mASCot
MANAGING AUTISM SPECTRUM CONDITION OURSELVES TOGETHER
Supporting Local Families

Autism Services in Brighton and Hove: Failing our Most Vulnerable Children

Abstract

mASCot members' experiences of SEND provision for their autistic children and young people

May 2023

Contents

1. Introduction

mASCot is a Brighton and Hove-based Community Interest Company which supports families with autistic children and young people. We have been running for 15 years and currently support over 1,600 members, equating to approximately 6,400+ family members.

Brighton and Hove's services for children and young people with special educational needs and disabilities (SEND) were inspected by Ofsted in March 2023. To complement the Ofsted inspection, mASCot also issued a survey to its members, asking for feedback on their experience of SEND services for their autistic children and young people. The survey was issued on 21st March 2023 and closed on 31st March. A total of 471 mASCot members completed the survey. [1]

mASCot has been raising awareness and campaigning for better services for autistic children and young people for the past decade. Despite regular dialogue with statutory service providers and several formal complaints[2] about the chronic failures in services, the survey results set out below, show that Brighton and Hove is still failing some of the city's most vulnerable children and young people.

The key findings emerging from the survey are summarised below. Further information on each of these issues, including survey data, then follows:

2. Key issues

2.1 Education

Too many autistic children in Brighton and Hove do not have access to an appropriate or timely education.

- There is highly variable SEN support for autistic pupils in mainstream schools. Almost one in every two (47%) of Brighton and Hove's autistic children and young people are "very unhappy" in their educational placement. Fewer than one in every 10 autistic pupils is "very happy".

  > *"I sent a happy and confident child into primary school. By secondary I have a child who has complex mental health issues, who is on the brink of suicide."*

- There are not enough specialist school places, especially for autistic children who do not have a learning disability. Almost two in every three pupils who attend a specialist secondary school are forced to go out of area to find an appropriate placement (62%).

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[1] The mASCot survey asked questions that are important to parents and carers but that the Ofsted survey did not ask. mASCot issued its own survey immediately after the Ofsted survey had closed, so as not to undermine engagement with the Ofsted survey.

[2] Most recently, in October 2021, mASCot raised a formal complaint on behalf of its members, regarding Child and Adolescent Mental Health Services (CAMHS) in the city.

- The lack of appropriate school places for autistic children leaves many pupils in limbo, without any form of education for significant periods. For pupils who have no education provision, almost 35% had not received any formal education for more than two years.

There is a chronic failure by the City Council to adhere to statutory guidance and law in respect of EHCP processes and timeframes. Education health care needs assessment requests are routinely declined despite the threshold for assessment being (more than) met. Advice from relevant professionals is consistently excluded from Education Health and Care Plans (EHCPs) and there is a consistent failure to adhere to statutory timeframes or processes. 82% of EHCPs are taking more than the statutory 20 weeks to complete in a way that accurately reflects a child/YP's needs and required provisions. Caseworkers are seen as gatekeepers who, too often, are ill informed of SEND law or statutory guidance, lack decision making power, and are unaware of local provisions. 57% of survey respondents found the EHCP process to be "*traumatic*", 77% found it "*frustrating*" and 46% found it to be "*obstructive*".

> *"Traumatic, awful experience and has had a HUGE impact on my family and in particular my mental health to the effect that on 2 occasions I have wanted to take my own life as it has become all too much."*

These issues leave a strong perception amongst parent/carers of a deliberate, systematic attempt by Brighton and Hove City Council to obstruct the provision of appropriate and timely education to autistic pupils. Parent/carers report that the City Council will consistently employ wilful incompetence, intransigence, and other delaying tactics to obstruct the provision of SEND provision to autistic children.

> *"I just cannot express how much it feels that obstacles are thrown in your way to put you off getting help. It feels like there is an active wish to stop people accessing support. I consider myself a resilient person and someone who is able to fight my corner and understand governmental bureaucracy (I am a barrister). If I find the navigation of the system for my struggling neuro diverse child difficult, then there are going to be very many parents who simply cannot manage it at all."*

2.2 Social Care

Autistic children and young people without learning disabilities are routinely denied access to social care support such as respite and in-home help on the grounds that their child or young person is "only" autistic. Parent/carers report being driven to thoughts of suicide by the chronic long-term stress that they are under because of their child / young person's disability and the lack of support available.

> *"I asked for help from social services when I was 4 weeks postpartum, and I was a single parent. My son had become so violent that I would be asleep, and he would attempt to attack me or his new sibling. There was never a break from the violence. It was all day, all night. I had no family support, so my only option was social services. I was shamed from the start. Made to feel like a failure. Told I was the problem*."

Parent /carers consider that there is a pervasive lack of understanding of autism amongst social care professionals. This includes:

- A culture of parent/carer blame, and misrepresentation of information in reports.
- Support offered that is not tailored to, or appropriate for, the child's or family's needs.
- In a separate survey conducted by mASCot in early 2023, 65% of respondents felt that their social worker did not have a sufficient understanding of their child's condition.

> *"Dangerously ill-informed about Neurodivergence. Caused more harm than good…Terrifying process."*

Dissatisfaction with social care services is high. Almost 8 out of every 10 survey respondents stated they are either "very dissatisfied" (54%) or "moderately dissatisfied" (25%) with the social care support that their child/YP had received.

> *"If social care In Brighton and Hove were a person it would be a narcissistic, violent and pathological liar in the body of Mr. Blobby…aimlessly bashing around, destroying everyone and everything, totally oblivious to the harm caused."*

2.3 Health Care

Autistic children in Brighton and Hove wait far too long for autism, ADHD and mental health diagnoses and support. There is a lack of commissioned provision for autistic children/YP. Parents report cases of their child/YP self-harming, having suicidal ideation and suicidal attempts, yet being turned away from CAMHS.

> *"He was wanting to die and taking frightening actions. CAMHS did not feel he needed any support and discharged him after one initial meeting."*

Health care is often inadequate. 77% of survey respondents are either "very dissatisfied" (49%) or "moderately dissatisfied" (28%) with the health care provided for their autistic child/YP. More than 72% of respondents found health care provision for their autistic child / YP to be "frustrating", more than one in two considered it was not "well-communicated" or "high-quality".

> *"My child has struggled since a very young age, in the last 5 years alone my child has tried to jump in front of cars, trains, and recently cut his wrist to attempt suicide. 60% of his body is covered in self-harm. Yet he, and we, get no support."*

There has been very little change in the quality of health care provision for autistic C&YP since mASCot raised a formal complaint in 2021. Communication is still disjointed; there is still a severe lack of health care provision, and a culture of parent blame persists. mASCot's complaint and the multi-agency response can be found here: Collective Voice (asc-mascot.com)

Further information on each of these issues, including survey data, is set out In Section 3, below.

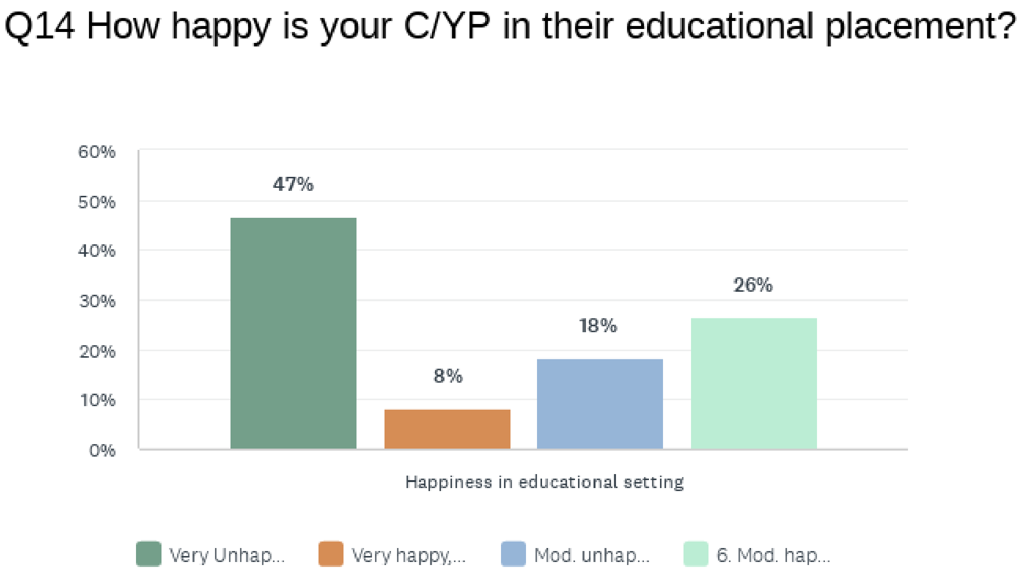
3. Detailed Survey Results

3.1 Education

3.1.1 Too many autistic children in Brighton and Hove do not have access to an appropriate or timely education. This is for four main reasons:

- **There is highly variable SEN support for autistic pupils in mainstream schools.**
    - Across the city, almost one in every two (47%) of Brighton and Hove's autistic children and young people are "very unhappy" in their educational placement. Fewer than one in every 10 autistic pupils is "very happy". See Figure 1, below.
    - At secondary school level, more than 70% of autistic pupils at mainstream secondary schools In the city are either “very unhappy” (52%) or “moderately unhappy” (18%). Fewer than 2% are "very happy". At nursery and primary school levels, 61% of autistic pupils are either “very unhappy” (33%) or “moderately unhappy” (28%).
    - Worryingly, almost 1 in every 3 autistic pupils at specialist secondary schools are "very unhappy" (32%).

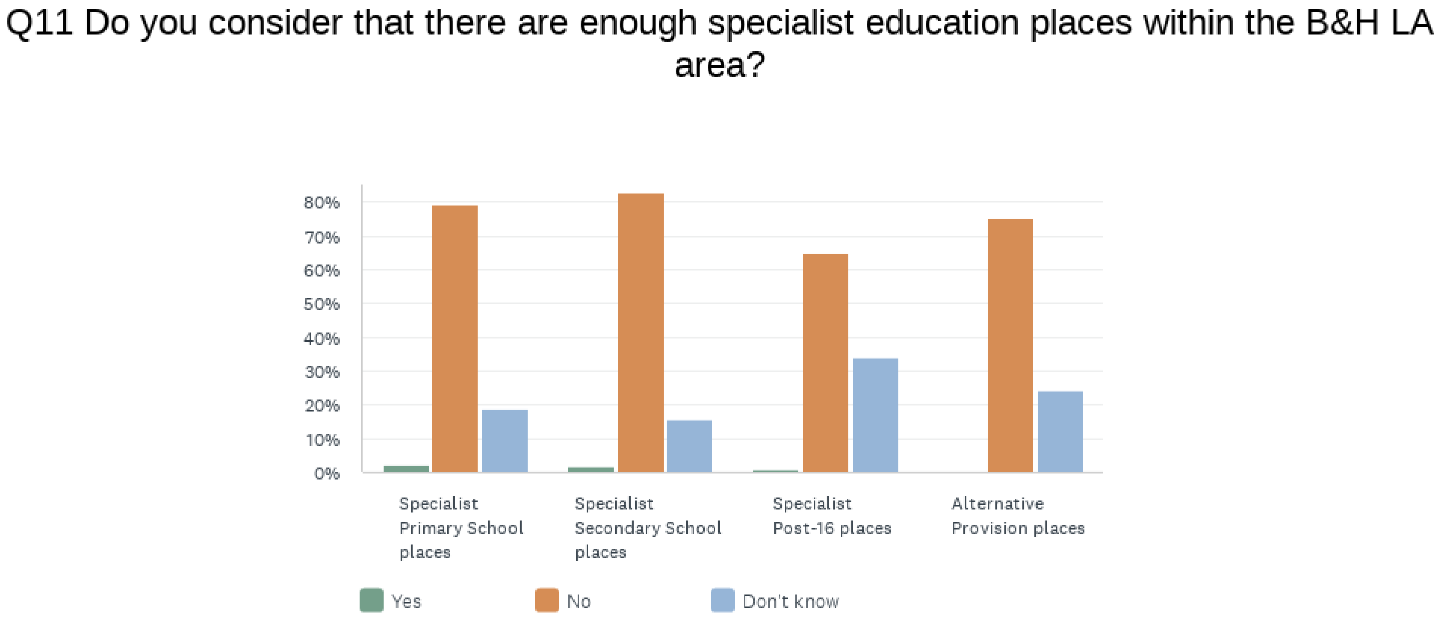
Figure 1, Happiness of C/YP In School



Parent/carers report that although there are some examples of good practice there are also many examples of schools being slow to act when children start struggling, especially for children who mask. Provision of support is often too little, too late resulting in pupils having mental health breakdowns and being unable to attend school. See Annex 1 for illustrative examples of mASCot members' experience of education provision in Brighton and Hove.

