

## Family Voice Norfolk Consultation on SEND Funding

### Consultation

Parent carers of children and young people with special educational needs and disabilities (SEND) were consulted in July 2019 via an online survey to inform this report. Family Voice Norfolk will share this report with the Department of Education (DfE), the National Network of Parent Carer Forums (NNPCF), Norfolk County Council (NCC) and our own membership.

### Background

Family Voice Norfolk (FVN) is a collective of parent carers from over 880 families across Norfolk and represents 1,092 children and young people (0–25 years) with SEND. FVN has been the strategic voice of parent carers working in partnership with NCC and the five clinical commissioning groups (CCGs) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and by the five CCGs. It is a member of the National Network of Parent Carer Forums (NNPCF) and the Eastern Regional Parent Carer Forum (ERPCF).

12.5% of pupils in Norfolk are on SEN Support (11.7% nationally) and 3.1% of pupils have an Education, Health and Care Plan (EHCP) compared with 2.9% nationally. NCC have around 6,500 EHCPs. Tribunal figures are higher than they have been since 2011, mainly lodged for special school placements, as parent carers feel that mainstream schools are unable to meet their children's needs.

While it is very difficult to distinguish between cuts in services that are solely related to the High Needs (SEND) Funding and cuts in other educational funding, we asked parents to tell us whether funding had been given as a reason why services for their children and young people with SEND had been discontinued, reduced or denied.

Parent carers were invited to complete an online questionnaire and had the opportunity to add further comments on their experiences of SEND funding. The survey ran from 15<sup>th</sup> to 19<sup>th</sup> July 2019 and FVN received 185 responses.

We would like to stress that with a brief time to complete the questionnaire, and at a time of year that is very busy for families, especially those already dealing with additional difficulties, this is a huge response for us, showing how strongly families feel about this issue and how powerless many parent carers feel to ensure that their children have the services they need.

### Key Messages

- Over 80% of parents who responded said they had experienced a discontinuation, reduction or denial of services for their children and young people with SEND with lack of funding being given as a reason. Of these:
- 46% of parent carers said that they had been specifically told that this was due to lack of SEND funding;

- 34% of parent carers said that they were not sure if cuts in SEND funding were the cause but were certain that the lack of services had had a negative effect on their children and young people with SEND.

Parent carers reported that the results of lack of services included:

- Failure to diagnose children and young people quickly enough;
- No services for children and young people even after diagnosis;
- Parents privately funding assessments and getting into financial difficulties doing so;
- Schools openly saying that they have no money for children and young people with SEND;
- Children, young people and parent carers suffering from stress, anxiety and low self-esteem;
- Families facing crisis through emotional, financial and mental health stresses.

### **SEND Code of Practice**

The SEND Code of Practice: 0 to 25 years sets out statutory guidance for those who work with and support children and young people with SEND. Many of the key principles in the Code are not being met and children and young people are being let down and failed by professionals employed to help them. Here are some factors that the key principles are meant to support and what the survey revealed:

*The early identification of children and young people's needs and early intervention to support them*

- Children and young people's needs are not being identified as they are unable to access services such as educational psychologists, occupational therapists and speech and language therapy.

*Greater choice and control for parents and young people over support*

- Children and young people are being refused SEN support, thus have no choice or control over it.

*Collaboration between education, health and social care services to provide support*

- "Cannot get a pediatrician appointment without educational psychologist report ... just stuck in limbo."
- "Education professionals seem to be making decisions best left to health professionals."

*High quality provision to meet the needs of children and young people with SEN*

- "Having no 1:1 in September is going to affect my sons progress. He is non-verbal and having to go into a mainstream setting because 'SEN settings are full'."

*A focus on inclusive practice and removing barriers to learning*

- Children and young people are being permanently excluded and on reduced timetables due to lack of support.
- There are significant barriers to learning as children and young people are unable to access the necessary specialist equipment.

*Successful preparation for adulthood*

- "My son is now almost 22 years old and only just 4 months ago the transition to adulthood has started."

## Findings

Over 80% of parent carers had experienced services that had been discontinued, reduced or denied either specifically because of lack of SEND funding or because of general lack of funding for education. Almost all of the remaining 20%, many of whose children attended special or complex needs schools or were out of the school system, cited examples of cuts affecting other families.

46% of parent carers had been told that access to services had been discontinued, reduced or denied specifically due to a lack of SEND funding. Of these parent carer responses, cuts had been to one-to-one provision, intervention and transition services (76%), obtaining assessments (71%), specialist equipment (19%) and after school clubs (15%).

Children and young people are reported as:

- Suffering increased levels of anxiety and stress and lower levels of self-esteem;
- Falling behind peers and struggling to keep up;
- Being permanently excluded or on reduced timetables due to lack of support;
- Being refused SEN support and 1:1 support that is specifically written in their EHCPs;
- Waiting for places at special schools because mainstream schools cannot meet their needs;
- Being unfairly disadvantaged;
- Unable to access services such as educational psychologists, occupational therapists and speech and language therapy;
- Unable to access the necessary specialist equipment;
- Being taught by inadequately-trained teaching assistants and teaching staff, who are not adequately trained to support their children's needs.

