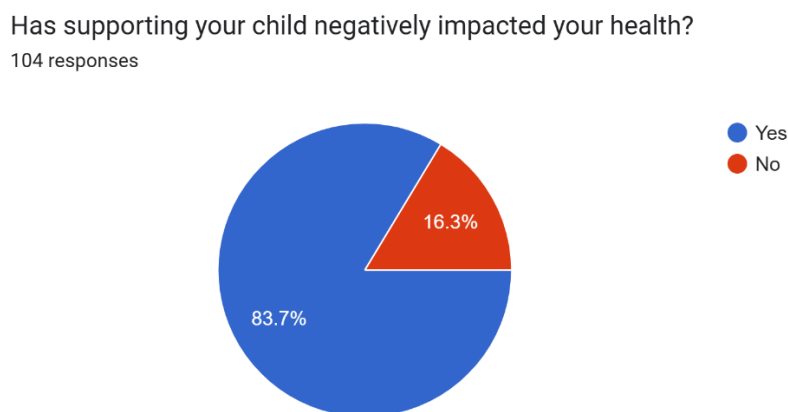


Fig. 2 – Pie chart to show the proportion of people whose health has been negatively impacted as a consequence of supporting their child with special needs.

It must be noted that the majority of these parents are essentially unpaid care workers dealing with extremely stressful jobs, often suffering injuries due to insufficient support, lack of sleep, and added financial stress due to not being able to work normal hours. Many parents have reported having to leave work to take care of their children's complex needs, or due to the impact on their own health. This is not helped by interaction with Local Authority: for the vast majority of this group, respondents reported this has worsened their health and wellbeing.

According to a survey by UNICEF UK<sup>1</sup>, 59% of parents with young children in Britain reported struggling with their mental health. Our respondents' score was 28% higher, with a range of children from 0-35yrs. On an age comparison we would expect it to be lower than 59%.

Figures from a CIPD survey<sup>2</sup> of workers in UK suggest between 20% and 30% of respondents reported negatively on some major aspects of work. Our figure of 84% is around three times higher

It can be concluded that negative impact to health of the respondents is proportionally higher than negative responses from both average working population, and parents of young children in the UK.

Many parents mentioned that they had asked for carers assessments. Either this was ignored, or no change was made to care provision, which only added to their stress levels.

*"I have never had a carers assessment in 18 years of being in ccc even though my complaint was upheld I should have one. They have mainly been hostile to me and certainly not in keeping with most laws!"*

There were a range of issues identified in supplementary explanations, and it is noted how many times the following conditions are mentioned: mental health problems, stress and anxiety,

<sup>1</sup> Report from UNICEF UK regarding the mental health of parents of young children.

<sup>2</sup> Good Work Index 2023 shows that people are less engaged, less fulfilled, and more stressed in their working life



*“Has caused mental health issues, depression, 2 x bulging discs, severe osteoarthritis in hands, knees, back. High levels of long term stress and trauma. IBS, Gastritis”.*

*“Supporting my child is a full time job. Not just supporting his mental health and as a carer but the forms, the meetings, the amount of admin caused by lack of support from the LA and NHS. I spend every day correcting the wrongs made by professionals. It’s a full time job. I have had to give up work. It has had a negative impact in my mental health and my other children.”*

*“Yes, but only since involvement of LA due to the amount of stress caused to us. I have been struggling to meet my child’s needs. My physical and mental health has suffered significantly due to what they have done to us.”*

*“I have panic attacks at work and had to go part time because of this which is financially crippled us. And carers allowance doesn’t cover the loss of earnings”*

*“Me and my child had an accident on the stairs where it caused permanent damage to my spine. Also due to no fault of his own the lack of support have made me feel isolated, anxious and depressed.”*

*“The time spent battling has impacted my mental health and supervision when I had to work, it has impacted my partner’s physical health too.”*

*“Periods of depression and stress. Also not being able to continue in my career means less income, fewer social interactions and less self worth. It’s a negative spiral which you can see no end to.”*

*“I have stress induced heart arrhythmia, PTSD, memory loss from sleep deprivation”*

*“Physical - I’m in pain, can’t exercise . Mental - isolation, stress, worry”*

Clearly, the trauma that 84% of these Cambridgeshire parents have experienced is not unique, and unfortunately it is primarily a consequence of the system’s design. This is documented and supported by work Professor Luke Clements of Leeds University has led about ‘System Generated Trauma’. Dr Peter Baker of the Tizard Centre, and the Challenging Behaviour Foundation, were commissioned by NHS England to write the report *Broken*<sup>5</sup>. They very helpfully made a 12 min video<sup>6</sup> to summarise their research. In this video, they discuss how the system generates trauma for parents, and how, instead of just patching up carers with counselling, the system needs to be changed to prevent this trauma in the first place.

Clements led a conference in Leeds in July 2024 titled ‘Building practical solutions for traumatised families’<sup>7</sup>. Cambridgeshire County Council and the C&P ICB were informed about this research many months ago. The ICB are now working with some parents to create a casework team that will support the families who are moving over to the ICB shortly. Despite our repeated attempts we have had very limited engagement from CCC.

**It is clear 84% of the respondents are suffering both physical and mental trauma that has impacted their long-term health as a result of the system design.**

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<sup>5</sup> [Broken CBF final report Dr Peter Baker, CBF](#)

<sup>6</sup> [Family Trauma: A Broken Care System - Cerebra short video](#)

<sup>7</sup> [Building practical solutions for traumatised families - Cerebra, link to website regarding conference in July 2024.](#)

## Section 2- Information about children

**Our sample of children were 60% Male, 40% Female.** This male dominance is representative of the national figures: boys make up 64-66% accessing SEN support in English schools<sup>8</sup>.

Does your child have a special educational need or disability?

106 responses

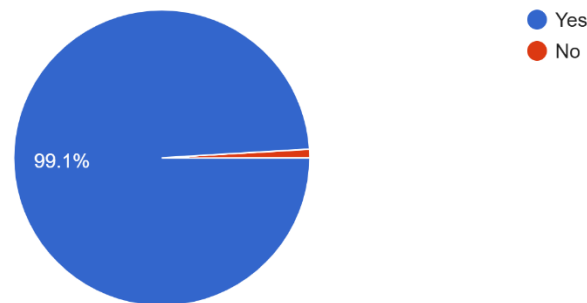


Fig. 4 – Proportion of respondents with children with an educational need or disability

If yes, do they have an EHCP?