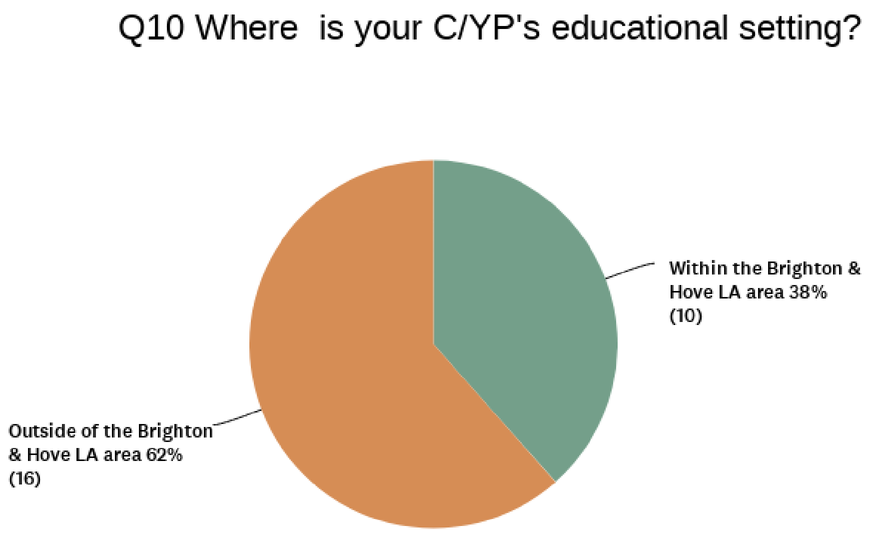
- **There are not enough specialist school places, especially for autistic children who do not have a learning disability.** As outlined in Figures 2 and 3 below:
    - An overwhelming majority of respondents consider that there are not enough specialist places, at any level of education.
    - Almost two in every three pupils who attend a specialist secondary school are forced to go out of area to find an appropriate placement (62%).

Figure 2, Sufficiency of specialist education places In Brighton & Hove LA Area



Q11 Do you consider that there are enough specialist education places within the B&H LA area?

Figure 3, Location of educational setting, specialist secondary level

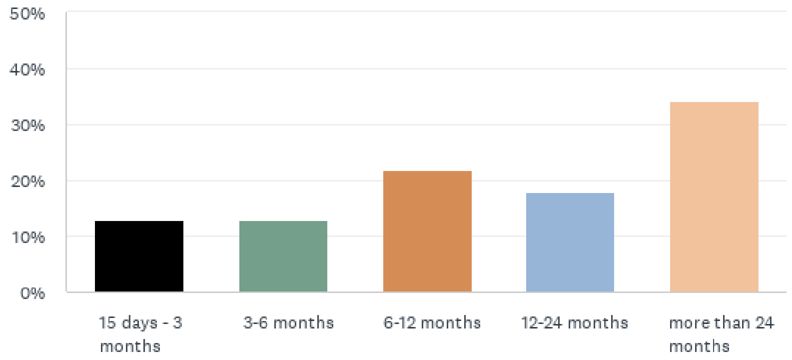


  - Although mASCot has worked closely with Brighton and Hove city council around getting these provisions right, it is still concerned that not enough provision is available. As such, although the new Hive School is welcomed, an additional 40 places across the LA is wholly insufficient.
  - Parent/carers also report that there are also limited post-16 preventative interventions for children at risk of dropping out of education, training, or work. BHISS and YES teams are inadequately resourced to meet need.

- **The lack of appropriate school places for autistic children leaves many pupils in limbo, without any form of education for significant periods.**
  - More than 17% of survey respondents have children who are not accessing full time education, due to lack of appropriate school places across the city. These are families whose children are either out of school and receiving no formal education (8%), are receiving informal, part time education packages (5%), or are receiving longer term "alternative education" (4%), often amounting to just six hours per week.
  - Currently there are more than 220 members in mASCot's '*Kids at Home'* Facebook group. These are not families who have elected to home educate but are largely families for whom there are no suitable education places available.
  - For pupils who have no education provision, almost 35% had not received any education for more than two years. See Figure 4, below.

Figure 4, For those who are unable to attend, or have no named setting, for how long has your child/YP not received any state funded education?

Q12 For those who are unable to attend or have no named setting, how long has your child/YP not received any (state-funded) education?



- **There is no clearly defined pathway for the provision of tailored education packages to autistic children who are unable to attend school due to mental health reasons.** This includes full EOTAS packages, off-site, blended learning arranged by schools and flexi-schooling. Annex 1 sets out illustrative examples of our members' experiences of alternative education provision.
    - Parents report that very little information is available from either schools or LA caseworkers, around what options might be available and what access procedures should be followed. There is widespread misinformation from the LA around whether schools or the LA is responsible for ensuring education for out of school pupils.
    - When they are granted at all, Alternative Provision education packages are generally approved for just six hours, or less, each week. Parent/carers report enormous struggles trying to secure additional hours.
    - The LA's two main providers of mentoring and tutoring services are overwhelmed with referrals and sometimes offering inexperienced, inappropriate, or unreliable mentors and tutors. Yet the LA is reluctant to use a broader range of providers (some of whom are slightly more costly) or provide personal budgets so that parent/carers may source themselves.
    - The LA has a narrow and irregular interpretation of EOTAS, viewing it as a department within the LA, providing traditional academic tutoring, by tutors who are often not SEN trained. Some parents report that they have been asked to produce statements of mental health needs from CAMHS, before being eligible to access the EOTAS department, even though waiting times for CAMHS assessments take many months, if not years. This is in breach of explicit guidance from the Department for Education.

3.2.1 There is a chronic failure at the LA level to adhere to statutory guidance and law in respect of EHCP processes and timeframes.

- 82% of EHCPs are taking more than the statutory 20 weeks to complete in a way that accurately reflects a child/YP's needs and required provisions. More than 14% are taking more than two years. See Figure 5, below.
- 57% of people found the EHCP process to be "traumatic", 77% found it "frustrating" and 46% found it to be obstructive. See Figure 6, below.

Figure 5, EHCP Timeframes

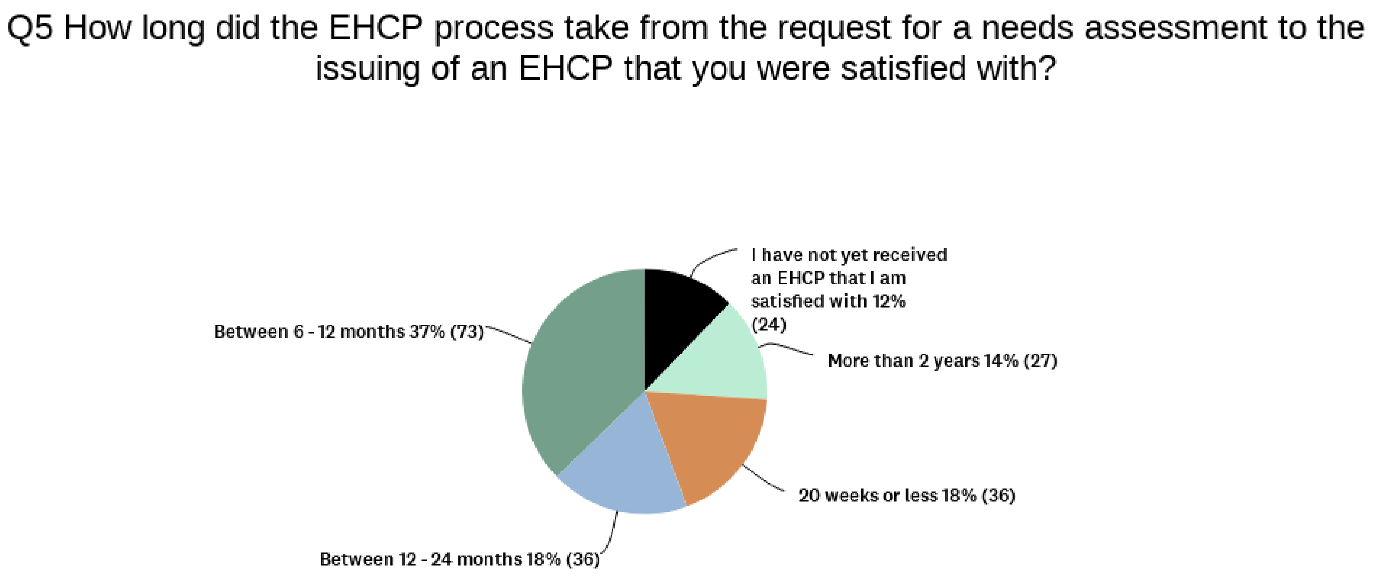
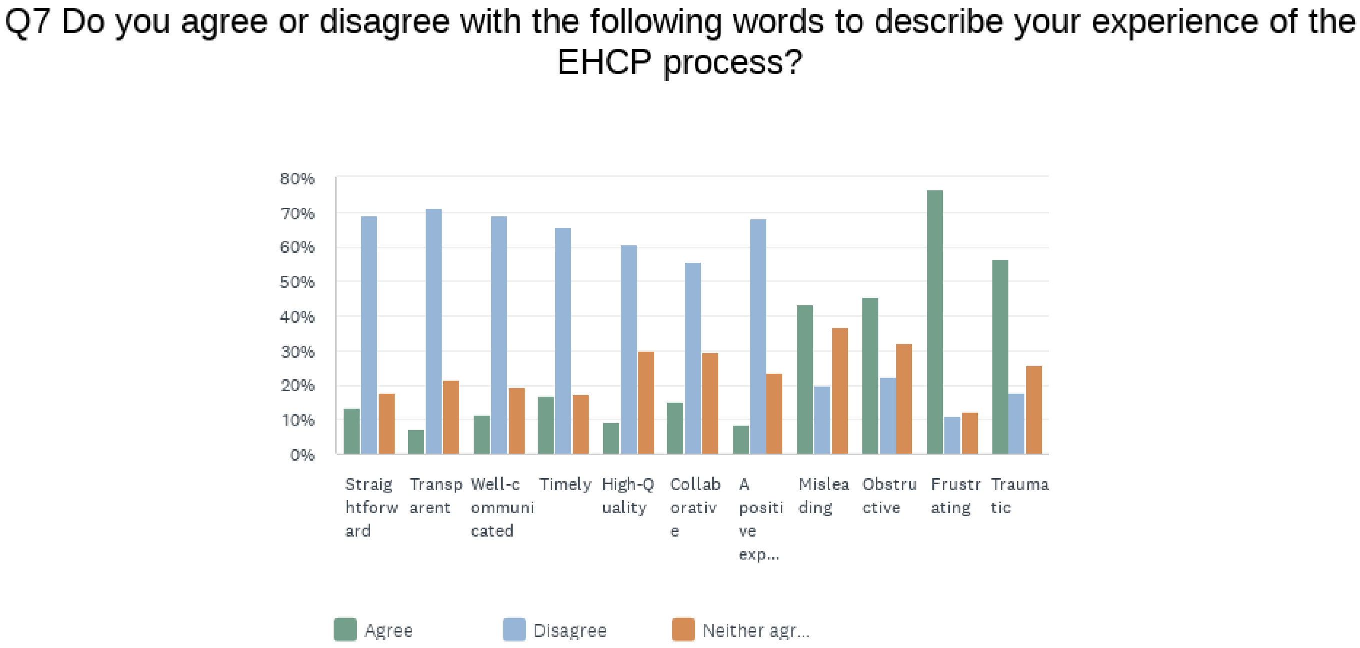

Q5 How long did the EHCP process take from the request for a needs assessment to the issuing of an EHCP that you were satisfied with?