Parent carers were also asked what impact this was having on them and their families and said they were:

- Suffering significant emotional stress and anxiety that had an effect on marriages and family relationships;
- Worrying about who would look after their children when they are no longer able to;
- Angry and frustrated at the lack of funding and provision;
- Suffering significant financial difficulties with having to fund assessments privately and loss of income from not being able to work;
- Constantly having to fight for services that are clearly set out in EHCPs;
- Enduring social isolation;
- Feeling desperate and living from crisis to crisis.

Parent carers were asked who had told them that SEND funding cuts were affecting services (they could indicate more than one source) and over 80% said that the educational setting had told them, while 42% said that it was the local authority and 7% said it was social services.

Many parent carers gave examples of communication with educational settings:

- "School are always telling me that their SEND funding has been cut and they can't afford things. They even asked me last year to fund (or find sources of funding) for my son to have a 1:1 teaching assistant.";
- "Schools are really struggling with providing SEND resources and are having to make huge cuts.";
- "School has told us they don't get any extra funding for children with SEN.";
- "My school SENCO has no idea if my child is on the school's SEN register. But there is no money anyway apparently, even if he was.";

Of the 54% of parent carers who said that they had not been told that lack of SEND funding was the reason for services being discontinued, reduced or denied, many of them cited

general lack of funding as the reason they were not receiving services. Parent carers say that they are:

- Unsure SEND funding is being used specifically for children and young people with SEND;
- Aware that there are not enough places for children to attend special and complex needs schools or special resource bases attached to mainstream schools;
- Struggling to get a diagnosis for children with ASD;
- Struggling to get support for middle-needs children;
- Aware of a lack of 1:1 support and teaching assistant support in classrooms.

Schools are required to publish information about SEND funding. When asked, only 9% of our parent carers said that their educational setting published information on its website about how it spends SEND funding. 37% said no, their school did not publish information and 54% of parent carers did not know.

Following on from this, parent carers were asked if they knew how much their child's educational setting was allocated for pupils with SEND. 86% of parent carers did not know, with only 14% knowing the SEND allocation. One parent carer said:

- "I would like to know how much funding each child is actually allocated and how it is spent. I have asked repeatedly for my son's information."

78% of parent carers said that current funding arrangements were having an effect on what could be put in place for early intervention. There would need to be a shift in thinking and funding if early intervention strategies were to be adopted and implemented. However, without early intervention, there will be more crises later on, such as exclusion, mental health issues, financial difficulties and marital breakdown, which, ultimately, is more expensive to fund and adds stresses to other government-funded services. Parent carer comments include:

- "Life is tough enough without constantly being turned away every time I ask for help."
- "Hardly leave the house. If we do it takes days to recover."
- "It has left me unable to care for my children for 3 months due to mental health illness."
- "Living from crisis to crisis. Living with constant uncertainty."

In just under a week, 185 parent carers completed the survey. Below is a chart of the ages and educational settings of their children and young people.

	Mainstream	Complex	Home Ed	Not in school	<b>TOTAL</b>
0 to 4 years old	4.9%	0.0%	0.0%	0.0%	<b>4.9%</b>
5 to 11 years old	42.2%	9.7%	0.5%	0.5%	<b>52.9%</b>
12 to 16 years old	17.3%	9.7%	1.1%	3.2%	<b>31.3%</b>
17 to 21 years old	3.2%	5.0%	0.0%	0.6%	<b>8.8%</b>
22 to 25 years old	0.5%	0.5%	0.0%	1.1%	<b>2.1%</b>
<b>TOTAL</b>	<b>68.1%</b>	<b>24.9%</b>	<b>1.6%</b>	<b>5.4%</b>	<b>100.0%</b>

The smaller number of respondents for older children and young people reflects, we believe:

- the fact that many young people have no access to continuing education between 18 and 25 because courses where progress is measurable by traditional means 'run out', whether their EHCP outcomes have been met or not;
- parent carers have less contact with colleges than with schools and less knowledge of whether their young people's needs are being met;
- it becomes therefore more difficult for parent carers to advocate for their young people.

## **Comments from Parents**

The following appendices contain all the comments from the survey and are the voices of our parent carers. They do not make for easy reading but vividly demonstrate the degree of frustration, anxiety and anger that parent carers feel.

When an educational setting tells families it cannot afford services, parent carers have few ways to respond constructively. Those who can afford to self-fund, do so, but this is a small proportion of parent carers. It should be borne in mind that no parent carer who is raising a child or young person with SEND is likely to have been able to maximise their own earnings.

Parent carers do not usually feel that it is their role to challenge the schools with which they need to have a productive relationship. Those parents who have responded to our survey are among the most proactive. Many more, through their own difficulties, are less able to articulate what they experience.