106 responses

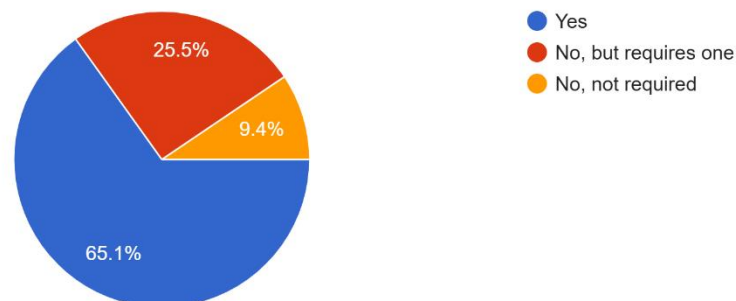


Fig. 5 – Proportion of people with or without an Educational Health Care plan (EHCP)

**As expected, the population who responded to this survey have a high proportion of pupils who have or need EHCPs.**

**Overall, however, Cambridgeshire has a lower proportion of EHCPs vs the national average. As of January 2024<sup>9</sup> 3.5% of pupils in Cambridgeshire have an EHCP compared to 4.8% of pupils in England.**

<sup>8</sup> [Girls less likely to be diagnosed with special educational needs – new research - Durham University](#)

<sup>9</sup> [Special educational needs in England, Academic year 2023/24 - Explore education statistics - GOV.UK](#)



Respondents were asked to list labels relevant to their children, including long-term physical health conditions.

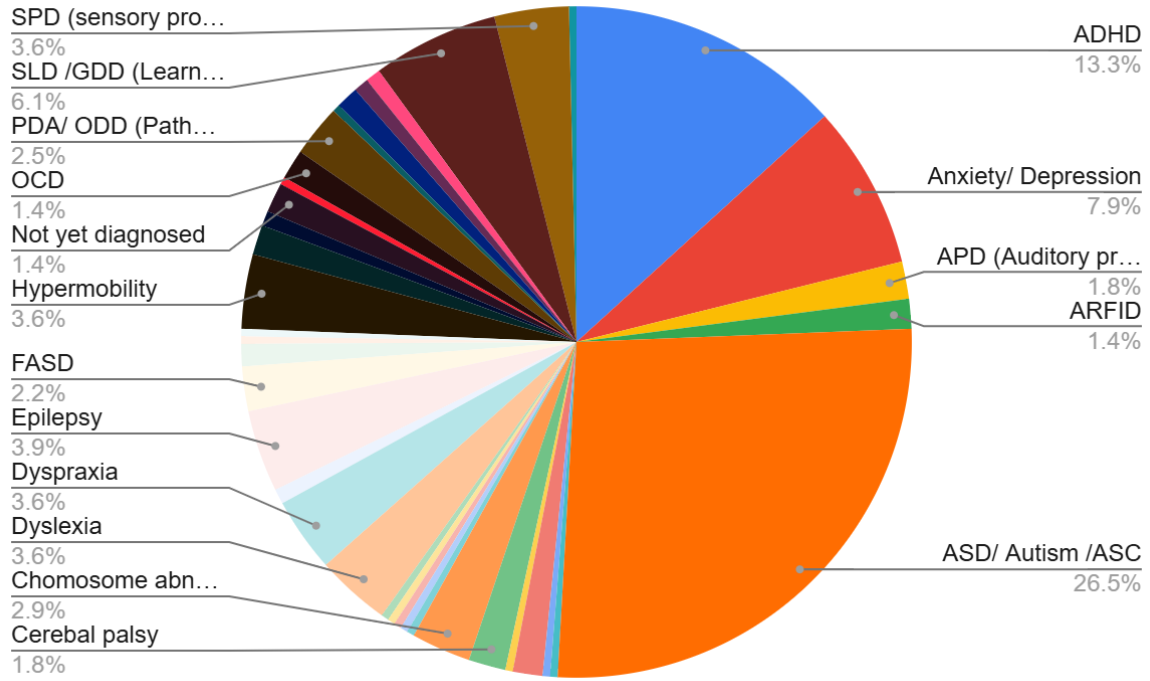


Fig. 6 – Range and prevalence of diagnosis

### Number of children vs. Number of diagnosis

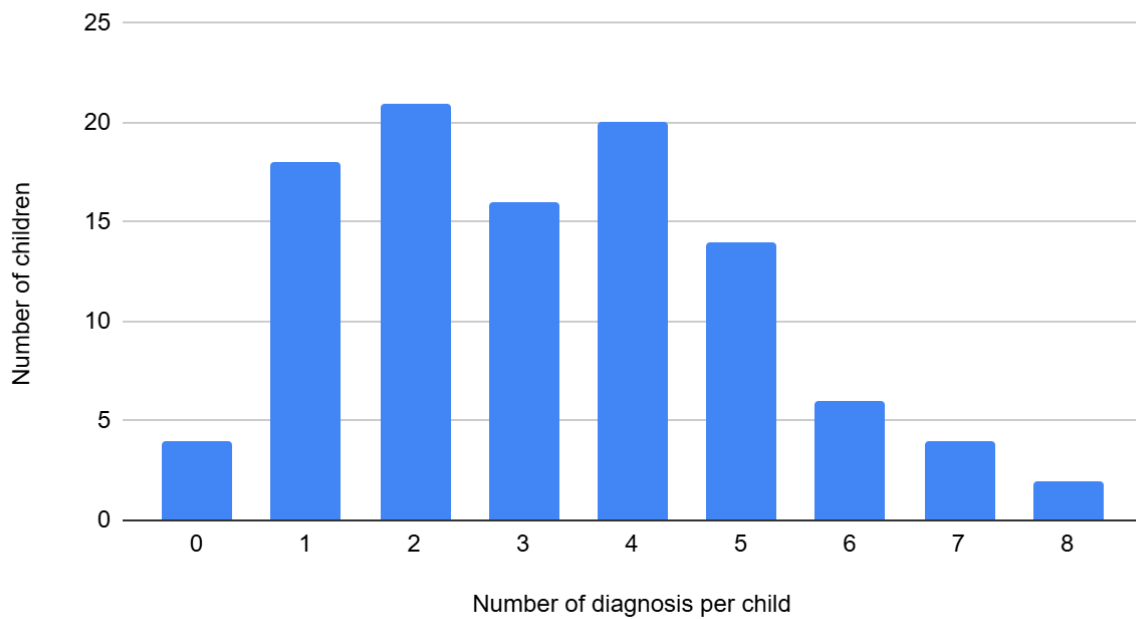


Fig. 7 – How many diagnostic labels each person has



Many children have complex multiple diagnoses. Figs. 6 and 7 demonstrate the complexity of the children in this survey, some having up to eight identified diagnostic labels.

A number of parents commented how hard it was to receive a diagnosis and then get the support required. It appears from this survey that it is the children/parents with the most complex needs who are not being understood and supported by the authorities.