Figure 6, Experiences of the EHCP Process

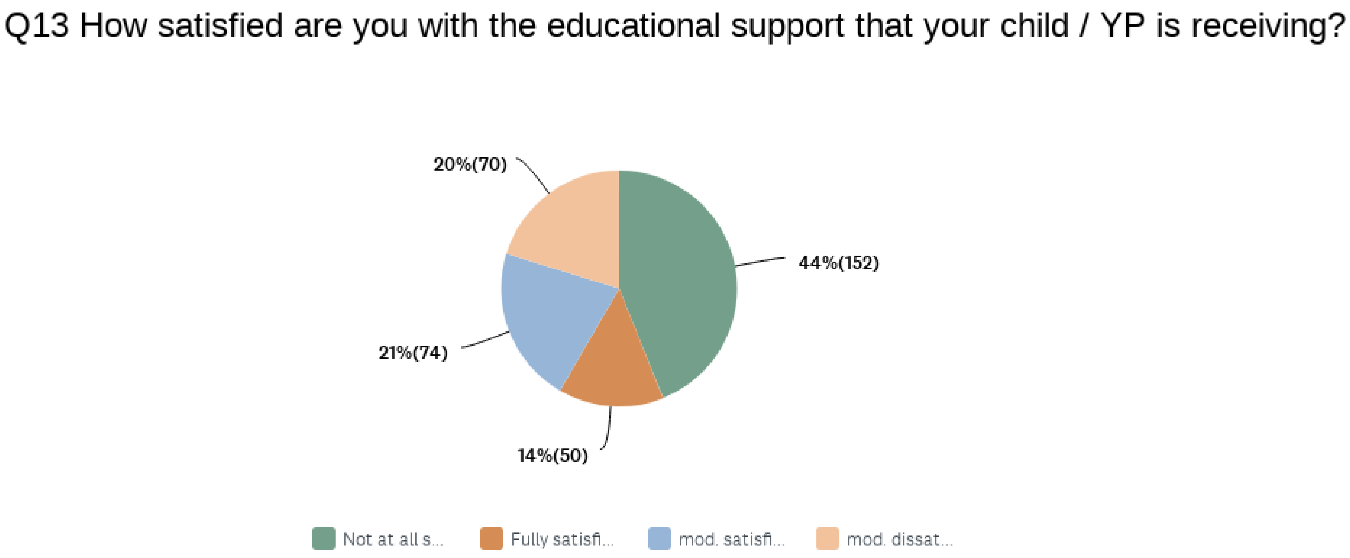


- Issues highlighted are: that EHCP Needs Assessment requests are routinely declined despite the thresholds for assessment being (more than) met; advice from relevant professionals is consistently excluded from EHCPs; Outcomes and Provisions are rarely SMART; there is little meaningful co-production; there is a consistent failure to adhere to annual review timeframes or processes and ARs frequently fail to produce any meaningful change in provision; unauthorised sharing of personal, sensitive information to third party providers; caseworkers being unresponsive and gatekeeping provision, routinely claiming they are not authorised to make decisions on comparatively straightforward issues; caseworkers who do not have basic knowledge of SEND law or statutory guidance, and often (claim to) know little about available provision; lack of transition planning for post-16. See Annex 1 for illustrative examples of mASCot member's experience of the EHCP process.

3.1.3 These issues leave a strong perception amongst parents, carers, and front-line support networks of a deliberate, systematic attempt at the LA level to obstruct the provision of appropriate and timely education to autistic pupils. Parents/carers report that the LA will consistently employ wilful incompetence, intransigence, and other delaying tactics in an effort to obstruct the provision of necessary, though sometimes costly, therapeutic, and educational services to children. As well as being unlawful, given that autistic children are more likely to be poor and from other marginalised backgrounds[3] this is a highly regressive strategy, inevitably resulting in a failure to provide support to those who need it the most.

As illustrated in Figure 7, below, overall dissatisfaction with SEN services for autistic pupils is high with almost one in every two parent/ carers stating they are "not at all satisfied" with their child/YP educational provision. Trust between parent/carers and the LA SEND departments is low.

Figure 7, Parent/ Carer satisfaction with educational provision



3.2 Social Care

3.2.1 There is a gap in social care provision for autistic C&YP without learning disabilities; such families are routinely turned away from social care such as respite and home support on the grounds that their child or young person is "only" autistic. Support is also often declined when being requested as a preventative measure. Parent/carers report being driven to thoughts of suicide by the chronic long-term stress that they are under as a result of their child / young person's disability and the lack of support available.

3.2.2 Dissatisfaction with social care services is high.

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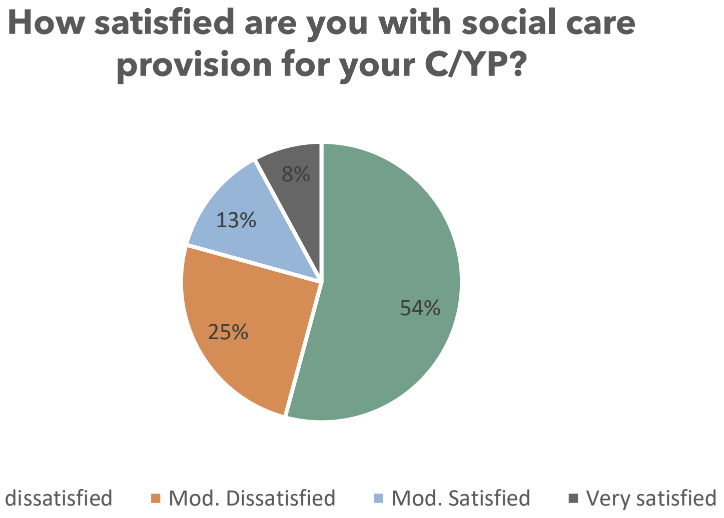
[3] See for example, The experiences of marginalised families with autistic children, University of Birmingham, Autism Centre for Education and Research, 2023. See also Autistic Children at the Intersection of Race and Poverty Experience Compounding Health Risks, National Autism Indicators Report, 2022

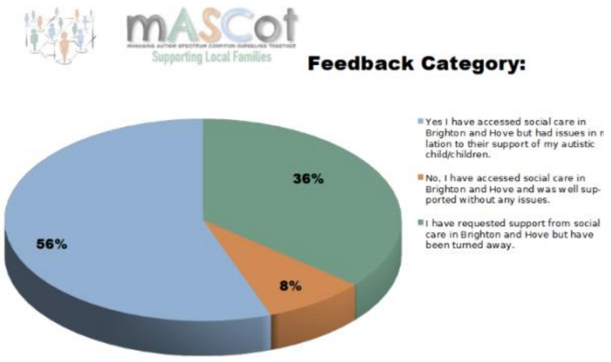
- Almost 8 out of every 10 survey respondents stated they are either "very dissatisfied" (54%) or "moderately dissatisfied" (25%) with the social care support that their child/YP had received. See Figure 8, below.
- Almost 2 in every 3 respondents (60%) felt that they had "no" or "limited" participation in their child/YP's social care plans.

Figure 8, Satisfaction with social care provision



In a separate survey conducted by mASCot in early 2023, 56% of respondents who had accessed social care for their child had experienced challenges in their support; 36% had requested support but been turned away and just 8% felt well supported. See Figure 9, below.

Figure 9, experiences of accessing social care.



3.2.3 Parent /carers consider that there is a pervasive lack of understanding of autism amongst social care professionals. This includes:

- A culture of parent / carer blame and misrepresentation of information in reports.
- Support offered that is not tailored to, or appropriate for, the child's or family's needs.
- In a survey conducted by mASCot in early 2023, 65% of respondents felt that their social worker did not have a sufficient understanding of their child's condition. See figure 10, below.

Figure 10, professional understanding of child's condition(s)

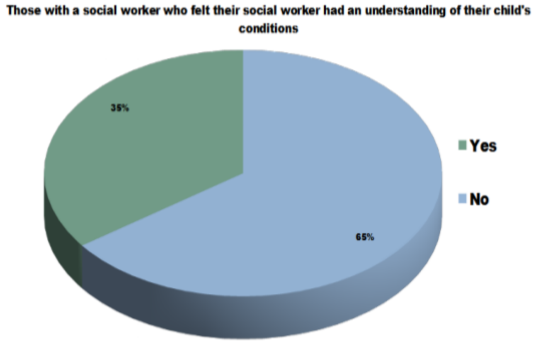
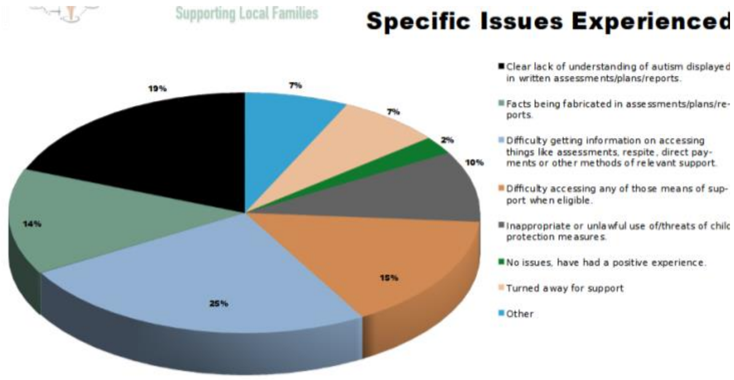


Figure 11, Specific Issues experienced with social care.



Annex 1, below, sets out some illustrative examples of mASCot members' experiences with social care.

3.3 Health Care

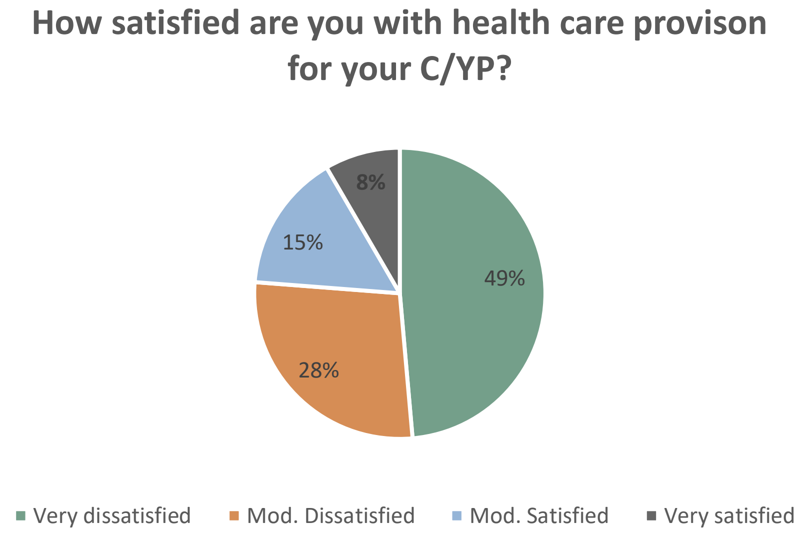
3.3.1 Autistic children in Brighton and Hove wait far too long for autism, ADHD and mental health diagnoses and support.

- There is a lack of provision being commissioned for autistic children/YP.
- By the time diagnoses and mental health support is available, children's mental health has often declined significantly, and chronic challenges have set in.
- Parents report cases of their child/YP self-harming, having suicidal ideation and attempts, yet being turned away or discharged from CAMHS.
- Annex 1, below, sets out Illustrative examples of parent/carers' experiences with health care for their autistic C/YP.