- Appendix A – How has the lack of services directly relating to SEND funding affected your child or young person? – pages 5–8
- Appendix B – How has the lack of services directly relating to SEND funding affected you and your family? – pages 9–12
- Appendix C – Comments from parent carers who said that lack of funding was NOT the reason that access to services had discontinued, reduced or denied – pages 12–14
- Appendix D – Comments from parent carers who said that lack of funding WAS the reason that access to services had discontinued, reduced or denied – pages 15–18

## Appendix A

### How has the lack of services directly relating to SEND funding affected your child or young person?

- Can't go to holiday club.
- Has stopped my son doing something he loves.
- My child has been discriminated against in a variety of ways. He has been denied access to wrap around care, admitted access but with conditions attached (I.e. restricted access).
- She no longer gets valuable practice at independent life skills away from us at a time when it's more important than ever ie becoming 'an adult' next year. NCC want to 'assess' her to see if she can catch public transport to school next year!!??
- They have not been diagnosed.
- Won't affect until after April 2020 when funding is reduced/ withdrawn.
- Cannot get a pediatrician appointment without educational psychologist report...just stuck in limbo
- They have been refused SEN support.
- Not getting the full support from school, and opportunities to diagnose ASD is lost, as school is only interested in kids with obvious outwardly traits
- Quite badly.
- We have had to pay privately for SLT and OT support as our son needed the support, which wasn't available.
- Delayed diagnosis and support, loss of education, mental health difficulties
- Hasn't been assessed in six years, not making progress academically in his school yet nothing done to address this
- Extreme anxiety and self-harming in class
- Severely
- Anxiety
- There is no alternative service
- Is only in school for 10 hours a week!
- No academic improvement
- Less access to weekend and holiday daytime services therefore less variety in his social activities.
- He has missed a year of school.
- My son is now almost 22 years old and only just 4 months ago the transition to adulthood has started, very slow, he still doesn't have a Social Worker signed to him and our battle to fight for his basic rights carries on as the provision of 4 hours support a week seems to be abundant in the eyes of the system.
- Child is acknowledged as a non-independent learner yet school states that teaching assistant is only affordable for part of the year 1 day (the morning). This means every afternoon with 30 children, 1 teacher and 3 SEN children in a classroom (those are whom I am aware of including my son, there may be more). This applies to year 1 which is the next school year for us. Reception had a full time TA. We are nowhere near being able to provide 1:1 for my son.
- He isn't able to take part in certain activities because he needs additional support and they can't provide it due to lack of staff and funding.
- At the moment there hasn't be any change.
- Funding for PA time has been reduced so... less PA time.
- My child has been discharged from the speech and language therapist in February 2018 and I have just found out about it now! We are in July 2019! He has received NO sessions since then and for over a year I have been worried that his speech had gone worse.... I am furious!
- Having no 1:1 in September is going to affect my sons progress. He is non-verbal and having to go into a mainstream setting because "SEN settings are full".

- I cannot even imagine how my son will cope at school without a 1:1 support in September. 1:1 will be taken away from him due to lack of funding which is really unfair.
- It has made his school day more difficult and stressful than it needs to be.
- Impact will cause more long term issues. Emotionally etc.
- Unable to receive necessary support in school. Falling behind. Damaged self-esteem and confidence.
- My son is nearly 3 years behind at school, there is not enough money for the school to provide more direct teaching on a daily basis that he needs. I have also asked early years for help and they have not supported us at all.
- He already struggles enough, now he has no personal support.
- Son is very frustrated and is falling further behind his peers as school cannot offer one 2 one as his EHCP states. Feeling low and low self-esteem. Longer wait for professionals meaning he requires their assistance more.
- I don't feel they have been able to access services and support they would otherwise have received, this has had the effect of causing stress and unhappiness for my child, and they have been unable to get supported.
- Badly
- Non-attendance.
- Medically signed off school due to stress and anxiety.
- Severe anxiety and school phobia.
- Emotionally he is really struggling leading to problems with work in school.
- My son needs a one to one which even the headmaster says he needs but they won't provide it due to funding and I have been told not to bother applying for a EHCP as they all get refused. My son has tried to self-harm and has diarrhea most school days due to stress. I have asked several times for another assessment by the psychologist but this is refused due to funding. My son is at school very unhappy with his needs not being met. His education is suffering as the environment is not right. There are waiting lists for ASD placements in mainstream school. My son would be fine with a one to one but this will not be provided. The head teacher is not supportive and admits that he doesn't know much about autism. My son is treated like a naughty boy even though he isn't. He lacks the support he needs in school. He is a bright and sweet boy outside of school. He is like a different child at school through stress.
- This has meant that she is not getting the support that she needs.
- Is struggling to keep up at school and falling further and further behind. Her anxiety about attending school has increased dramatically.
- Their self-esteem is most affected as a result of limited academic progress compared with peers.
- Not been in full time school
- Reduced ability to achieve learning potential
- Unfairly disadvantaged
- They have had next to no help
- No or very little support and long waiting lists! Emotionally distressed daughter as not receiving support or diagnosis
- One-one despite having 30 hours EHCP
- Unable to get assessments done, once done privately the diagnosis was accepted but as of 5 months on we still have no support in place. Child is too anxious to attend GP and GP won't refer without her consent. She refuses to go to dentist and has untreated skin condition, no one seems to offer any solutions or help. Health send you to education. Education send you back to health, both signpost you on to charities. All charities I have contact have yet to reply.
- His learning has suffered below expected.
- Exclusion from school due to lack of support.
- Caused depression frustration and a stress breakdown.