### Who does your child get funded support from?

Please tick all that apply. Does your child get support/ funding in Cambridgeshire from:

80 responses

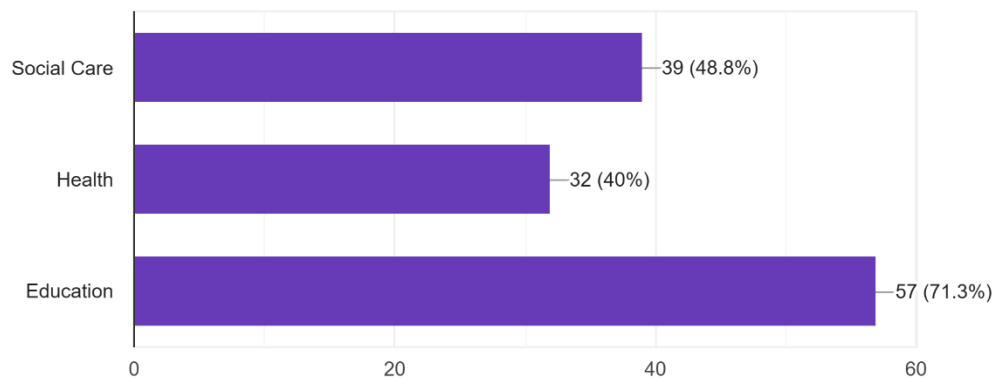


Fig. 8 – Chart to demonstrate where each child receives funding from.

Fig. 8 represents responses from 80/106 respondents, this leaves 25% of the respondents with no support. The remaining 75% have one or a mix of support. Responses in Fig 6&7 suggest there are a lot of young people in Cambridgeshire with complex health and education needs who are likely to need multiagency support. However, Fig 8 suggests only half this group have support from one or more agency. The high level of stress experienced by parents can be correlated with complexity of needs, and suggests a lack of Education, Health, and Social Care support.

### Residence

Residence - Does your child live

106 responses

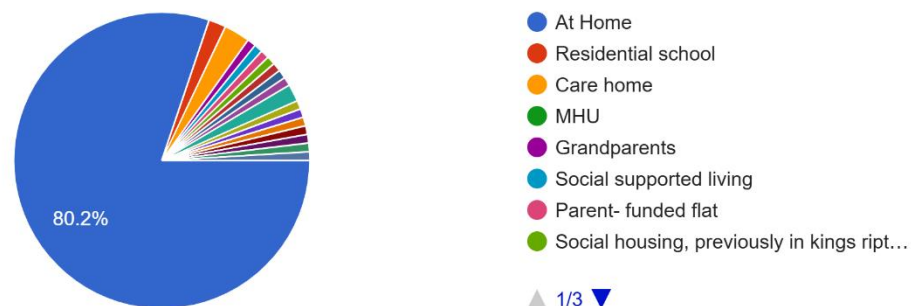


Fig. 9 – Pie chart to show residence of respondents' children.

The majority of respondents reported their children live with them at home. The remaining 20% live in residential homes/schools, Mental Health Units (MHUs), social housing or in their own home with support.

I asked of those 20% of parents if they wanted their children back home. The theme of the answers was that there was not enough support offered for children to safely remain at or return home, so parents were left with no other option as their health was failing. One parent shared they had to make their child homeless in order to get support she needed. Others couldn't find schooling in their locality. There were also parents who said they were thinking of trying to move care back home as the quality of care provided in supported living was so poor.

## Questioning if level of support provided meets needs?

Support - is the correct support in place? (Lack of support and/or support in place being inadequate includes but is not limited to: poor staf... risk or problem based rather than strengths based)

105 responses

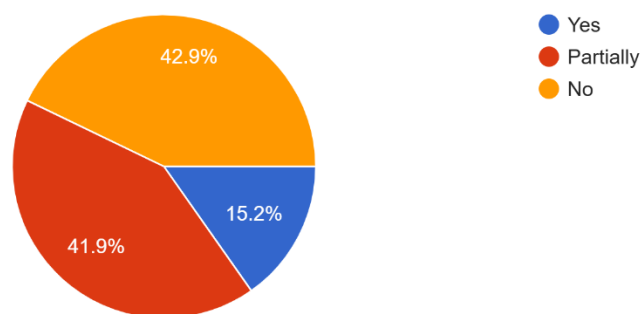


Fig. 10 – Respondents' opinion on if needs of their children are being met.

Fig. 10, shows that 84% of respondents don't think they received the right level of support for their child. They shared a number of reasons why they didn't have the right care and the impact that the lack of support has had on them and their families. These have been summarised below.

**Emotional and mental abuse by Social Workers:** Reports of parents feeling bullied, victimised, and emotionally and mentally abused by social workers. Parents also face false allegations, gaslighting and a lack of personal budgets or support to recruit carers. There are instances of care staff emotionally abusing children, with no action taken against the perpetrators by social workers. These systemic failures are leading to trauma.

*"I feel victimised by social care when asking for help . I feel bullied by them and that they don't actually listen. As my son is now an adult I have no say in his care and have been emotionally and mentally abused by the social worker. Nobody communicates and I end up doing the jobs of others".*

**Neglect by Social Services:** Families feel neglected by social services, with reports of inadequate support, poor communication, and lack of follow-through on care plans. Some children have been placed in inappropriate settings, such as nursing homes, where needs cannot be met. This neglect from Social Care (SC) leads to serious harm and requires costly intervention from higher authorities e.g. Court of Protection (CoP).

This neglect forces families to provide a high proportion of the care necessary, leading to severe caregiver burnout without support. Furthermore, poor Direct Payment payrates mean parents cannot recruit carers directly. Families are left to navigate support and care systems with little guidance or help.

*“Refusal of carers assessment, no support over the years which amounted to child protection happening and all sorts of allegations which weren’t true like I was hiding my child or FII type allegations. No personal budgets. No support in any way.”*

**Inadequate training and support of agency carers:** Poorly trained staff and high turnover rates lead to inconsistent and inadequate care. Some staff members lack the necessary skills and English to manage medical conditions or behavioural issues, resulting in dangerous situations.

*“Lack of support, lack of staff, poor staff training all of the following as described (Lack of support and/or support in place being inadequate includes but is not limited to: poor staff training, lack of staff, poor staff communication, inappropriate housing, lack of activities, poor risk assessment/care planning, care risk or problem based rather than strengths based).”*

**Lack of proper oversight and accountability:** Agencies and social services often fail to provide sufficient care plans and supervise and manage care workers properly. This leads to poor care quality, with families left to manage and train staff themselves. Inadequate monitoring of care plans and transitions, results in poor implementation and significant gaps in support. Families feel ignored, and end up doing the jobs of Social Care staff.