3.3.2 The quality of support is often inadequate. Parent/carers report that

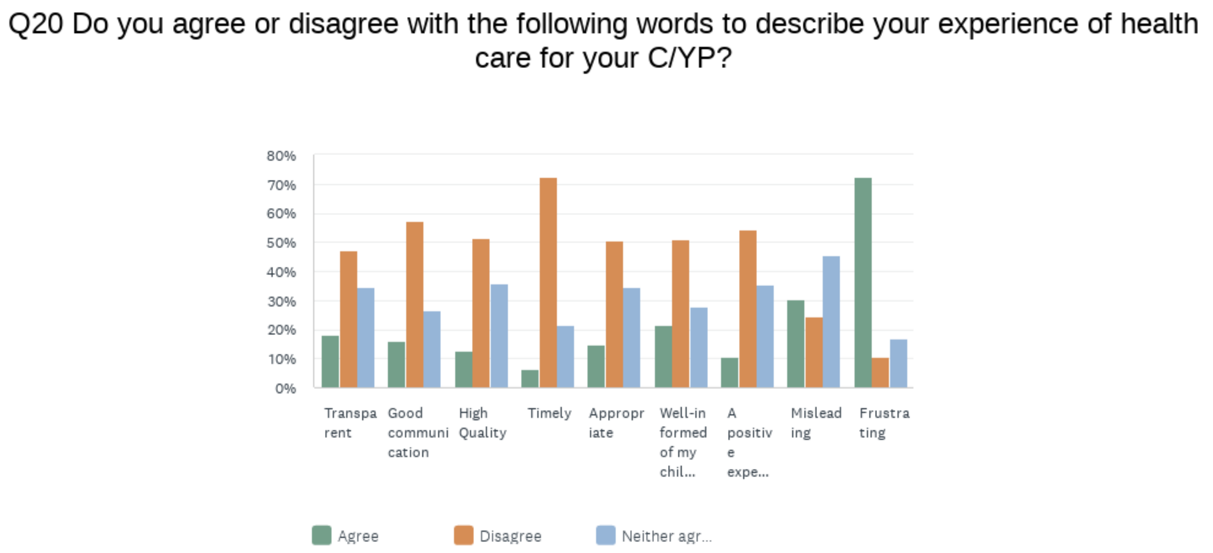
- 77% of survey respondents are either "Very dissatisfied" (49%) or "moderately dissatisfied" (28%) with the health care provided for their autistic child/YP. See Figure 12, below.

Figure 12, Satisfaction with Health Care



- More than one in every two respondents (54%) consider that they had "limited participation" in their child/YP health care plans.
- More than 72% of respondents found health care provision for their autistic child / YP to be "frustrating", more than one in two considered it was not "well-communicated" or "high-quality" and more than 70% of respondents disagreed that health care was "timely".

Figure 13, Overall experiences of health care



3.3.3 Key commitments made by SPFT, BHCC and Sussex CCG in response to mASCot's letter of complaint have still not been actioned. In October 2021, mASCot submitted a formal complaint, accompanied by extensive supporting evidence, to the SPFT, BHCC and Sussex CCG, outlining concerns around the following issues:

- Disjointed communication and assessment process; Lack of ASC and neurodiverse appropriate therapeutic intervention; Poor management of medication; Disrespectful and insensitive attitude towards families; a culture of 'parent blame'.
- In January 2022, following a meeting with mASCot, a multi-agency response was received, acknowledging the failures, and outlining key commitments and actions. However, to date, very little has changed for autistic C&YP. Communication is still disjointed, there is still a chronic and severe lack of health care provision for autistic C&YP, and a culture of parent blame persists.

4. About mASCot

mASCot is a Brighton and Hove-based Community Interest Company which supports families with autistic children and young people. We run clubs, events, and activities across the city for autistic children and young people. For parents and carers there are one-to-one support and advice meetings, coffee mornings, a Lawstop drop in, and much more.

Since 2014, mASCot has been recognised for the important work we do in filling gaps in local services. We are a vital communication channel and want the right services commissioned to better fit the very real need out there. Our aim is to inform and to work with statutory services, but there's the ever-present strain of knowing families are going under.

Annex A mASCot Voices

The quotes set out below are extracts from just some of the many hundreds of comments that mASCot received via its survey of SEND services In Brighton and Hove.

A.1 Overall comments

- *I believe Brighton and Hove deliberately avoid and delay requests for help from families with SEND in order to save money. Thereby leaving families like ours to struggle on unsupported and in a near impossible financial situation and extreme emotional distress.*
- *I am just sad, worried...for my daughter. As parents we try to do the best, we can but finding help has been difficult, quite often the result of a chance conversation with another parent or professional. The help that is out there feels hidden away and when you do find it, tough luck anyway!!! Or...you are misled!!! To think the Council can mislead you is particularly upsetting, the governing body of our local community...very sad times indeed.*
- *I just cannot express how much it feels that obstacles are thrown in your way to put you off getting help. It feels like there is an active wish to stop people accessing support. I consider myself a resilient person and someone who is able to fight my corner and understand governmental bureaucracy (I am a barrister). If I find the navigation of the system for my struggling neuro diverse child difficult, then there are going to be very many parents who simply cannot manage it at all.*
- *The issue that needs to be looked at by OFSTED is that the failings that everyone is experiencing are deliberate and systematic, not accidental, due to lack of training or something. It's a deliberate strategy to limit resources. The Director of Children's Services earns £125,000 per year. The Deputy Director of Children's Services is paid almost £100,000. At this level of pay, they MUST do better, to come up with a system that allocates limited resources more fairly, more transparently, honestly, and more creatively. The current system destroys people's mental health. And it is highly regressive - only people with the time, education, confidence, and money are able to secure the diagnoses, education, and support that their children are entitled to. And only then after a lot of fighting and stress to the whole family. Honestly, living in Brighton and Hove feels like living in a country that isn't governed by the rule of law. The LA breaks the law so systematically, blatantly and without any fear of redress. It's soul destroying.*

- *In summary, the LA SEND team are useless... They do not advocate for parents. They do not know or follow the law. They do not follow correct procedure. There is no transparency in their decision making. They are WOEFULLY INADEQUATE.*
- *My son and whole family are being let down in so many ways by the local authority. No appropriate education, no appropriate therapeutic support, no appropriate social care. All support we have been able to scrape has taken a huge amount of energy and a huge emotional cost. B&H LA take advantage that the families of disabled children are so worn down and exhausted by lack of support that we do not have the energy to fight for what we are legally obligated to receive. It is absolutely disgusting.*
- *The entire system needs a revamp with more training provided to the panels and case workers. Or hiring extremely competent individuals perhaps who have children or family members with disabilities or needs - therefore they will actually understand the situations that families and people are in.*
- *I have completely lost confidence in the ability of education and health services to support my son and us as a family. I feel that my only option is to work as hard as I can to save money to get private support for him. For many people, this is not an option, and they are being completely failed. I recognise that funding and government cuts and policy is a major contributing factor to these failures, and this should be recognised in the inspection.*
- *I asked for help from the school, attendance, wellbeing/CAMHS, BHISS, EOTAS, GP, Amaze/SENDIASS and many others and my child is worse off after 3 years with barely any support and I have zero support.*
- *Parents of kids with additional needs, neurodiversity or other issues are doing the best they can in extremely tough and adverse circumstances. There is a lack of funding and staffing but there seems a lack of even basic understanding of the needs of neurodiverse children and YP even by the supposed specialists, and also the needs of their parents, carers, and families. There's an assumption that you need training in how to be a parent, not that you need support for your circumstances.*
- *The whole education, health, and social care support for SEND children, young people and their carers/parents is in absolute crisis. It feels that the agencies BHCC SEND that should support families put barriers up at every opportunity. There appears to be a complete lack of following any guidance or basic legislation relating to SEND - e.g., proper transition planning, accessing support services. There is lots of report writing but no resources or substance to this! I feel completely exhausted battling a system that is not fit for purpose!...My child was ignored - we don't matter - that is the message I get loud and clear!!*
- *We are discharged at every turn. Every service trying to get us off their books. Charity, council, school support, health care, no one wants to see us. We are a problem to them.*
- *Complete overhaul needed. From management culture to resources to special needs holiday clubs to recruiting carers. It’s in crisis and we are all suffering more than ever. We've been given 1 day of Extratime in a 2-week Easter holiday. How am I supposed to work with this provision? No family or friend can cope with my child's needs.*
- *There is no support or information provided by the SEND team to help identify the options for a child. The process leads the parent/ carers to believe that they don't have choices for their children.*
- *The whole of the LA needs a total overhaul. Parents are treated disgustingly by staff at the LA and CAMHS.*

- *If you want higher standards you need to pay a lawyer to get your child's needs met. I feel stuck and I know we have no option other than to stay stuck.*
- *Non identified autistic kids with high care needs have been abandoned and ignored for virtually all support in B&H in my kid's lifetime.*
- *An uphill battle and one which should not be this hard.*
- *Provision in B&H is shocking.*

A.2 Education Experiences

- *Traumatic, awful experience and has had a HUGE impact on my family and in particular my mental health to the effect that on 2 occasions I have wanted to take my own life as it has become all too much.*
- *"I sent a happy and confident child into primary school. By secondary I have a child who has complex mental health issues, who is on the brink of suicide.*
- *My child went from an enthusiastic child who fully embraced education to a withdrawn and traumatised child due to school not fulfilling their obligation to provide reasonable adjustments. My daughter has been out of school for a year.*
- *The last four years trying to keep my child (with severe mental health issues and ADHD) in education has been the biggest struggle of my life.*
- *If Brighton and Hove had listened and accepted my appeal, my child 100% would not have the mental health crisis they are in today.*
- *The LA/school utterly failed my child and there is no accountability for the devastating lifelong impact this has had.*
- *BHCC are failing to acknowledge my child's needs and manufacturing delays at every opportunity and causing extreme stress and anxiety for our whole family.*
- *You're on your own was the message from the education provider.*
- *Complicated, traumatic, confusing process.*
- *LA expect families to fight, appeal or take legal action every step of the way.*
- *Staff are rude, dismissive, and uncooperative most of them time.*
- *Diabolical communication, zero knowledge of what provision was out there and no sense of urgency whatsoever to ensure alternative provision."*
- *It is absolutely unacceptable that it takes as long as it does for support. Had my child received support in year 4 when I first asked for it, when he was just struggling to engage and focus in class I honestly believe that would have been enough. He was left so long that he needed much more intensive support. He missed almost 2years of school.*
- *Getting adequate support in school for our daughter has been an ongoing battle which has been exhausting and draining. It shouldn't be like this.*
- *It is urgent that more places are made available in specialist schools, otherwise many of the city's children with special needs will continue to be failed by the educational system.*
- *Home Schooling team have been very helpful and invested. SENCO at school seems hopelessly out of her depth.*

- *In light of the woeful lack of provision in B&H for the many children who have academic ability and potential but for whom the school environment causes damage to their mental wellbeing and developmental potential - I strongly believe, from our own experience, that the way forward is to promote and support families AND schools to engage in a Blended Learning approach. And that this should be offered a viable pathway, as a choice BEFORE the trauma of school experience is allowed to take hold.*
- *Huge change needed.*
- *There is a lack of vocational learning and opportunities for SEND Students - they are treated as second class citizens.*
- *Post 16 support has been for us non-existent. I have no idea what happens post 18 and whether we will get any support, advice, guidance. I am terrified as I have no idea what happens if he doesn't stay on at college this year and don't know if there is any support - or who's meant to give the support.*
- *No one is working with my son. Feels like there is no help at all. Since he has started at school, it feels like they just passing him over, but no one, absolutely no one, helps.*
- *It needs a huge overhaul, the system if failing far too many children/young adults. There needs to be more places available for children with hidden disabilities, mental health issues. They all deserve a decent education, and it seems no one is getting one. Things need to be made easier for assessments etc. and a lot more support for parents trying their best to get their children into some kind of educational setting. Specialist settings for those with Autism who don't have a learning disability so they can reach their potential and gain the qualifications they will need to go forward in their lives. Stop making everything such a fight!*
- *One size does not fit all. There needs to be more specialist provision that are quality provision available for our children.*
- *There are not enough special schools within Brighton and Hove!! We need more free support as our children are suffering and so are their families.*
- *Education for children with SEND is horrible. Not enough special schools. Schools with smaller classes for Autistic kids not an option, only 1 unit in Brighton and Hove for primary age, it is an absolute joke. Most of these kids could learn the same things just need different settings. They are in mainstream schools struggling the whole day until the point where they just refuse to go to school again. The whole Education system need to change.*
- *Lack of understanding in mainstream school about girls with autism "she seems fine at school" and dismissing the meltdowns at home with "it's not happening here so…" lack of support staff in school, inconsistent adults appearing in class so not forming good relationships. Therefore, trust issues - who is a safe adult to talk to? Lack of support at break times, lack of support with relationships in school. Teachers, SEND support not acknowledging our emails or getting back to us.*
- *I have been told over and over that I am a unique case by services that I have sought for help. The missing in Education officer said that I was a unique case as 'many autistic children thrive in mainstream' my daughter has been let down time and time again. She has no secondary education, minimal social skills, no social life and is in a constant state of anxiety/ fear she has developed OCD and mental health issues because she has not been able to access the appropriate support.*