- Left to struggle in a mainstream school.  
Spends each day in a class 2 years behind her.  
Mental well-being and self-esteem issues by being removed from her peer group to learn with younger class.
- Does not attend school. Is unable to fulfil potential. Mental health problems in addition to original SEND requirements.
- Missed out on four years of education.
- He is not able to fully access the educational system and is often excluded.
- He feels different to everyone else as SEN units taken away now and all children put in together so makes him feel stupid.
- Less support in school.
- Delayed speech therapy, no personal budget available for Salt, no laptop,
- My daughter is unable to access a very much needed programme of Speech Therapy. She has verbal dyspraxia which is greatly affects her ability to communicate and express herself effectively which has a very negative effect on her learning and her ability to make friends. We have fallen into significant debt in the past paying for private therapy which is hugely beneficial but expensive. This is also the same for Occupational therapy. She is seven now and has only ever had one 6 week block of 1-hour therapy sessions. We have privately paid for Occupational therapy again at huge expense but which fantastic results although again it resulted in us amassing a huge debt which caused us to remortgage our house. What is impacting us hugely right now are the educational cuts being made which in our school has meant a significant loss of teaching assistant help which my daughter is hugely dependent on. It is no good expecting mainstream schools to increasingly accept children with special needs if they isn't the funding to support them.
- Placement at school failed causing significant trauma and stress. No education until new placement found. Now having to travel nearly an hour each way to school, this also means that he cannot have friendships with peers out of school.
- Lack of independence for my son and stress for me which affects my son.
- Not getting on as well in school.
- They are worried as they no longer have equipment that has helped them, the support they relied upon is taken away and it has really affected confidence.
- He losing opportunities that are there for any other child and feel segregated from others.
- Denied support/assessments needed.
- Not receiving education to meet needs, being excluded and missing out on full time learning and building relationships.
- He is stuck, mentally. His self-esteem is non-existent; anxiety levels are really high. Badly lacking social skills. Feels people have given up on him. Has missed almost all of four years high school education.
- Caused depression anxiety and numerous meltdowns.
- Hasn't attended school for 14 months now.
- My son is progressing very slowly. Even with an EHCP, the school say they can't afford to do what he needs.
- School refusal.
- Missed a year of education so far.
- Current school did not understand her and did not realise until too late that her behaviour was driven by anxiety and inability to manage her emotions at school.
- It caused his anxiety to escalate.

## Appendix B

### How has the lack of services directly relating to SEND funding affected you and your family?

- No respite for any of us during the holidays. Especially impacts upon his sister.
- My sons anxiety has rocketed as he thinks he has done something wrong
- Really badly. I have suffered with serious mental health issues and had a period of long term sickness absence from work. I've been through counselling; I've lost part of my job because of the discrimination. I'm now having to pay extortionate amounts of money to a solicitor to fight the case for me if not I will end up losing my job completely. It has affected the amount of time I have to spend with my children because I've been to so many meetings, spent time sending emails, making phone calls. This really is destroying me and my family.
- A lot of worries and thinking of how we can provide alternative arrangements above and beyond what we already do for her,  
More worries as we know from personal experience NCC do not have our child's best interests at heart and that this means we have yet another fight on our hands.
- We are still struggling.
- Greatly affected it as we know our child has special needs.
- It's put a huge strain on supporting child at school.
- It has put pressure on me as the parent, as I am not getting the support for my kids that they deserve, and it is adding extra strain on my family.
- It's been very stressful for us all.
- Financially and stress.
- Affected my own health and family dynamics.
- Emotionally exhausting to have to battle every little thing or financially drain us to provide for him privately.
- Stress
- Stressful
- Worry for our child.
- Puts a strain on my relationship with my other child and I had to give up work.
- Considering moving house for better provision.
- Threatened permanent exclusion.
- More strain on us as parents to fulfill this deficit but equally then trying to get chores done and rest anywhere possible. Long term will have less energy all round.  
Since short breaks money was cut in half. (No real reason.) Social worker now fighting to get a NHS care element in place to assist this shortfall and recognise some extra needs has to occur.  
Which is the case, although for us still some further funding for short breaks is really needed. Waiting to hear on NHS package after appeals.
- I cannot work. My youngest child is distressed over his older sibling's time at home. I do not trust the LA and am skeptical of the standard of care.
- For the last 6 years we have my son around the house, ill, depressed, and causing havoc, rather than have support to do positive and constructive things.
- Lots of hard work and worry for mum especially as I try to navigate the system. Son enjoys school and has only achieved what he is achieved in reception with the dedication of the class TA. School acknowledges this but says there is no money for additional classroom support next year.
- Difficult to know at the moment. We have had so many difficulties with sorting out appropriate PA help so this is just another issue to tackle.