*“Several agencies involved that do not work together nor communicate with each other. Inadequately trained staff arrive who cannot meet my child’s needs. Some don’t know how to manage seizures and one even didn’t give my child their epilepsy medication. My child’s communication difficulties and learning disability mean that they cannot comment on any aspect of their care. This is so incredibly dangerous. Workers are sent in at short notice who do not know how to support the cared for family member to communicate and they can also be poor housekeepers and keep poor records. Poor language skills of the workers - and they are working with someone whose most serious problem is communication. Almost no supervision of the workers by their agencies who rely on reports on their in-house Apps sent by the workers on their mobile phones. No handovers, no team, no team meetings, no key worker, agencies have no in house professional who can help e.g. with behaviour or communication.”*

**Education issues:** Many parents face challenges in obtaining EHCPs due to lack of evidence or school cooperation, resulting in inadequate support for children with complex needs, with some not attending school for extended periods. Children experience long absences from school, inadequate support plans (EHCPs) not being implemented, and a lack of appropriate school placements. Some children are pushed into home education due to the system’s shortcomings. The LA fail to address urgent schooling issues, support for Speech and Language Therapy (SALT), and Occupational Therapy (OT). Long waits for assessments and lack of appropriate educational placements contribute to the trauma parents and children experience.

*“My son hadn’t been at school for over a year now. The LA should be sorting out the school issue or providing alternative provision as per the law. Haven’t managed to speak to them once.”*

*“Once got EHCP I have still had to fight to get support within school”.*

**Health services:** Respondents identify a lack of oversight from community paediatricians for complex medical needs; poor mental health support and insufficient services post-adoption; and intermittent and insufficient access to physiotherapy, Speech and Language Therapy, and mental health support. Families often turn to private care and assessments due to long NHS wait times.

**Mental health and emotional wellbeing:** Experiences include minimal support from Child and Adolescent Mental Health Services (CAMHS) and not enough one-to-one mental health support available. Challenges include self-harm and aggression by and from children, with families feeling alone and at breaking point. Children face emotionally-based school avoidance and disengagement from learning due to insufficient support and long waits for assessments. The system's inability to provide timely and appropriate support has led to significant stress, trauma, and feelings of neglect.

*“Special school place has failed, CAMHS only appear to offer medication, no trauma support, social care give respite funding but nowhere or help to spend it.”*

**Employment and Independence:** Struggles with transitioning into employment, lack of support, and resulting issues like homelessness.

**Impact on Families:** Significant stress and physical symptoms in parents due to lack of consistent support and communication. Inadequate services causing anxiety and meltdowns in children. Understaffing leads to insufficient care hours. Parents providing 24/7 care seek emergency backup and more mental health support.

**This analysis highlights the severe impact of abuse and neglect within the care, education and support systems, leading to significant trauma and stress for families.**

Questioning if you have needed more support, have you asked for it? If not, please explain why?

75 responses in total

**Yes, 51 responses have asked for additional support and have experienced the following:**

- **Frequent requests:** Many have asked for help repeatedly and not received any, resulting in feelings of being ignored. Long waits for panel decisions while in crisis.
- **Fear of retaliation:** Requests have sometimes resulted in threats of placing children in care homes. Many mentions of 'fear' and 'afraid' in the responses.
- **Fear and trauma:** Some parents have asked for help in the past but are now afraid to due to negative experiences with Social Services.
- **Lack of services available:** Shortage of safe care workers, parents not informed of services that could be available, oversubscribed services, lack of capacity to even respond.
- **Interventions:** A number of requests for additional support, like OT referrals, wheelchair services, and summer clubs have not been met, leading to more stress for parents.
- **Complaints:** Parents have raised complaints but faced inaction or inadequate responses.
- **Lack of Accountability:** Authorities fail to take responsibility or provide adequate follow-up on requests for care and on complaints.
- **Impact on Families:** Continuous stress and burnout due to insufficient support and constant fighting.

*“Yes I begged for help to get no help at all was left on my own”*

*“Yes, but I have been very brow beaten and afraid if I ask too clearly that they will move my child many miles away into an institutional setting. I am only now realising how I have been "holding my breath" for many years, frozen and traumatised by previous experiences of what happened when I tried to get adequate social care support for my child.”*

*“Afraid of social services”*

**No, 24 respondents didn't ask for the care for the following reasons:**

- **Lack of knowledge:** Some parents don't know who to ask for help.
- **Fear of negative consequences:** Fear that asking for help will lead to their child being taken away, through use of parent blame and gaslighting among many mechanisms.
- **Systemic Issues:** Structural issues and lack of capacity within social services prevent timely support.
- **No Responses:** No replies or actions from agencies when help is requested.

*“I've given up now because it just becomes parent blaming. I'm now paying for private therapy for my children. I recently asked for access to the ASF (adoption support fund) but this was denied and evidently that's also my fault. I've used the LGO complaints system and 7 complaints were upheld yet they still manage to gaslight me?! No accountability for correcting mistakes and putting them right. Too much ignorance and arrogance from certain managers. Lack of accountability and inability to listen to children and parents.”*

**Overall, the data reveals that while many parents have sought help, they are often met with inadequate responses or ignored, leading to significant stress and trauma.**

Where parents have not sought help, fear appears to be a significant barrier for many families in seeking the support they need. This is also documented nationally by Clements.<sup>10</sup>

A paper was written by Carol Anderson Chief Nurse of C&P ICB, *Supporting good health outcomes for people with learning disabilities*<sup>11</sup>. Anderson explores LeDeR (Learning from Lives and Deaths) and risks to our young people, and the concept of how important it is to have the right support for that young person at the right time, delivered by the right person.

There are many interventions and approaches mentioned in this report. Some are in place and others are proposed to achieve this holistic approach within the next two years. As far as I am aware this is only proposed for young people with Learning Disabilities (LD) who have 100% CHC (Continuing Health Care) funding or those that are receiving a combination of LA and ICB funding. It is not clear at this time that if CCC are interested in participating in this approach in non CHC cases.

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<sup>10</sup> Luke Clements' presentation template for lecture on Institutionalising Parent Blame.

<sup>11</sup> *Supporting Good Health Outcomes for People with Learning Disabilities* is a paper written by Carol Anderson. Presented to Adults and health committee to present information on transformation forward plan for service for people with LD.

The ICB will have oversight of their cases being managed by CCC, however it is not clear how well this will be managed.

From Fig. 10 only 15% of the respondents believe the right support is in place for their children. It is clear from Fig. 7 and Fig. 8 that these children are complex, and this survey suggests 85% are being failed by the current system in place. While the ICB appear to have a plan to create some change, we are not yet clear how this is being addressed by CCC.