- *It's all been incredibly traumatic, long winded, confusing and a complete minefield.*
- *It feel like a minefield, not transparent, not straightforward. There simply isn't the capacity to be able to deliver the consistent support, at an early enough stage, for these children. My child was let down again and again in issues that really mattered. The ONLY things that have been helpful to my child's recovery and progress have been input from professionals and services outside of LA provision and have come from research and exploration done by myself.*
- *Nightmare! He was 'dumped out' of mainstream secondary within weeks of starting year 7 having had a good primary school experience. Various APs - all focusing on behaviour management and punishment/reward systems rather than low arousal approaches - no specialist provision for neurodiverse kids who are cognitively able. Approached over 20 schools - either full or stated couldn't meet needs. I'm exhausted (end of my tether several times) and child is depressed. His dad is angry. Brother is severely disabled with care needs of a baby.*
- *Going to tribunal was incredibly stressful. The strain on me as a parent and the deliberate evasive and delay tactics used by the council over the 2-3 years since my son was excluded from [school] have been utterly draining. For parents who already have challenging circumstances with SEND children to be forced through this process in order to get a minimal education for our children. I think this is totally unacceptable and unethical.*
- *Secondary mainstream establishments cannot meet need of autistic children. They are too big, busy and teachers don not know the child.*
- *We've had to self-finance part-time schooling as mainstream school was not suitable. Huge financial drain. Not 'in the system' so no support given. Basically left to fend for ourselves. All because large class sizes and lack of SEN provision means she couldn't attend, and we couldn't watch declining mental health, so our hand was forced to deregister.*
- *My marriage ended up breaking down. It was an incredibly stressful time.*
- *Absolutely traumatic. There is no support, services don't listen. We are currently in financial Hardship as I've had to leave my job to provide full time care for my child as she isn't able to manage mainstream education. My child is 14 and has no secondary education at all.*
- *The lack of options of educational provision have left us to choose the least-worst option - in our case, part-time alternative provision supplemented with home tuition- which is not only unsatisfactory, but it relies on me as a parent to arrange, coordinate and fill in any gaps. All of these things combined have negatively impacted the mental health of our child, as well both of us parents, making it even more challenging to continue to respond to our child's increasing needs.*
- *Awful. My son has not been in school for approximately 2 years, he was traumatised by secondary school and has needed time to recover. The LA has been a hindrance rather than a help.*
- *[my son] struggles every day. Some days are so bad he just cries by himself in the library. He never eats or drinks anything and he's out of class a lot. The EHCP process takes far too long and damages our children.*
- *Too little, too late is a good summary of our experience. My son had a mental breakdown in year 7 but had no EHCP and nobody (school, BHISS, etc.) alerted us to the existence of this kind of support. My son struggled through mainstream whilst his mental health continued to deteriorate, and we only secured*

an EHC Plan for him in Year 10. The lack of specialist provision for academically able autistic students who aren't coping in mainstream is extremely limited, and he ended up in specialist provision in West Sussex - the school only had a handful of students and could not cater to his social needs, so he has stopped attending. His mental health has continued to rapidly deteriorate. We are concerned that the devastating impact that lack of suitable educational opportunities have had/ are having on his mental health will take many years to recover or move on from. Our son had to go into complete crisis before he was offered any kind of support. He does not believe that he has any chances in life and we are focused on safeguarding him, particularly as most of his peers will be sitting GCSEs and planning out their next educational steps in the next few weeks - options he now longer has but would like to have. To say our son has been let down is a massive understatement. He has been failed, and this failure will mean he will struggle with trauma and poor mental health for a very long time to come.

- *The difficulty of securing education for my child has been at times actually traumatic, and at all times frustrating, dispiriting, demoralising, upsetting and difficult. I have had to battle for what little support they have had.*
- *My child has been trying to teach themselves the GCSE curriculum for most of their year 11. Their educational prospects have plummeted, their self-esteem also has, and it has been hugely traumatic for them. I have been shocked at the obstacles placed in our way and the difficulties I have had trying to get help for them. It has had a massively negative effect on our family.*
- *My child was out of full time schooling for 3.5 years. B&H were not helpful and made it difficult and traumatic. Finally got a placement out of Brighton.*
- *This is the most stressful experience me and my family have been through. All the systems are broken, convoluted, feel designed to make it challenging at every step and even then there is no positive outcome. My child still has no education or mental health support, their mental health has deteriorated. My child is bright and capable and will most likely not receive an education at all at this stage as the months and years slip by with nothing in place. My mental health has suffered, I have developed fibromyalgia and anxiety and depression. My other child (also autistic and dyspraxic) doesn’t get as much support as he needs with his education because as parents we have to spend so much time fighting for our daughter who is not receiving any education. My husband has had to go part time at work and may have to leave his job to oversee our child’s care and education as she’s unable to attend school. This will affect our financial stability and quality of life as a family and probably his mental health too.*
- *My 13 year old daughter has many unmet needs associated with SEND at school. She has at least one or two days off school every week due to anxiety and/or overwhelm and fatigue. She should be in a smaller provision that meets her needs. I have had to reduce my days at work from 3 to 1 per week and my partner also works part time to meet both my autistic daughters’ needs.*
- *I had to go to tribunal as LA ignored myself, SENDCO and private reports. They eventually agreed the day after he left primary school. I was signed off work due to burn out from tribunal.*
- *The lack of provision is astonishing.*
- *My daughter has been resolutely FAILED by the LA. It took a huge amount of stress, effort, and research on our own part to drive forward her EHCP application. They did not follow correct procedure (they issued a final plan, without giving us the opportunity to view and comment on a final draft). The plan is*

also woefully inadequate, as it is not specific and measurable and only speaks in very vague generalities. As such, we have had no choice but to go through a time consuming and hugely stressful appeals process – our appeal is not due to be heard until Feb 2024, by which point my daughter will be in Y10. Additionally, they LA has just cut funding for the only alternative provision my daughter was accessing – indeed, the only AP she has been able to access for over a year – despite the fact she has been out of school for months. She is hugely isolated and has no friends or peers. She is receiving little or no education. She is depressed, highly anxious and utterly lacking in self-confidence and self-belief. Our need to advocate on behalf of our daughter to try and secure what she is legally entitled to, and what she is needs to meet her complex needs, means we spend a HUGE amount of time doing this, rather than parenting and giving her the quality time she deserves. The stress is enormous. It has fractured our family and caused irrevocable damage to my daughter. Every day, I wonder at what point will she become suicidal because it has all become too much for her. (This is not something I wonder *if* it will happen – I fully expect it to be a case of *when* it happens...) I will never forgive the LA for their utterly woeful failure.

- _Traumatic, life changing._
- _My child had to endure 3 years of mainstream schooling before I took the very difficult decision to pull her out for her own safety after she had broken her nose and no one knew how it happened, climbed onto a school roof at the age of 5 and went missing for almost an hour and the school failed to notify the police or myself. It was quite evident from the beginning my child should never have been placed in a mainstream setting, my child missed out on an education for the first 3 years of school life which has had a detrimental effect on her learning. It’s had a devastating effect on my mental health having to drag my child to school, screaming, crying, and begging me not to leave them there, it has also had a devastating effect on my child’s mental health, my child now has attachment disorder, PTSD, and depression._
- _Horrendous. It's been literally the worst experience of my life. Dealing with the LA and their constant lies and tricks has made me unwell. I've now had to set aside £13,000 to pay for a solicitor to deal with our case. It's not because it's particularly complicated or nuanced - the LA has very clearly broken the law many, many times in the last 13 months. But every email from the LA was making me very upset and anxious. I've spent hours and hours and hours dealing with a system that is totally broken when I should have been caring for my unwell daughter. And the worse thing is that the LA know what they are doing. It's certainly a systematic process of lying, blocking, misdirecting, gas lighting and stalling in an effort to save money. The experience of dealing with the LA has been worse than the experience of my daughter having a mental health breakdown._
- _Hellish and quite traumatic. Obstacles at every part of the way. Timely and constant unreasonable delays. Lots of inconsistencies and blurred lines between truths and untruths._
- _Needed counselling. Almost lost my job again - 3rd time this has happened and changed careers twice to care for my children to find a job that works CD or me around family Marriage issues Need counselling Child needs therapy She’s traumatised Anxious Sleep issues. My MH has been impacted greatly and so has the well-being of the whole family Financial strain in an already challenging cost of living crisis Basically awful._

- *It has been traumatic: - I had to leave my job - we've had to pay for therapy for him ourselves - I've had to pay for my own counselling be used of the strain.*
- *Every post 16 setting we looked at would not supervise at break times, even in the SEN parts of the colleges-which is bizarre. I have no idea where my child will be going from September. The caseworker(s) from the council have been less than helpful.*
- *Securing education, hmmmm. I haven't been able to secure anything since she last attended school in November 2021.*
- *Since the age of 11 my daughter has significantly struggled with school. I have tried and tried to get help for her since this time and it has only been in the last year that any support has been forthcoming. I was constantly told she didn't reach the threshold for support and now she is self-harming, suicidal, is leaving school this year with no qualifications due to lack of support and no further education place to attend. These issues have been years in the making due to ignorance around mental health in YP's and total lack of understanding (including by CAMHS) of girls with autism.*
- *My child started to struggle in year 6 and is now in year 9. She won't leave the house or leave me. It's been months- meanwhile my daughter is having no education and I am unable to work or leave the house and my own mental health is declining.*
- *It took two years for him to recover from the trauma of being in a mainstream school that didn't understand him and tried to force him to be like other children.*
- *The last three and a half years have been so incredibly challenging. To be honest I can't even go over how hard it's been. But suffice to say, the lack of suitable provision for an autistic child with SEMH and no learning disability coupled with the local authority's complete disregard for following the law have added unnecessary stress that at one point led to me being in hospital. The system is so broken, and the damage that is causing to families and young people is unprecedented.*
- *Following a breakdown at mainstream school, my son had to wait 1 and a half years until finding an alternative placement at a more suitable school. I have had to give up work to look after and educate my son at home, but he has lived in complete isolation and suffered severe depression at times, with no real help from LA caseworkers.*
- *The experience has been nothing short of traumatic for us all. And still, 4 years later we are being failed by the system and my child being not only let down but deprived of the setting she requires. We truly are broken, traumatised and exhausted. It pains me that my child is being denied the education she truly needs and deserves.*
- *Struggle, Struggle and Struggle. There is not Autism specific schools in at Secondary level for children with Autism. My daughter ended up in the only school available, [a] generic special needs school. To be honest I can only describe it as "complacent". They seemed to ignore all of my child's strengths and potential - everything was set at a basic level, and just get on with it. Everything was too much trouble. I noted my child's interest and abilities decline from Year 9 and felt helpless! There needs to be more specialist provision for Autism and other specific needs.*
- *In West Sussex there are Sixth Form SEND colleges - we have nothing like this for our SEND students in Brighton and Hove. They have to go into FE Colleges, this a potential nightmare for students with Autism.*

Large, busy, and difficult to manage, these FE Colleges are not appropriate for many, many young people with autism.