- I am extremely angry about the incompetence and red tape of the school and speech and language services who have let my son down. I have expressed my thoughts to the SALT services on the phone and will do with the school too. How can parents not be kept up to date with services their child is supposed to receive? None of this would have happened if the Child Development Unit at Upton Road Norwich had not been shut down as I would have taken my son myself and witnessed what would have gone on. My son's speech has not improved and indeed has regressed and I now know why. No sessions for more than a year!
- We are now having to deal with angry outbursts.
- I will start a new job in August and simply cannot take my son home in the middle of the day if he doesn't behave well.
- Frustrated, angry, fearful for the future. Facing paying for private help and having to pay a large bill off the credit card over a long time.
- Lost in an unsupportive system.
- We've had to fund a private assessment and tutor. I estimate that it will cost us over a thousand pounds just for 1 year.
- It is upsetting to see our son so behind, unable to read his writing, read like his friends.
- Considering special school rather than mainstream.
- Feel very helpless. Having to have more time off of my job to support son. Considering leaving my job to support him! Meaning I feel frustrated, stuck and very isolated in my position. Pull and strains on relationships.
- Life is tough enough without constantly being turned away every time I ask for help... we never seem to "fit the criteria" to get any help or support, projects are constantly shut down due to lack of funding, or there is no support because there is no funding for staff to do the jobs to help support children and families.
- Badly
- Disruption and unsettled
- Hardly leave the house. If we do it takes days to recover.
- Almost broke us
- Financial impact and home life.
- I barely sleep. Sometimes I can only sleep up to a maximum of 4 hours, I average 2 hours. It is affecting my marriage and causes great stress on my family. I feel exhausted at the constant battles with the school. My husband and I are fed up with the school not providing the support my son is entitled to and find it shocking that it took 3 years to meet the SENDCO. When we did meet her she told us the school wants to move my son to another school even though no interventions such as a one to one have even been tried. Again we were told it is a funding issue and I have been told by the head teacher that even adjusting their current staff to provide support is not an option at present. It makes me sad that my son is treated as disruptive as the support he needs is not there. He is not violent and is starting to be bullied now. Other children with special needs are also in the same boat and there are other parents at the school that are feeling just as deflated as me. It's shocking how the school treat my son. He is not allowed to play at playtimes and had to stand with an adult. I now refuse to support the school in their fund raising activities and no longer volunteer there.
- Her frustration and anxiety is often expressed at home leading to challenging behaviour. We feel worried about her and her mental health.
- General anxiety about her schooling and her future in education. Has been a cause of tension between family and school.
- We as a family have spent money to pay for his dyslexic assessment and for interventions to work on with him at home. We are happy doing this but not every family could afford to and the support we give is disjointed in the sense that we don't really know what he is doing at school on a regular basis so could be covering the wrong ground or the same ground?

- Very difficult, I can't work and youngest child also suffers as cannot go to preschool age things.
- Increased stress and feeling of disillusionment.
- Unfairly disadvantaged
- Out a huge strain on all of us.
- Desperation!
- A very anxious and school refusing child, has put a great strain on family life, finances as he is often not in school because he is unable to manage without a one-one. All I am told it's not how secondary schools work, but won't say how the funding is used.
- Child's behaviour at home is deteriorating, more outbursts/meltdowns which are seriously effecting her younger sibling. Anxiety is worse. Child is Aware of ASD diagnosis but no-one has talked this through with her and she won't allow me. School try and help but info never gets passed on/acted on. My daughter doesn't trust school anymore to do what they say. EHCP is in process but I believe that what would be best for her she won't achieve as everyone is fighting for so little provision. As long as she can manage at school and only lashes out/breaks down at home I don't think anyone cares.
- Strain
- Stress, loss of income and poor relationship with school.
- It has left me unable to care for my children for 3 months due to mental health illness.
- As a couple we have no support and have lost all friends  
We have done all we can to get our daughter and EHCP and fight for a place in the right school to help create a better, calmer happier home life.
- Living from crisis to crisis. Living with constant uncertainty.
- Stress, carer's fatigue, mental health problems, loss of job and income.
- It creates a lot of hardship and tears, we are trying to help our child achieve but are constantly being pushed back.
- My son's confidence is at the absolute lowest. He even sometimes wishes he wasn't here so that he wasn't made to feel stupid.
- More meltdowns. Less help.
- Impacted learning, made it hard to learn and understand instructions causes frustration and meltdowns at home.
- We have incurred huge financial debt trying to pay for services that just aren't available on the NHS. This has caused significant stress to us all.
- Significant stress having to resolve it and have child at home not receiving an education
- Stress, depression, lots of arguments.
- More pressure on us to fund items.
- Such a worry, don't know who to turn to or where to go to get things he needs
- It's limited our support and understanding of our child and we feel he's missing out because he is different.
- Family life a struggle.
- Major stress not being able to plan or do much during school hours due to calls from school and having to pick child up for lunchtime then take her back.
- Our lives revolve around his needs on a daily basis. We cannot plan any activities as he always feels he can't participate. We are all stuck in a vortex of negativity. We feel he has been very badly let down and fear what the future holds for him. He isn't employable. We worry about what will happen after we are no longer her to care and advocate for him. We are mentally exhausted having to continually jump through hoops to try to access information and services that maybe available, then justify his needs. We are currently being told his medication is not licensed as a liquid, so will be stopped! We are up against it all the time.
- Stress a constant battle with for our child.