*“Yes, I have constantly contacted the young adult team for support I put in a complaint some months ago about lack of support and I’ve had to raise the issue yet again as it is impacting on my health and my childs”.*

*“Yes, I have asked for more support but social care have not had the capacity to respond. They will only action support if there is a crisis. This is down to lack of capacity and resources.”*

*“Lack of people, confusing structures, people say have to wait for panel, but we are in crisis now.”*

*“He could do so much more if he/we had some help”*

*“I have asked for more support but no-one has come back to me yet. If you do ask for more support, you are threatened with nursing or care homes for your child, which is not an option.”*

## Section 3 - Organisations and Professionals

The respondents were asked if they have raised concerns about the following organisations:

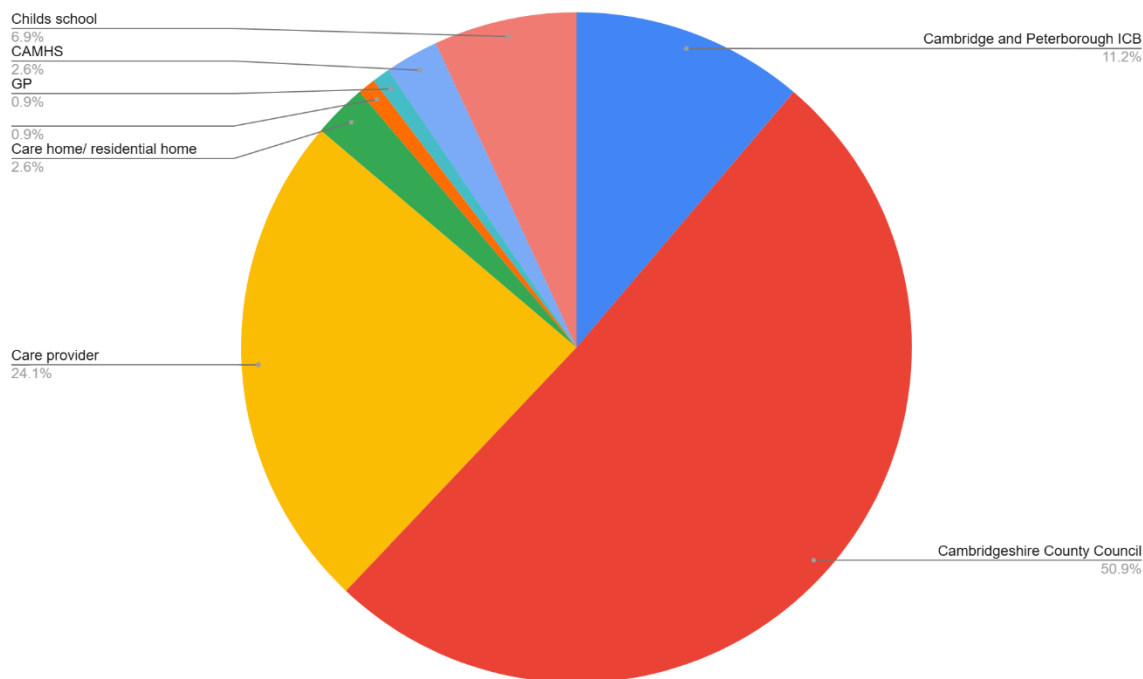


Fig. 11 – 34/104 respondents did not raise concerns. 70/104 respondents did raise concerns about one or more of the above. This pie chart represents 70 respondents’ feedback, sharing concerns raised about organisations.

The largest number of concerns (51%) are regarding CCC, followed by Care Providers at 24%, (if we include residential homes and schools under the category of Care Providers this figure would significantly increase), and then by C&P ICB at 11%.

Currently the LA manage many ICB cases, as ICB does not have the framework to case-manage children and young people under 18, and those with shared packages of care. There is a Section 75 agreement in place to enable this arrangement, whereby the ICB give the LA responsibility and funding to arrange care for those above 18 years old with Learning Disabilities. This arrangement was set up around twenty years ago and is set to end in Spring 2025, as the LA have given notice on this arrangement for adults with LDs. These cases will be moving over to the ICB, for them to directly case-manage. Children under 18 with a LD will remain with the LA regardless of their health needs, as far as I am aware.

It is also useful to note the Care Providers are mostly commissioned by LA and ICB directly. Very few parents use these services through private means and Direct Payments (DP) or Personal Health Budget (PHB). While these are regulated by CQC (Care Quality Commission), most have regular contact and audits from both LA/ICB. It should also be noted even when parents use DP/ PHB, LA/ICB have a very heavy hand in steering how, when and what they are used for.

“100% failed, gaslit and trauma caused by school and LA”



The survey then asked which professionals respondents have concerns about?

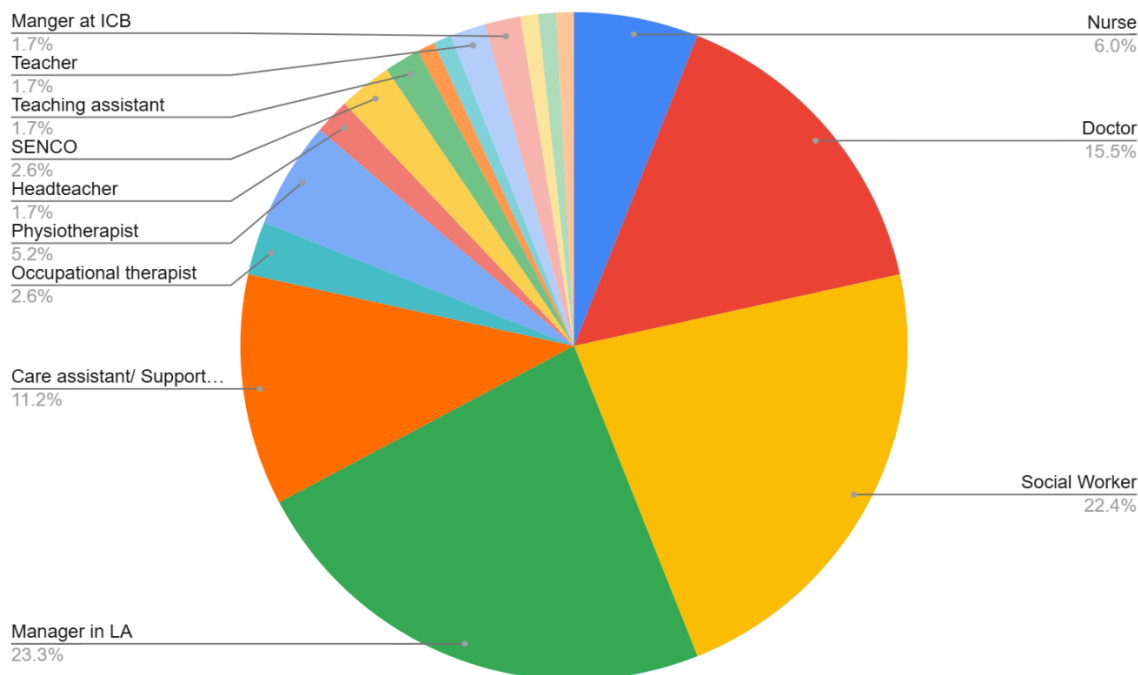


Fig. 12 – 46/102 respondents did not raise concerns. 58/102 respondents did raise concerns about one or more of the above. This pie chart represents concerns raised by 58 parents about professionals involved in their children’s care.