- *Without an EHCP (rejected twice) there seems to be very few options, especially for a child that can't attend school and won't engage with any kind of learning from home. Huge and stressful impact on the whole family.*
- *Horrendous effects for my whole family. both parents have had to give up jobs and have mental health issues despite being disabled themselves. loss of financial income has impacted on every aspect of life causing massive amount of stress to whole family.*
- *Horrendous. Fines being thrown around are no way an incentive to get your child to school. Schools have little knowledge of neurodivergence.*
- *Her emotional overload at having to attend mainstream school was so great that in the end, we had no choice but to 'elect' to home school. There were no other options and were advised by BHCC Home School team that there were no suitable schools for an autistic yet fully verbal and intelligent child in Brighton and Hove. We were told she was 'too special' for mainstream, but not 'special' enough for specialist schools.*
- *My son is 22 years old and in July his EHCP will be terminated, and he will be out of the education system. I believe they have the right to be in education until they are 25. He has still a lot to learn, but we cannot do anything about it, as we keep hearing 'there's no funding'.*
- *A relentless nightmare with no support.*
- *Our non-verbal, autistic child was referred to [a] specialist nursery but did not get a place. There are not sufficient places in specialist settings (nursery or school) to meet the needs of the children in the city.*
- *Experienced single parent bias and blaming and shaming of parenting.*
- *The whole process from when I first applied for a needs assessment has been (hopefully) the most distressing period of my life. I quit my job as a nurse because I was being called away so often. My relationship broke down.*
- *My daughter was approaching her GCSEs and struggling at school and although I really tried to support her with them I failed. She left school with nothing.*
- *Absolutely awful. My son has been demonised. Punished. I have never been listened to as a parent. Due to being completely demonised by the LEA It actually made my son increasing mentally unwell and is under CAMHS. It has had a devastating impact on our quality of life My mental and physical health. I have had to have frequent episodes of time off from work because I have been too unwell to work due to stress.*
- *Awful, traumatising. Endless appeals, tribunals, mediations. The LA actively put barriers in place to make it as difficult as possible.*
- *My child is only managing a couple of hours in school a day if that. He is in the gifted range of IQ but has significant challenges (ASC, PDA, ADHD, ODD, SPD, Anxiety). All of the [specialist] schools are full. He is therefore suffering from ever increasing levels of trauma in a very large primary school. I am frightened to take him out of education completely because I know at that point, without the backing of a school, we will be completely ignored by the LA.*

- *My son was left with absolutely no provision for over 2 years - he was rejected by EOTAS twice and left at home.*
- *Trying to secure an education for my child has been impossibly challenging. We ended up in crisis. We ended up removing our child from school as it was doing so much damage which then meant we had 'chosen' that action and would get no further support. Parents are put in the impossible situation of trusting the authorities with their child and when they are doing harm to then act and be abandoned with no help. This has enormous emotional and financial ramifications for the whole family as one parent becomes the home educator and carer. It took a year to undo the damage that school did, and we are expected to provide a full time secondary education with no resources. It's unconscionable.*

A.3. Education Health and Care Plan Experiences

- *"Horrific process that made many in the family sick with stress.*
- *The parent is left with the responsibility of navigating a completely crazy world, out of their depth whilst trying to fight for their child.*
- *Caseworkers meet all suggestions with claims that "managers won't agree that", without ever having asked. They're gatekeeping rather than advocate for the kids.*
- *You are told there is parental choice regarding school placement, but this is totally untrue: there is only a choice if you have the resources to go to tribunal.*
- *EHCP process needs to be sorted. It is damaging.*
- *Schools will only apply for an EHCNA when a child has completely failed. This is detrimental to the emotional and academic well-being of the child and class. Not to mention the stress and the blame that it puts upon the families.*
- *Nobody to contact directly, ridiculous amount of time waiting for answers, ignored emails, still no provision and child has been out of school over 3 years.*
- *Have been trying to reach my case worker for weeks, but no reply. I have an EHCP meeting coming up.*
- *reports and submissions are always late, sometimes received half an hour before the review meeting giving no time to read things and process them.*
- *Support has been less than appalling. Neither school nor LA follow required legislation. EHCP plans are generally 10 months late - following the Annual Reviews.*
- *Took LA to tribunal and got all provisions I requested. 5 months after and still nothing has happened and none of the agreed provisions have been actioned.*
- *LA didn't update the EHCP from when my child was in year 7 to year 11. We had annual reviews, but they were not updated in writing.*
- *EHCP has been sent to private tutoring company without consent and contains highly personal and traumatic information. Really disappointing.*
- *It was a very stressful time constantly chasing my caseworker and the impact this had on my mental health resulted in me contacting the mental health and wellbeing service at my GP surgery."*
- *The LA has broken the law countless times during the EHCP process. First they refused the EHCNA request even though my daughter was out of school, suicidal and physically violent multiple times each day. We were in crisis. The pain and distress we were all in was unbearable. She had had 19 accommodations in*

place at her primary school and it wasn't enough. Her school had run out of ideas. The BHISS worker was well-meaning but totally out of her depth. Once I appealed the LA after some weeks changed their mind and agreed to assess. We had to commission 3 private assessments at a cost of thousands of pounds. All 3 assessments recommended a specialist school and lots of accommodations and therapeutic input. During the draft EHCP stage I spent days pulling out all the needs and provisions from the reports and putting them in the Working Document. The LA then removed them all and issued the EHCP with no discussion and without my agreement. It's a useless document. I am now appealing the content, but the hearing date is October. 2023 – 12 months after I submitted the appeal. The LA is still refusing to agree to a specialist placement even though my daughter has been out of school for 13 months now and her mainstream school (which has an excellent SEN reputation) has said in writing that they can't meet need. It is very clearly just a delaying tactic to avoid paying for any education for my daughter. By the time of our tribunal hearing it will be 21 months since I submitted the EHCNA, and my daughter has had literally no educational provision or any therapeutic services from the LA in that time. She has developed an eating disorder, is withdrawn and depressed and rarely leaves the house. She's 8 years old.

- *I have applied a couple of times and been declined for my daughter as they say she isn’t behind enough academically. However she is unable to access huge parts of the curriculum and struggles emotionally, cognitively, and often misses out on huge parts of the day due to her being distressed and disruptive. She is diagnosed ASC and the school have exhausted all their options. And the local authority refuse to help.*
- *To turn our son down for an EHCP when he struggles so profoundly was heart wrenching. We have been left to struggle alone with no support.*
- *My daughters EHC needs assessment has recently been refused. The rationale is unlawful, and I am appealing. But this shouldn’t be the case. Many others won’t have the strength, capacity, or capability to go through this extremely stressful, difficult process.*
- *The EHCP system is broken - the child/young person is not at the "centre" of anything, there is nothing holistic about any of the process, it is all about cost, and putting barriers up to stop access to support, or just ignoring a child's needs. It is exhausting.*
- *I requested an emergency review a month before AR as my child was in crisis - neither the emergency nor the annual review (his first) have happened 6 months later.*
- *Annual reviews are NOT annual. Often every 2-3 years in my experience.*
- *The biggest problem with the Annual Review we have had for my then 15 year old was lack of suitable options when his mainstream placement had broken down.*
- *My sons AR for transition to secondary was painful. His needs ignored and no care taken about him transitioning from small primary to secondary education. SENDCO and myself requested changes but ignored even when evidenced.*
- *Annual reviews haven't been helpful at all.*
- *the EHCP is always late - 8 months after the Annual Review, and this was before Covid.*
- *Over the years my son’s annual reviews have been farcical. Sometimes with only his teacher in attendance and an unwillingness to raise or address crucial unmet needs.*
- *Following last year when it took 8 months to receive our draft review after the annual review, and only then when lawyers and MPs became involved I didn’t think it could get worse. However, this year the*

annual review itself was 11.5 months late! Even with constant requests from the school and ourselves. We were told "off the record" that due to the high number of new EHCP's (which take priority) and the low level of staff retention, it had been decided within the department to ignore the reviews this year. My child had three new diagnoses since his last review. And needed a significant amount of extra support. Because he did not have his review and receive this support he was excluded lots of times and was almost permanently excluded - it took a huge fight for this not to be the case. We are being so extremely let down as a family, and my son in particular as a disabled individual, resident in Brighton.

- *Time taken to amend EHCP after reviews is far too long. Typically taken 9-10 months to get final amended EHCP and that is with constant chasing.*

A.4. Alternative Provision, interim packages, EOTAS

- *"Long term "alternative provision" is not recognised within BHCC, and everything is aimed at getting the child back into school even when there is evidence that school it not a suitable environment for my child.*
- *Unreasonable level of evidence of anxiety required. When awarded, only 2 hours per week allocated on a temporary basis (4 months)*
- *Multiple months have passed without responding to my requests for alternative provision. When finally I did get communication no satisfactory provisions could be suggested.*
- *We were told my son could access alternative provision at the start of year 7. Six months later it isn't in place.*
- *We requested this and the LA are taking months to respond. Meanwhile my child gets nothing.*
- *We were not offered any alternative provision for years while my daughter was not in education. This is despite her secondary school reporting her as missing in education. They offered us and the school no support.*
- *We only got 6 hours which the LA recently cut to 3 hours.*
- *Brighton and Hove only offer online or at home tutors for EOTAS. This is not what EOTAS is. It is a much broader package than that. They seem to have no knowledge of what EOTAS and PB really are.*
- *We were informed today that her alternative provision will no longer be funded after the Easter holidays. So it looks like my daughter will not be offered any alternative education while we go through the appeal process.*
- *When we needed it - when unable to leave the house for several months - was never even made aware that EOTAS existed! No Ed provision offered at all.*
- *I asked the school about what they could do to help our son and it took 7 months for [school] to reply, saying they couldn't do anything at all unless he was willing to engage. He has long Covid, MH issues and a complex SEN profile with bouts of depression.*
- *He's home saying what's the point in his life when government is making such a mess of their lives and he's worried about having a future to live into*
- *The LA's response to his 'poor attendance', is to threaten us with legal action and issue a long line of detentions.*

- *The EHCP completely minimised my child's challenges. After being out of school for three years, he needs so much more support re-entering a placement.*
- *My child has previously accessed EOTAS but only after we fought for this with a solicitors help. We were only able to access 4 x 45mins sessions weekly.*
- *Child has Blended provision whilst on roll at a mainstream secondary. The provider is xxx. The first Tutor didn't turn up and it was months until another one was found. The second Tutor either couldn't understand or couldn't cope with the academic side of things. Finally the third Tutor has been brilliant. But this has taken a year. We also had online tuition with xxx provider. This was incredibly bad. At one point the tutor left during the middle of a lesson and simply did not ever return.*
- *Our 14-year-old daughter has been turned down for EOTAS on the basis that she is on the school premises for 50% of her timetable…but attendance actually in lessons is around 25% (no English or Maths lessons attended)."*
- *We had to fight the LA for a personal budget and EOTAS for our child. It took years and cost us a lot of money. As well as was incredibly stressful and resulting in my marriage breaking down. We were forced to go to tribunal to get our child's needs met.*
- *EOTAS took 2 years to organise but now in place it is great.*
- *I haven't been able to secure any education for my child.*
- *From Jan 2022, my daughter was receiving weekly sessions at [an] Equine Assisted Learning /Therapy. She also recently started mentoring sessions, via Mindjam. However, the LA just cut the funding for both of these alternative provisions. My daughter is out of school and is unable to attend. The LA claim that, since they have recently named a school in her EHCP, she no longer requires alternative provision. However, she has not even been able to visit the named school yet due to her anxiety; her professional reports state a long transition will be required, which is likely to "take months, not weeks"; the named school is not specialist, even though the LA agreed (in writing) that she would need a specialist setting; and, finally, we are appealing the named school since it is unable to meet needs (and we have this in writing from the school). [But] they have withdrawn funding for the current (limited) AP she has.*
- *I've been trying to arrange this for months and it's been a nightmare. There is no system in B&H for sorting out interim packages or AP. It all seems to be ad hoc, not clear what the processes is, where the money comes from. Caseworkers are clueless. The LA has messed up the definition of EOTAS and understands it to be one department within the LA that provides traditional academic tutoring to (mainly physically) unwell children. The tutors are mostly not SEN trained. The LA will only use 2 tutoring companies and they are both totally overwhelmed with referrals. We have been sent CVs for potential mentors for my daughter who are completely unqualified - have literally no relevant experience whatsoever. I've asked for a personal budget so I can find a mentor / tutor myself, but this has been declined. All the while my 8 year old daughter has been out of school for 13 months with no education or any support whatsoever.*
- *They have some work to do around safeguarding and management in my opinion…my son has been receiving some kind of EOTAS for nearly 2 years and I haven't been invited to a review or meeting of any kind. Nobody senior has touched base with me about his progress or what's working/not working. Also-*

tutors seem to use their own phones, emails and zooms and none of it is recorded or monitored. So far this hasn't affected us negatively, but I just find it bizarre!!