- Horrendous. My son has been let down by all who were supposed to be looking after him and he no longer trusts school.
- Massively. We spend so much of our own money on private tutoring to try keep our son at an educational level that won't leave him bullied, upset and feel like he's no good at things.
- Social isolation
- Extremely stressful trying to work, care for SEN child and secure education for them E.g. via tribunal. Problems with my own mental health.
- Daughter stopped trusting people could help her and stopped attending school. It is very stressful watching an intelligent unable to sleep, manage anxiety and feel no-one can help. I am no longer able to work. We struggle financially, I do not get enough sleep. There is pressure on whole family.
- Family life had to be re-arranged and we had to ask friends to help out with transport either with him or his siblings.

## **Appendix C**

### **Comments from parent carers who said that lack of funding was NOT the reason that access to services had discontinued, reduced or denied**

- Haven't had anyone come to us.
- I believe although I have no evidence to back it up that our child's funding is being used to assist other children without funding.
- I find schools are often very evasive and vague about how they spend SEND funding and it's hard to make them accountable sometimes SEN money is used to prop up mainstream budgets such as TAs for a main class rather than for specific child's needs.
- I've heard of cuts affecting lots of other families but has not affected ours so far. Our son is at a complex needs school.
- My son needs a nurture provision put in place but the school have told myself and LA that they can't put it in place until he is actually attending the school next term. They can't set it up before ready for him which is stupid so my sons been put in a classroom temporarily with a TA until they can fund it!
- Staff aren't trained or experienced enough to deal with the demands of a SEN child.
- We know funding is impacting. We were 'encouraged' to look at special provision schools for our daughter when she should be supported with the current EHC plan that is in place.
- At annual review we asked for an EP to come out and do a re-assessment of needs for my child's EHCP. We have waited so long that the plan has now been re-written without the new advice we wanted and now we don't think the plan is reflective of the needs. We are sure the school is deliberately putting off getting the EP in.
- My daughter's primary school is excellent in terms of the quality of teaching, support and overall commitment. But they are increasingly having to do more with less funding. The local authority is hamstrung with (EHCP) process and has long lost any commitment to children with special needs and their families.
- My daughter has extra funding but due to recent illness educational provider has returned this money to LA. LA now won't release these funds back to provide SALT etc itemised in her EHCP so I am having to fund this privately. Reason given is that she is not fit for education as ill. I'm saying she needs the SALT etc as itemised on EHCP so becomes fit again for education. SALT is part of her education.
- Due to SEND funding it has taken until child 12 to be finally diagnosed even with older sibling with same diagnosis and now finally the third child and 16 for their OT appointment and further diagnosis, and finally achieving an EHCP in year 11 in time for further education at college, funding and services are failing my children.