LA managers and social workers make up the bulk of these concerns (45.7%). In previous questions in this report, respondents have mentioned words such as “abuse”, “neglect”, “threatening”, “afraid”, “stress”, and “trauma” related to their interactions with authorities, in particular social-work staff. However, it is not understood why abusive tactics are used with these very vulnerable families.

**From the widespread lived experience of families, it is not unreasonable to assume that these abusive methods of dealing with parents have become normalised throughout the LA/ICB. My view is this current system is broken and leads to nothing but expensive legal battles and poor health outcomes for individuals and families.**

*“My child was abused with by their care worker and the service provider and social work team failed to refer this. I have had to deal a court order being sent to my child (who lacks capacity) due to incompetency of the SW team manager and debt departments within the LA and the experienced gas lighting when trying to fix their own error. I have experienced poor professional practice from inexperienced SW seemingly encouraged by her team manager. When highlighted they swapped worker instead of addressing the poor professional practice. I have had to deal with poor service delivery instead of SW doing their job and challenging this. I believe the LA young adults team does more harm than good and have fed this back clearly to senior managers who ignore. I have contacted the CEO regarding concerns who ignored my concerns- it’s not surprising that his subordinates are so unprofessional if he shows a complete lack of interest in the corruption going on within the LA.”*

Have you, your family or your child experienced any of the following as a result of your child’s needs, or the way their needs have been met/ not met? Agency refers to LA/ICB/Professionals/Care Agency.

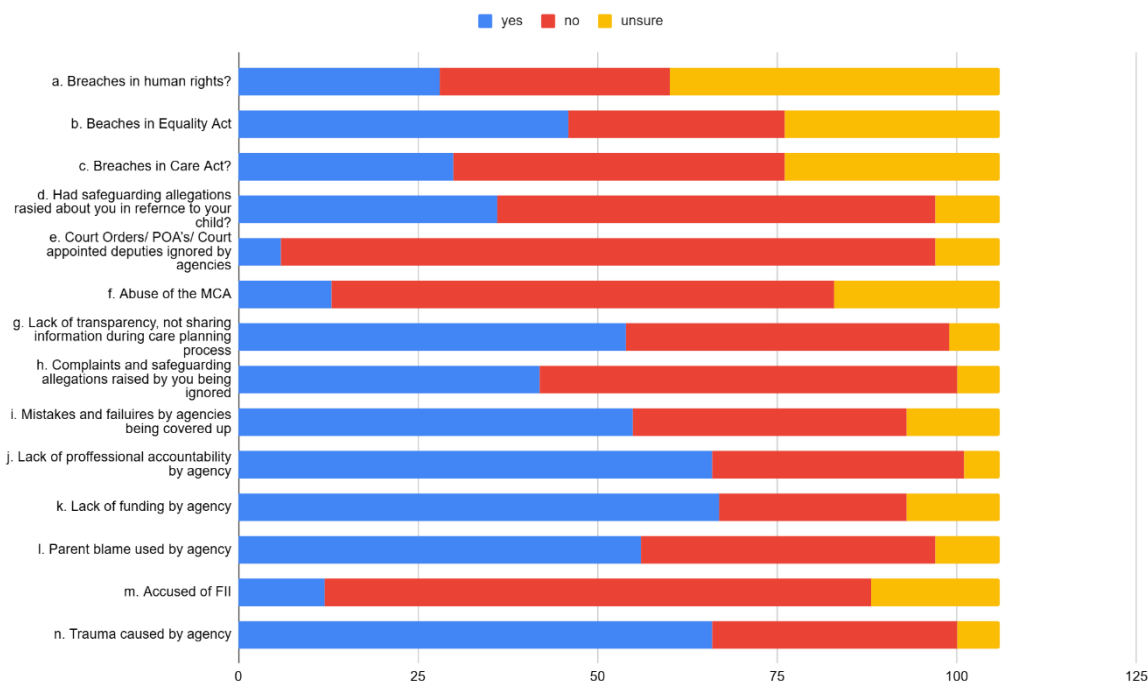


Fig. 13 – Experiences of parents with Local authority, ICB, care providers and professionals involved in their childrens’ care. (note regarding integrity of results - Questions m and n on didn’t go on until after two people had added their responses so I added 2 unsure on both questions. This makes virtually no statistical difference to the end results)

From Fig. 13, the top six experiences that 50 or more respondents marked ‘yes’ were: lack of funding, parent blame used by agency, trauma caused by agency, lack of transparency and accountability, and mistakes made by agencies and covered up.

**From these experiences there appears to be a culture of blaming parents and covering up each other's mistakes and wrong-doings, perhaps in order to save money.**

The parents were asked to elaborate answers if yes or unsure. There were 53 responses (50% of total) who cited examples of the following...

- **Lack of transparency and communication:** Repeated issues with withheld information, lack of transparency in processes, and failure to return calls or emails.
- **Inadequate and delayed support:** Long waits for assessments and support, underfunded services, and poor management of care providers.
- **Parental frustration and helplessness:** Parents feeling powerless, blamed, and gaslighted, leading to significant stress, anxiety, and burnout.
- **Systemic corruption and mismanagement:** Descriptions of the system as corrupt, mismanaged, and prioritising bureaucracy over actual care.
- **Trauma and emotional impact:** Extensive trauma experienced by families due to systemic failures, including inappropriate sectioning, inadequate support in education, and mental

health struggles. One parent said they were too afraid to even give the survey the information.

- **Legal and ethical violations:** Breaches of mental health acts, data protection laws, and concerns over potential malpractice.
- **Negative impact on children:** Children witnessing and experiencing trauma, poor educational support, and mental health issues as a result of systemic failures.
- **Misallocation of resources:** Funding being spent on legal fees and bureaucracy instead of training and support.
- **Lack of parent training:** Many people were not sure what MCA was and they may not all be aware what their human rights are and what the Care Act contains.