- *My child has been referred, I've heard nothing and have no idea what they do. It's been at least 6-8 months.*
- *We were told EOTAS is not given.*
- *EOTAS - Medical Tuition alternative provision rejected due to not meeting "the criteria". Awaiting alternative provision through the LA - The LA SEN manager advises it's the school's responsibility to fund and seek alternative provision but Law states it's the responsibility of LA so just keep going round in circles. Parent having to pay for alternative provision.*
- *EOTAS is an amazing set up. We have had really supportive and understanding tutors. It's a shame it's just for the core subjects though and doesn't cover other topics.*
- *We feel that the only option available to us now is to aim for a blended learning programme as there isn't sufficient provision in Brighton and Hove for a child like mine who is academically able, has no cognitive disabilities but for whom the mainstream school environment and classroom teaching system is detrimental to their wellbeing and educational development.*
- *3 years of total hell! Child now receiving EOTAS. Takes months and months of jumping hurdles and through hoops. child was out of education for 3 years and no provision despite desperate pleas for provision or help was constantly told no funding. The LA do not abide by the Law they work on their own policies, and they are unlawful.*
- *[EOTAS] absolutely appalling had no idea how to support my son at all. It made him worse and increased his vulnerability.*

A.5. Social care experiences

- *"I asked for help from social services when I was 4 weeks postpartum, and I was a single parent. My son had become so violent that I would be asleep, and he would attempt to attack me or his new sibling. There was never a break from the violence. It was all day, all night. I had no family support, so my only option was social services. I was shamed from the start. Made to feel like a failure. Told I was the problem.*
- *The trauma of my son being removed unnecessarily from everything he knows has had years long consequences on us all. It was honestly the cruellest decision made by a deeply unprofessional social worker who at the time I was too exhausted to fight.*
- *Despite suicidal thoughts and self-harm, CAMHS took months to take any action at all. I was told that because she had not attempted to take her life, she was not a priority. Even though she wrote it down and drew picture. I was told to hide the paracetamol and keep knives away from her.*
- *Our assigned social worker has consistently fabricated facts in assessments. She clearly has little understanding of autism and I have had to repeat many things to her in regard to my son's needs.*
- *SW had limited understanding of additional needs and the impact on the child and family.*
- *Complete lack of understanding and meltdowns were blamed on me as a parent and 'poor parenting'. I had to go on numerous Triple P parenting courses. Felt unheard and ignored.*

- *It took so long to get support from social services, asking almost weekly. At this point my son was physically violent to me on numerous occasions. He would run away to the point where the police had a safeguarding alert on my mobile number. I was unable to leave the house for days at a time because he wouldn't leave, and I couldn't leave him with anyone. When I finally got someone from social services it was an Early Years help worker who talked to me about trying reward charts and setting boundaries. I was essentially in an abusive and controlling relationship and she was suggesting I offer a sticker if my son brushed his teeth. She was completely out of her depth with the severity of the situation.*
- *If social care In Brighton and Hove were a person it would be a narcissistic, violent, and pathological liar in the body of Mr. Blobby…aimlessly bashing around, destroying everyone and everything, totally oblivious to the harm caused.*
- *Dangerously ill-informed about Neurodivergence. Caused more harm than good then just referred back to CAMHS who already couldn’t help. Terrifying process.*
- *Took a very long time, over a year for panel to agree my child was eligible and now a year later still no P.A. or respite.*
- *Front Door for Families interviewed me. A horrid experience as they clearly didn't understand autism.*
- *The social worker doesn't seem to have a clue. [She] said to me it's rare to have an ASC child that doesn't want to leave the house. There was things on reports that I had to correct that was not factual. She doesn't seem to be aware about ASC at all.*
- *My child also is now on antipsychotics due to severe mental health issues. The SW [is] trying to force him back into school which would be devastating for his mental health. The focus on education for a child who wants to die and can’t leave the safety of his room without self-harming is bonkers, and harmful, and parent blaming, and child blaming.*
- *Whenever I ask for respite they say that this doesn't exist anymore.*
- *We pleaded as we're in crisis for respite and was told there's no money, the threshold is too high and your children are not physically disabled enough, despite two being home full time, with complex needs.*
- *The Children's Disability team refused to assess his needs as he "doesn't have a learning disability" so we couldn't access respite even though his challenging behaviours were the same as a child with a LD!*
- *4 referrals have been made to Front Door for Families (2 by the school, 1 by us, 1 by GP) - received calls from case workers who said there was no support available for us because our son is ‘only’ autistic.*
- *The lack of support by social care for those without a diagnosed intellectual disability is shocking. You are nearly always turned down as it being a MH problem. But it’s far more complex than that.*
- *They offered things they knew they could not deliver, and none of it was tailored to meet needs.*
- *Disability Social Services is not fit for purpose. They give nothing.*
- *Unfortunately I'm disabled too and whole lack of social care has not only affected child and siblings’ wellbeing but also worsened my own, leaving me unable to work. Reason we were turned away was that child doesn't have learning disability.*
- *I am a single adoptive parent to a child with complex medical, social emotional and mental health needs. When I became seriously unwell her specialist nurse and psychotherapist have contacted the team three times and they have not even responded leaving us with no help or support.*

- *I asked for help but NO, they parent blamed, and we even had threats of taking my daughter away if she didn't attend school. Disgusting treatment for a family that needed support.*
- *The overall feeling was of not being believed.*
- *Their involvement has been so stressful and so damaging we don't want their help at all.*
- *They took an already stressful situation and made it ten-times more stressful. They don't help families in need. There's no support, only empty promises.”*
- *After three years begging social services to be involved, because I am so worried about the safeguarding of my disabled son AND my other two younger children, social services are finally involved, and I am astounded by the lack of understanding about my son’s needs and the lack of support for our family. The social worker sees my disabled son as a problem to be ‘gotten rid of’ to safeguard his siblings and is very focused on him being removed from our home despite him being a very vulnerable 9-year-old. The social worker has only worked with one other family with an autistic child before ours and therefore compares constantly but also admits she has no real understanding of the condition. My son has very complex needs and yet because he does not have a learning disability, he cannot be seen by the disability team who have an understanding of my son’s disability and are able to support more appropriately.*
- *They gave us advice which was not appropriate for an ASC person with sensory issues such as stand under a freezing cold shower for anxiety. I do not think they have a clue that a teenage autistic boy is extremely difficult to get in the shower in the first place and with sensory issues is never going to get in a cold one. The advice given was more appropriate for a neurotypical adult. I was so fed up I did not bother to complete their feedback form.*
- *The GP we saw suggested joining a club or sports team, again no use to an autistic anxious person. Fighting for everything and filling in a mountain of paperwork to continually prove the need is exhausting, draining and negative. It is almost easier to carry on without help. All the 'social care' we access now is via friends of kids with similar needs, the Mascot groups or Amaze.*
- *We have had no intervention with social care until May 2022 when my daughter presented as suicidal in A&E. We are lucky enough now to have a very good social worker, but we have had years and years with very little support or understanding, during which time my daughter’s mental health has deteriorated significantly.*
- *Awful*
- *My understanding is unless your child has profound learning disabilities there is no support from social care. We get support for our older son and was made to feel bad for asking and that we should not approach unless we were a family in crisis whose kids were neglected.*
- *Waited 13 months for assessment. Since assessment has taken place been waiting 3 months for an outcome.*
- *Huge lack of resource and provision. Total lack of duty of care.*
- *Terrible*
- *Lack of staff training and awareness of SEN issues to support families properly.*
- *We have been told many times by various services that as my son does not have a ‘learning disability’ he does not meet the CDS criteria. However, on learning I am legally entitled to the carers assessment I requested one. It was done by a student social worker who had never done one before. Through tribunal*

we were awarded 6 hours PA time for my son. However, no PA has been found as the pay offered was so low. Our social worker has since signed us off as it was felt they could not do anymore to help. A clear social care need has been shown but they are doing nothing to fulfil their care responsibilities.

- *Yet again no resources to meet the need, been a long battle - I must have had 12/14 different professionals providing reports - but I have no provision??!!*
- *Still no response from any organisation with regard to social care.*
- *Awful, zero support.*
- *As a teacher and aspiring SENCO of 20 years, I'm more qualified than the professionals who work there and give out advice. A waste of time. You need to be seen to be cooperating though/ so go through the tick box motions. This takes up my time and no one benefits.*
- *Stressful, upsetting, ill-informed, made to feel a burden and wasting time, judgmental.*
- *Very challenging. It takes years or indefinitely for social care to understand the complexity of the needs. You feel disbelieved or an over-reacting mother. The resources are shameful and the creativity to think outside the box is negligible. There is no point in having outstanding special schools if the wrap around care for families doesn't exist. Everyone passes the buck in social care management. It's a very demoralising and frustrating system to deal with.*
- *It's a I felt like we are alone to struggle on.*
- *Had a family coach for 9 months who was amazing. There has been zero support since that ended despite multiple referrals to Front Door for Families by the school, GP, and police. We are told that there is nothing more they can do for us and CAMHS are the best people to help. We have called 999 only to be told to call social services. We call social services, and they tell us to call CAMHS. We call CAMHS and nothing happens.*
- *It took a long time to get in place for our family and was too late for one of our children (he was an adult by the time we received help and was not eligible)..*
- *Not fit for purpose. Autism not seen as needing social care support. My son is socially isolated and struggles accessing the community and no support given as has ASC.*
- *We were allocated a Keyworker. It was excellent in the early years. It's completely different now. I cannot get hold of anyone, nobody cares, and the support is just not there, AT ALL!*
- *Not accessible due to lack of intellectual disability.*
- *CAMHS put in a referral to social services regarding my son in the summer. The social worker carried out an assessment with us and I never heard from her again.*
- *Took a very long time to secure 18+ months support for 10 weeks of sessions.*
- *Gaslighting, endless signposting from one service to another ending up going round in circles with no outcome. Strain on the whole family, my son's mental health has been affected by my daughters' behaviours, we have no support/guidance on how to manage my child's mental health. Family now is in financial hardship as I had to become my daughter's sole care giver 24/7. I have sought help, I have applied for an EHC needs assessment, was turned down because we did not have enough services involved!! because the wait times to access these services are insane! My child was on a reduced timetable the 2nd week she started secondary [school] because she could not cope and from that she*

only attended an hour a week, yet that still was not enough to trigger any support from either school or services, this resulted in my child having an autistic burnout leaving her mental health in crisis.

- *When we asked for help, they refused to undertake an assessment, my son does not qualify for a disability social worker despite a diagnosis of autism, ADHD, depression, and anxiety. I experienced a lot of parental blame. Thoroughly negative experience. Social workers had no or very limited understanding of my child's needs.*
- *I feel like we had every intervention thrown at us. They have made limited difference as I have been using all these strategies for years and probably have more expertise than the social care professionals. Feel 'obliged' to say yes to everything to show that I am working with them. Really, I just want to be left alone and not be blamed for my children's neurodiversity.*
- *Social care - took nearly a year to secure SW input despite several police incidents. Finally given amazing, dedicated SW Resource Officer who is mentoring my son weekly but otherwise limited input and one SW was parent blaming (others fine). No provision for ND kids without LD in disability team. So, no respite provision related to that child even though I'm emotionally drained and trying to care for PMLD (profound & multiple learning disabilities) child at same time as managing outbursts from my ADHD child.*

A.6. Health care experiences

- *"My child has struggled since a very young age, in the last 5 years alone my child has tried to jump in front of cars, trains, and recently cut his wrist to attempt suicide. 60% of his body is covered in self-harm. Yet he, and we, get no support.*
- *He was wanting to die and taking frightening actions. CAMHS did not feel he needed any support and discharged him after one initial meeting.*
- *CAMHS .... I'm trying to think of the right words to describe them that isn't too rude..... Inept, negligent, neglectful, thick. They don't know enough, they don't care, they have people working for them that shouldn't be anywhere near vulnerable kids.*
- *Total lack of any continuity or support at all until she tried to take her life last year. Within CAMHS I am utterly shocked at their lack of knowledge around girls with autism presenting differently to boys. During her face-to-face assessment my daughter was told 'you don't look autistic' by the ASC professional assessing her!*
- *We had to have a private autism assessment due to the waiting list being 3 years long. Because we went private, we did not have any follow up support. Our child was then on the waiting list for CAMHS for over 3 years, led to them becoming more depressed. Is now anorexic and seriously depressed. Something that we feel, if treated quicker and in a better way, could have been prevented.*
- *My child is still waiting for CAMHS appointment (2.5 years on) for ADHD as he was not considered autistic at Seaside View. 3.5 year waiting lists for child mental health initial consultations is an absolute disgrace. By the time they get seen, the difficulties have turned into full-blown problems and even severe and crippling disabilities. There is no structured support, and it feels very much as if the waiting list only exists to hide the fact that the services do not really exist in the first place.*