- Insufficient funding.
- It does depend on the high school as we went from one who refused to give any form of support to my child or even try to gain funding as the it's just not possible according to them. Now we are with a school that fully supported my daughter who is now in a SRB and on a full EHCP with travel! It makes the difference if the school itself knows what it's doing.
- It is a disgrace that you have to fight for your child with a learning disability like Downs to access speech and language sessions, or ask for a review or for it to be increased as we believe our child's speech is progressing. Thus has not been granted.
- It is my hope that schools use the funding to support children for SEN purposes, i agree it should probably all go into one pot which sometimes enables more students to gain the benefit however there just isn't enough.
- It took over 3 years to get our son with ASD any support during which time he was treated as a 'naughty child' by teachers, bullied by other children, and generally unhappy at his mainstream school due to being misunderstood. He is so much happier and better supported in his special school but he is a child that may have been able to cope in mainstream had earlier appropriate support been available. For instance, he now receives Occupational therapy support at his special school - no one in his old mainstream school has access to this. When the LA talk about wanting to target early intervention what they are really doing is passing the burden for dealing with SEND onto schools who do not have the expertise or resources to be ambitious for these children. As a parent it is really hard talking to schools about SEND issues (especially if you have other children at the school such that you do not wish to upset the school) because I know I will be told there is no money and other children with problems - it would be really useful to have someone independent of the school to act as an intermediary. EHCP coordinators would be the obvious person but getting a reply or to talk to ours is impossible so in reality would not be great at this role and many children with SEND don't have an EHCP they are just on the school SEN register.
- It's so disturbing that a child that clearly needs a specialist setting isn't provided one due to limited space, which could be as a result of limited funding.
- It's underfunded, seen a lot of support for children withdrawn since my kids started schooling, no more nurture club, no more sensory circuits. My child who has obvious needs but no EHCP (as yet) absorbs a lot of the TA time so other kids whose needs are less pronounced suffer.
- Lack of TA support because their jobs have been cut is an issue.
- Mainstream schools are using SEND funding to fill funding gaps elsewhere because it is not ring-fenced. This statement does not apply to special schools.
- More money is needed.
- My child didn't have suitable provision for over 2 years.
- My child struggled to get an EHCP aged 2 even though he was brain damaged at birth. The funding given is so poor that it impacted me being able to put him in a Nursery even though I wanted him to mix with his friends. Things are slow, we wouldn't have an EHCP at all if it wasn't for the Nursery. Nobody helped us before this to apply and it was left to them. I cannot access full 15 hours because my child's needs require full 1-1 support for safety and even the EHCP funding does not cover this. Very poor. I think Norfolk children are underfunded compared to other counties when I talk to other parents, particularly in nursery.
- My son has been excluded from mainstream because there was not enough provision to support him & therefore his self-esteem suffered, behaviour worsened & now he has spent an entire academic year in short stay apart from a failed attempt at reintegration. The problem has got much worse because it was not dealt with & support given early enough. We are still waiting diagnosis.
- My son has been out of school since January. The school requested funding for 1:1. The SENCO twice submitted detailed reports of exactly how the budget has been spent. It wasn't denied, it was ignored.

- Not enough help is given to the child, and the specialists needed to help are not called in, or frequent enough to benefit the child. Long delays in getting the help and diagnosis needed when the early the diagnosis the better results are always put down to funding allocation, and more than one child going through this! especially between cluster schools.
- Not enough placements for the amount of children needing them.
- Not good enough, abhorrent, pathetic, disgusting, need I go on?
- Nothing seems to be transparent
- Now at a special school but whilst at mainstream we were fobbed off and told he didn't need an EHCP.
- Nowhere near enough to support a child's learning.
- Our son has a diagnosis of ASD. When we discussed his assessment with his teacher we were told that if he was diagnosed, it "wouldn't come with any funding" and that this wouldn't make any difference to his provision (which is minimal). We accessed his assessment privately, as the wait was so long otherwise and we were getting desperate for answers in how to manage a very difficult situation. We were told unofficially by someone who works at the school that the school has a quota for the number of educational psychology assessments it can access in one year and that it had already met that.
- Since EHCP began the funding is getting less (as EHCP is hard to get) and the schools are having to use funds to try and give help. Local councils are making it harder to access grants and downsizing all services (saying they still offer a service but making it so small it's permanently snarled up).
- The school and LA refused to tell me how much my son received in high needs top up funding. I had to request a SAR taking 3 months. He got the 2nd highest funding, yet it wasn't spent on him. I called a meeting with the SENCO & head teacher who said "his intervention was do subtle he probably wasn't aware he was receiving it?????" In other words he wasn't. My son is severely dyslexic he knows when he's receiving 1-1 reading, touch typing. I reported it to the LA who couldn't care less. This system sucks! I have 3 children with SEN from complex school to mainstream school.
- There is not the funding in place to meet the need. Our children are suffering and falling behind as a result. The government should be ashamed.
- We are told nothing....smoke and mirrors
- We need more units attached to mainstream schools where they are staffed by professionals in SEND...building expensive new schools is not always the answer
- When a child can't attend school it's irrelevant. This is how so many children are falling through the net or being home educated.
- Without EHCP limited access to 1:1 support to allow child to reach actual potential
- You do not help SEN children enough in mainstream settings; I have had to go out of county to get better provision for my autistic son. Shame on you NCC.

## Appendix D

### Comments from parent carers who said that lack of funding WAS the reason that access to services had discontinued, reduced or denied