*“CAMHS were truly awful to work with, it took four referrals to get support from them. Repeated parent blaming and gaslighted. My experience with CAMHS was truly traumatic. Since moving to our current school provision 2 years ago we have had zero contact from our caseworker, they have not attended or responded to EHCP reviews. Due to school stress and school anxiety we have gone back onto a transitional, part time timetable. I feel the placement is close to failing. Zero interest from caseworker.”*

*“Breach of mental health act Breach of data protection legislation twice.”*

*“My physical and mental health has suffered significantly when inadequate/inappropriate agencies have looked after my child.”*

*“Totally unfit for purpose. They waste money on anything but support. Waste time covering backs and setting up decent good families who have adopted complex youngsters with disabilities from the care system. It is not fit for purpose. Our life has been destroyed by a totally abhorrent system.”*

*“They sent me to parenting classes twice before my daughter was diagnosed because they said it was me.”*

*“Needs have not been met causing deterioration of mental health in young person and carer.”*

*“Mostly it has been a matter of a total lack of communication. Staff turnover meant that there can be little to no continuity of care.”*

*“Unsure due to the scope of the Acts and I don’t understand what MCA is, as well as the scope of some of the statements. Schools have not been transparent and some have failed to disclose information about my child.”*

**This quantitative and qualitative assessment paints a stark picture of a failing system that significantly impacts both children and their families.**

## Have you used the LA/ICB complaints process? 33.3% said they had put a complaint in to LA or ICB.

### *If yes did it resolve your issue?*

There were **16% (6/37)** respondents that said **yes**, or **partial resolution was achieved**:

- **Resolved issues:** Occasional resolution of issues, documents released, increased budget, and some compensation received.
- **Increased attention:** Complaints leading to faster responses and increased attention to the child's needs.

**84% (31/37)** respondents said the **complaints process did NOT help** resolve the issues for the following reasons:

- **Inadequate responses:** Complaints often processed by those responsible for the issues, leading to no resolution. Response often very defensive.
- **Ongoing problems:** Continued failings and no solutions provided due to lack of resources.
- **Systemic failures:** System viewed as corrupt, unfit for purpose, and damaging, with no accountability.
- **Parental fear:** Fear of retaliation when making complaints, leading to a lack of trust in the system.

**In summary, while there are occasional instances of issues being resolved, the overarching sentiment is one of frustration, systemic failure, and a lack of accountability, with both parents and children experiencing significant emotional and psychological trauma.**

## If the complaints process was not used, what was their reason for not using it?

The data here is from **56** of the respondents (53%) and reveals several key themes around the reasons for not pursuing complaints:

- **Mental and emotional exhaustion:** Many parents are too drained, both mentally and emotionally, to deal with the complaints process on top of their existing responsibilities and challenges.
- **Ineffectiveness of the system:** Parents often feel that the complaints process is ineffective and leads nowhere useful, with some complaints being ignored or swept under the carpet. When you do get a response, it appears unrelated to the complaint.
- **Fear of retaliation:** Concerns about potential backlash or receiving less help if complaints are made discourage parents from pursuing them.
- **Complexity and accessibility issues:** The complaints process is seen as too difficult, time-consuming, and not accessible or disability-friendly, making it hard for parents to engage.
- **Lack of awareness:** Some parents are unaware of the complaints process or do not know how to navigate it.
- **Ongoing issues with no resolution:** Even when complaints are upheld, the issues often remain unresolved, leading to a sense of futility and frustration.
- **Parental burnout and stress:** Continuous battles with the system cause significant stress and burnout, impacting parents' capacity to advocate for their children.
- **Systemic failures and mismanagement:** The system is perceived as broken, corrupt, and focused on covering up issues rather than resolving them.

- **Immediate needs vs. long-term solutions:** Complaints often do not address urgent issues, leading parents to prioritize immediate support over filing complaints.

**Overall, the data paints a picture of a deeply flawed and exhausting complaints process that often results in more frustration and stress for parents, rather than resolution. And on balance a fear riddled process only used by the minority as it is not accessible to the majority of parents.**

We have had meetings with the CEO, shared our experiences with evidence from our Subject Access Requests (SARs) of the LA complaints system, and have suggested an external audit many months ago. He did initially agree to carry out an internal audit but we have yet to see any evidence of this, or been consulted for terms of reference.

We have also met with other senior members of the management team to help positively address issues from our SAR but have had very little engagement and response so far.

*“Never received an apology from social services after years of telling me my son was defiant and putting both my children on a child protection plan because of his behaviour. After years of fighting on my part, he was diagnosed as being autistic and they all flitted away like nothing had ever happened leaving us all traumatised and without any help.”*

*“No it was a total waste of time. My complaint was processed by the SW’s manager, which totally absolved her and did not bring any resolution for my son.”*

*“ICB - no fault found LA - partially upholds complaints but take no action to resolve. Had to serve LA a pre-action judicial review to obtain some education for my child.”*

*“I couldn’t have managed the process without all the help I’ve had. It’s not accessible or disability friendly. Further, they don’t follow their own rules and policies and find excuse after excuse to stall and confuse you.”*

*“Gave up after years of trying, we were seen as the bad guys.”*

*“Yes, but then I felt they hated me and didn’t do what they should have been doing because I complained.”*

*“Because the LA don’t take responsibility for actions, apologise then do exactly the same again”*

*“I don’t see the point. We’ve complained before and it didn’t help and can actually make the situation worse as the complaint can make the staff more hostile towards you.”*

*“I don’t have the energy or head space to fight any more.”*

### Respondents were asked if they had escalated complaints to other bodies?

40% had contacted the MP, legal advice 27%, County Councillor 18%, and less than 10% had escalated to LGSCO and PHSO. The respondents weren't asked if this action was fruitful.

To note from our personal experience, and for many of the respondents, for parents to put a complaint in takes a huge amount of time and energy. To then escalate a complaint to these levels requires vast amounts of energy and time invested, along with financial investment for legal services, and courage against fears of backlash against families. It has taken me many years to get to the LGSCO. Due to reduction of resources, they do not fully explore complaints.<sup>12</sup>

It is not clear if one person has used multiple bodies, however I think it is not unreasonable to assume that at least half of the respondents have escalated their complaints due to dissatisfaction with the complaints procedure.

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<sup>12</sup> [Decision making quality and the Local Government Ombudsman – Luke Clements](#)

## About the Author

I am a Chartered Chemical Engineer with many years of experience working in industry. I met David while working and we married 25 years ago. I paused work to have our two beautiful children, Rohan and Serena, and retrained in 2010 in a person-centred counselling method. I have worked with many people worldwide including parents and professionals, both 1:1 and with groups delivering bespoke workshops to equip people with tools to feel more empowered. I am very grateful for this training as I think it is one of things that has kept me going, as have our friends and family.