- *It has been so awful to the point my son became suicidal, assaulting me, nobody listening, I had to contact the local MP to get an appointment for my son. Front door families offer nothing other than telling you, you can do some parenting programmes.*
- *The autism assessment was good but by the time it came his mental health had significantly declined as mental health professionals and teachers did not understand how to keep him safe and pursued strategies that only accelerated him towards deeper crisis.*
- *2 1/2 years down the assessment pathway for ADHD and still in stage 2 of CAMHS' waiting list. Despite getting a private assessment which follows NICE guidelines, we are still waiting, and my son's condition is getting worse. School and BHISS are excellent though. But they cannot prescribe medication.*
- *CAMHS non-existent - even during major crisis. We waited over 4 years for ADHD diagnosis, no support over that period. I feel the delay and lack of input has led to my son's school placement breaking down. If [he] had been seen when he was 10, we might well have had a different life (he would have tried medication for one thing).*
- *Nothing available. Had to privately fund assessments and support.*
- *CAMHS are currently not answering emails, have been waiting to hear from their neurodevelopmental team since October.*
- *Currently waiting for a CAMHS appointment (2.5yrs since referral) also daughter was referred and assessed at wellbeing as High Risk, was referred to counselling last August 2022 still waiting. My daughter has panic attacks that turn into silent convulsions. When I called Wellbeing services for help, they just advised for my child to call the crisis line!*
- *We have had to go privately for autism assessment and for weekly sessions with a therapist. We have not used any of the council services due to the length of waiting lists and the mental health of our daughter. If we were not able to use private services, I think we would be in a very different situation and our daughter may have ended up self-harming or refusing to go to school.*
- *Long wait times and when initially seen, a frustrating appointment and was told he didn't have autism. We were dismissed and struggled to be seen. When we eventually were seen again, by the same individual, they admitted they were wrong, and my initial concerns were right from 2 years prior!!!*
- *CAMHS have been terrible. A long wait then a video call for mental health assessment based around self-harm. Insensitive questions. Clearly no understanding of young people or autism and was supposed to be a specialist in both.*
- *My child did see a play therapist via the wellbeing service - this took 18 plus months to come through and had limited success, mainly due to lack of training/ information about girls with autism I would say. Therapist unable to break through to my child; talking to a stranger about her feelings is something my child with ASC finds too difficult/ is not realistic. I feel there should be another approach or support for introverted children with ASC.*
- *Massively long diagnostic waiting lists, detrimental to the child and wider family. We paid private for an assessment which was positive for ADHD, but this is not accepted by CAMHS. We are having to pay privately for medication which gives our son a chance at school. We felt we had no choice as he was labelled disruptive.*

- *Our request for an occupational therapy assessment during the EHC assessment was seemingly ignored by the LA. After paying privately for an OT assessment, only then was an NHS appointment for OT assessment offered.*
- *We actually pay for private speech and language sessions for our son as the so-called provision he was promised never materialised.*
- *This is to do with CAMHS. The involvement of the FISS-ASC team was not helpful for my son, as he would not engage with it. My son has since had an assessment with CAMHS Depression and Anxiety pathway and was referred to group sessions, but he has stopped attending, as he felt they were not helping - his depression has become worse. The referral pathway is so long that opportunities to engage my son have often been missed when he was willing.*
- *Traumatic, difficult, frustrating, upsetting, demoralising, anger-inducing. Told incorrect information, told contradictory information, sent from pillar to post, having to repeat information again and again and relive traumatic things to yet another person. The lack of support and help has damaged my child's mental health, my mental health, and the wellbeing of our family. An "urgent" appointment takes months to obtain and then you are left for another few months without any practical help. The whole system is just appallingly funded.*
- *We have had no post Dx support whatsoever despite requests and a highly impacted child with high needs unable to access school or any activities suitable.*
- *It has been extremely frustrating, stressful, exhausting and upsetting.*
- *Pre-school assessments for autism and speech and language were fairly quick but it was almost impossible to secure an EP and OT assessment once he was at school. Had to pay a lot of money for private assessments despite my son struggling a lot with learning and anxiety.*
- *Waiting lists unacceptably long. Over 2 years for ASC assessment and 2 years between appointments. Communication afterwards is bad, varying between inaccurate facts, lack of/no follow up support, told something would be provided (psych support), then told it wouldn't be. Impossible to get information about an appointment to be able to prepare autistic child with anxiety about doctors/new people. Tactless and unknowledgeable doctors. Doctor rude on phone, defensive and dismissive when I was seeking support for my child.*
- *We received excellent care from SSV in the early years. This is then handed over to the school, but the same level of care isn't offered at the school. I'm quite sure he should be seeing an OT regularly and getting more incontinence support. I used to have a fantastic Keyworker but now I'm lucky to get any communication with the social care team. No responses to emails or phone calls. I have to nag for months to get anyone to talk to me. It's really bad. No one is telling me what we should be getting help with or directing me to get that help. Feeling very alone and as a single parent I feel quite lost with it all.*
- *No mental health support, they don't know how best to support so no support at all. Struggle to access hospital due to extreme dysregulation, no alternatives offered. Had to fight to get my son seen by Seaside View for physio instead of at the main hospital. There is no alternative for children who's can't access hospital appointments due to sensory overload and PDA.*

- *No support for PICA or restricted diet. Saw dietician once then discharged. No OT assessment offered. my daughter craves sensory feedback and eats nonedible things. My daughter is very vulnerable, craves boy attention does not see danger no support offered except in school but not enough.*
- *Still awaiting assessment for ADHD and ASC. CAMHS waiting times are shockingly inadequate.*
- *Too little too late. Disappointing. Disjointed. Disillusioned with the support systems in place. A real struggle and quite exhausting.*
- *CAMHS sort of came to us due to an incident but then there was nothing but long waits and no information. There was no way to contact anyone directly, the telephone was never answered.*
- *Waiting list for CAMHS is a joke. We make plenty of calls to the emergency line - someone calls back and says they are concerned about our situation and will raise it internally to see what help can be provided. Then we hear nothing.*
- *We've had limited experience but have had to pay privately for autism assessments for both my children, for speech and language support, for mental health support. Of course, CAMHS are not fit for purpose, but everyone knows this. Their understanding of autism and how to support the MH is autistic people is very, very, dated, ableist and could be quite damaging.*
- *Was misdiagnosed at young age, then left. Never reassessed, until crisis. Slow and unsupportive.*
- *CAHMS has failed my children. After 2 1/2 years, I had to pay for a private diagnosis which took 3 months from start to finish. We are still waiting to be seen and medicine to be prescribed. Our GP cannot do this. My children are failing.*
- *We are still waiting for CAMHS to offer an ASC assessment & probably will be waiting for years. I believe this affects an EHCP assessment. She had an assessment with the Wellbeing Service, we are now waiting to hear about counselling...I worry how bad does she potentially have to get before she/we are heard??? I'm sure an adult wouldn't be left in a similar situation!!!!!!!*
- *My child was referred twice for ASD assessment and the referral was refused for various reasons including being happy at school and going to school outside of Brighton and Hove. This was despite an OT assessment saying my son had significant sensory processing difficulties and despite the fact that he had begun self-harming and was increasingly distressed due to autism related anxiety. He was referred once for ADHD assessment, and I just never heard anything. In the meantime, he was diagnosed privately with ASD and ADHD. If I hadn't had the resources to be able to do this, I would still be waiting now, and my sons needs would have continued to be unmet.*
- *Healthcare in terms of Seaside View Paediatricians, SALT, OT are utterly fantastic. The ASC panel is a mess. Anyone involved from the LA is just disgraceful. And our previous involvement with Health Visitors was also a very poor experience.*
- *It has taken at least 4/5 reports and assessments for my child to finally be accepted onto Adult Disability Team, (not children's disability service) as the process took so long! I have had to share the same information time and time again. I feel it takes so much out of parents to get the support their child needs.*
- *Thresholds to get an OT/SALT assessment is ridiculous. Children with ASC and sensory processing disorder alongside selectively mute are not meeting the threshold to get a SALT assessment. Ludicrous. There must be many parents who just give up, as there are so many barriers.*

- *CAMHS ASC FISS service is not fit for purpose. It is not a bespoke service. This service puts undue pressure and stress on families that already are in crisis. Took over 5 years to get support for them to disregard our family after just 8 months and close with no further support at all. Disgraceful.*
- *It is a battle to get referrals and then the assessment process takes literal years. She is unable to access all the support and resources she needs through this long process, which just makes everything worse.*
- *Local authority provision is appalling. I have had to fight for fourteen years to get the support for my three children.*
- *B&H authority SEN provision is absolutely useless.*
- *The process is too slow, and the information provided during, and post assessment is borderline inadequate. The people in the service we have encountered have been nice and helpful, but the system is not working. The system is the real failure here, not the people working within it.*
- *Autism assessment process really time consuming. Some of our child's behaviours at home are really challenging and despite now having a diagnosis we do not feel we are particularly supported in knowing how to handle our child's difficult behaviours - we are just left to get on with it. We are not able to focus sufficient time on our younger child.*
- *CAMHS never respond to my multiple phone messages, only to say that I've been discharged and need to reapply for the waiting list.*
- *I'm not really sure of the care that is available. Apart from school input, we are on our own.*
- *The process of getting an assessment at Seaside View is ludicrous. Initially we were dismissed, the main reason he was doing ok academically, which seemed to imply that autistic children couldn't do well at school and that they had no knowledge of autistic masking. I had to email, write, and leave phone messages before I even got a reply and a first appointment. We had absolutely no idea what was to happen or that we'd need a second appointment. They couldn't even send the appointment letter to the correct address and if it hadn't been put through the door we'd never have known.*
- *Referred to CAMHS for an ADHD assessment but eventually went through financial struggles to get a private assessment as the wait times were so long. The neurodevelopmental service is appalling for waiting times and contact.*
- *The whole diagnosis process fails children and impacts severely on their schooling.*
- *Whole families not just the child is affected by process.*
- *Very little intervention for self-harm & suicide, parents told to go on courses.*
- *No support for families in crisis*
- *No preventative intervention, just crisis management, if lucky*
- *CAMHS and AMHS dangerous, disjointed, poor notes, siloed, accusatory, ill informed.*
- *Brighton and Hove autism panel refused to even consider my child for assessment. Her consultants were shocked to say the least, so they organised for this to take place at The Evelina."*
- *GPs were fairly hostile when I went to them for help with child's anxiety. Wellbeing Service was good, but they don't appear to be operating any actual courses anymore, such as Art Therapy and Drama Therapy. My son did Drama Therapy through YMCA and it was highly effective. He loved it, and he is painfully shy and anxious. I wouldn't know CAHMS if I fell over them in the street, such is the utter absence of them in my son's life. Please improve the services for ASD.*

- *Dangerously long waiting times for CAMHS referrals.*
- It is a struggle to get any "paperwork" side like a diagnosis from the local authority and the wait times are insanely long and dispiriting.
- *Terrible CAMHS provision. Dismissed my son as “unlikely to engage” but that’s exactly why he needs support. Waiting list beyond 2 years for ASC assessment which is damaging.*
- *CAMHS is still the biggest issue in terms of getting an ADHD assessment for my already diagnosed ASC son. We have been waiting nearly 3 years and by the time we actually get a diagnosis and move into any medication that may be needed he is likely to be in year 8/9 of secondary so he will have missed out on accessing so much of his education - how can he be expected to catch up at that point? It is so unfair on the individual and the wider family, who knows what/who he could/would have become if he had been given the early intervention support, he so desperately needs!*
- *Waiting times are ridiculous and damaging.*