## A brief overview of our experience

Our son Rohan is now 22 years old. We moved to Cambridgeshire when he was 3 years old due to David's work. We had a somewhat challenging time sourcing sufficient services when he was a child, but we were able to talk to the LA and present evidence to get part of what he needed, while I filled the gaps in care and education. The Local Authority were very impressed by the care and education we were delivering. I doubt there was/is a more loved and looked after young man on the planet. I retrained and went self-employed so I could work flexibly around Rohan's needs, I was his primary carer. Being a full-time carer for 21 years 24hrs/day has severely impacted our finances, my relationships and my health as a result of the intensity and complexity of Rohan's needs. I made the decision to continue every morning, knowing we have no other choice – Rohan would not survive in a residential setting.

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*"Your case is very unique; we receive more compliments than complaints".*  
*Adult Social Care Director CCC. August 2024*

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In 2020, when Rohan turned 18, we moved to Adult Services, 100% health funded. We were told Rohan would be supported as if he was in our home alone; this was not our experience. Even though written professional evidence advised 2:1 at all times, management in LDP (Learning Disability Partnership) team decided he needed half that, which would have left him and carers unsafe. They were also unhappy to pay the rates that Children's SC had, cut the rate of DP paid by a third, and told me to do the same with my staff. When I refused and was forced to go to tribunal, they manufactured Safeguarding Allegations about me in an attempt to remove our DP, and subsequently remove our son from his loving home. They sent us threatening Pre-action CoP letters, conjuring up conflicting allegations. They repeatedly attempted to destabilise his care by not paying care agencies so they would surrender packages, and ignored the Care Act and our Deputyship court order in an attempt to coerce and control us into a pre-decided agenda. They tried this again when our care company went into liquidation in October 2023, however, when we evidenced discrimination whilst in legal battle, they were forced to name a care company. We breathed a sigh of relief, but only for a moment – it didn't stop them trying to take our son. The ICB sent draft CoP orders to us a month later; they wanted court to decide where he should live. Our solicitor rebutted this, so in January 2024 the LA/ ICB had a secret meeting where they again manufactured Safeguarding concerns about our current care provider and my conduct, leading to a "breach of contract letter" from the ICB to the care provider in March 2024. I was mentioned many times in the minutes of the secret meeting



10<sup>th</sup> November 2024

and the termination letter without my knowledge, but there was never any mention of my husband. I was target number one, and our son's package was terminated through fear. We discovered all this after the fact, through SARs. With the aid of this information and help from our amazing County Councillor we were able to retain our care company with our son's current carers, most importantly keeping Rohan safe at home. In November 2023, the LA/ICB spent £67k (from FOI requests), Rohan received £11.7k in Legal Aid (LAA) and we paid £26k from long-term savings in just legal fees. In March 2024 we spent a further £15k and Rohan received a further £12.2k LAA. We also went public as we felt we had no other option; it was terrifying.

We have since engaged with the senior management team at the LA and ICB. The ICB have apologised for what has happened, and they are now working with us and other parents to change their systems so our experiences will not be repeated.

The LA, however, have been much more reserved. The former ASC director said to us in a meeting, "your case is very unique, we receive more compliments than complaints". This response is one of the reasons I have carried out this survey, as, in engaging with a wider community of parents of children and adults with special needs, we do not believe this to be the case.

Rohan is now 22 years old. While the first 18 were challenging, the last 4 have been the most relentless, damaging and traumatising time of my life, this is a consequence of dealing with a dysfunctional care and support system, as well as our son's complex needs. I have been left a shell of the person I was. We are blessed that we have had the capacity to fight it and survived. We decided in March 2024 we wanted to have an impact on the systems currently in place so that no other parent, child, or sibling has to experience what has been nothing short of horrific.

Reading through the comments of the other parents in this survey has been distressing, particularly seeing the same themes have run through all our experiences. Had this not happened to us I probably wouldn't have believed it ever happened. Sadly, we are not unique in Cambridgeshire; we are only one family of many. I am grateful to every parent who has trusted me to share their experiences. I am also very thankful for all the parents who have come together to support us and work alongside the ICB.

## Conclusions

Our own experience is congruent with the experiences of these 106 parents. A concerning result of this survey was discovering how fear plays a huge role in parents' motivation, capacity, and ability to ask for what their child needs in care assessment and planning processes, and sharing their dissatisfaction with authorities and agencies in Cambridgeshire. It is apparent that there is no or very little co-production. It is also clear that the complaints process is a mechanism to defend poor systems, rather than being an effective way for parents to seek help and improve the organisation.

We understand there are financial pressures on the LA and ICB, however we do not see how this justifies spending money from the public purse in hiring staff and expensive legal representation to vilify parents and avoid providing the care needed by the most vulnerable in society.

Our experience and the data collected from various parents highlights a deeply flawed and exhausting process particularly within the Educational and Social Care systems. Key themes emerged, showing widespread issues with transparency, poor communication, misuse of child protection/Safeguarding processes, coercive control, and support. The mental and emotional toll on parents is significant, with many experiencing extreme stress, anxiety, and burnout. The system's ineffectiveness, coupled with fears of retaliation potentially affecting parents and children, leaves parents feeling powerless and vilified.

The level of stress and trauma caused by authorities to families will have a huge financial impact on the local economy, from inability to work due to long-term health consequences, to families becoming dependent on benefits and health resources themselves. This requires a broader and longer-term review.

There is a clear need for systemic reform prioritizing transparency, adequate funding, co-production and accessible support services. To truly support families and children with Learning Disabilities, the system must shift from a bureaucratic focus to one that genuinely prioritises the well-being and needs of those it serves.

From Professor Luke Clements' commentary we can observe this is a national problem. We are already positively working with C&P ICB, we would also like to see an urgent commitment to change in CCC practices, which so far we have not had any serious engagement.

Most parents don't have the strength, resources and knowledge to fight this broken system. The consequences of not addressing the issues in this report are far-reaching and go beyond the potential cost to the public purse. The first being the immediate impact on parents. Further to this there are parents who believe their child's life has been endangered by the actions of the LA/ICB. Failure to address these concerns could result in an unnecessary loss of life.

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*"If you mean being worn out by the continual fight to justify all care and support in education and social care then yes. The lack of transparency from both causes unnecessary stress and anxiety where as transparency would allow parents to understand the process and hurdles. My feeling is the lack of transparency covers up unlawful hurdles put in place by the LA to try and dissuade parents from getting the care and support they need for their children due to restricted budgets."*

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