- School are always telling me that their SEND funding has been cut and they can't afford things. They even asked me last year to fund (or find sources of funding) for my son to have a 1:1 TA (I'm not rich!)
- Additional services were impossible to access in mainstream where my child was. It took 2 years of fighting, ending with a very expensive Tribunal to get her the OT/SALT she needed as well as a placement change. My child is half way through those additional services and yet its having to go back to SENPAG for funding even though it's clearly written in her EHCP. We fear another fight on our hands but I know we're more fortunate than many. I'm dreading her moving to Adult services as I know it'll be even worse.
- The funding levels are appalling and children are being failed all the time.
- Everything has to be fought for by the parent. It took 4 years to get an EHCP for my son who has 8 diagnosed issues + Ed Psych reports. 4 years of wasted non-effective education for him and a huge distraction to all other students in class trying to control his behaviour. Funding must be funneled into teacher & TA training. More SEND content needs to be included in teacher's university syllabuses. We get told contradicting information from school/social services and other external services. Would be great to have 1 central information cell to correctly inform parent what they apply for, who from, how to & when.
- They need funding as pediatricians are refusing appointments without certain reports which are required by schools....my child is suffering with no help. How are they supposed to get a proper education and diagnosis for help....parents are suffering as a result of this....children should be seen by NHS not have to rely on school reports to do so
- My child is recognised as a SEN kid, but it hasn't meant anything in terms of parental input, I am lucky if I get a piece of paper once a year with his targets on.
- Budget cuts have caused redundancies.
- Schools are really struggling with providing SEND resources and are having to make huge cuts.
- School has told us they don't get any extra funding for children with SEN.
- High functioning ASD needs to be addressed. Schools, teaching social and mental health also needed for kids that fit in but don't fit in to the school system.
- Parents have to fight so hard already, it's shameful that we have to fight the people who are meant to be looking after us.
- Lack of providing early intervention means more crises later on, which is more expensive to fund.
- Refused to tell me their SEN budget. Refused to tell me % spent on my son.
- Watching and waiting and worrying for the future about adequate funding for daytime services, transport monies and suitable overnight respite available.
- Bear in mind that Education does NOT end at 15 years old!!!
- I just think the message about the importance of early intervention is a difficult one to hear when funding is so tight all round and everyone seems to be struggling the day to day basic costs of running a school. A big shift in thinking, and of course more funding is needed for early intervention strategies to work and really result in preventing further problems for children and their families.
- It is a disgrace that you constantly have to fight for your disabled child's needs as if we are begging for the moon instead of the simple basics! This cannot go on anymore. What kind of society do we live in?
- I do not understand how my son could have a 1:1 in reception and suddenly now it has been decided that he will not have it in year 1 while all the teachers agree that he cannot function at school without 1:1 support

- My school SENCO has no idea if my child is on the school's SEN register. But there is no money anyway apparently, even if he was. He was privately diagnosed with autism - his report has been accepted by the local authority. As far as I am concerned we have saved the authority money by having him diagnosed, I would be very grateful for OT, support in school now etc. as every academic year becomes more difficult for my son.
- It needs to be improved, my son is so far behind and needs a more supportive school but not as much support that current SEN school offer.
- Funding gets spread across all children regardless.
- I would like to know how much funding each child is actually allocated and how it is spent. I have asked repeatedly for my son's information.
- My son has ASD and ADHD but no EHCP and therefore "doesn't qualify" for any special assistance, (and doesn't qualify for an EHCP, so therefore no one is interested because it's not "law" to help him) yet he has a disability, it effects his ability to learn and he is not achieving what he would if he got extra help and support he needs. He needs IT to help him learn, but I have to pay for it as the school has no money... and on and on it goes...
- There isn't any available
- I think the school doesn't apply for it as they don't think they'll get it!!
- These children deserve support. By not providing them with support you are failing them. Disgusting.
- I have been led to believe that funding is so tight that I am looking at private assessments even though I can't afford it. It is difficult to access the SENDCO teacher as there is no direct contact with parents. SEND code of practice is not or is loosely being followed. I have on many occasions been told that the funds are just not there.
- It is heartbreaking to see our school having to try to make the funding work. Without the support that the children need, all pupils are affected. The behaviour is more challenging and this affects everyone. Seeing children in crisis and not meeting their potential is letting them down for now and for the future.
- Our son is on the school's waiting list to be referred to a dyslexic outreach support service which only costs £100 for two 1:1 visits and a report. The school SENCO is happy to spend her time assessing our son's reading age etc. but they fail to implement appropriate support for him to make academic progress presumably due to lack of funding. Our son did not answer any questions on his SATS key stage 1 reading papers correctly, when I spoke to the school about this they just told me to expect the same at KS2 SATS, there is a lack of aspiration for children with SEND. With the right support dyslexic students can do very well so it is all very disheartening.
- They are reluctant to fund proper support in school, but little provision for bright ASD girls anywhere!
- Schools not spending it as they should.
- Shortages leave a huge amount of parents and children treading water with no help it's heart breaking.
- There is no help unless child behaviour is effecting others or is behind academically. If they are 'fine' in school no-one cares. You can even get them assessed. Educational professionals seem to be making decisions best left to health professionals. Help for invisible disabilities such as ASD, ADHD, anxiety, mental health etc. is no existent and often ignored. Staff training would be a start.
- SEND funding should make sure all kids are supported and can access all parts of school including trios.
- I am constantly being told that our mainstream school does not have the training to accommodate our Autistic son.

- Mainstream schools are unable to cope with funding available without the need to find additional funding for SEN children.  
Teaching staff without the right training struggle to support SEN effectively  
Stop funding generous pensions and start offering higher salaries to attract better quality of teachers as this is what the younger generation desire and need to afford homes of their own etc.  
Start modernising the approach, mental health is the biggest challenge our Generation Y are going to face, society will be better in years to come if we adequately educate, support and give life skills to those who sit outside of the normal distribution.
- My child was denied provision costing £10,000 a year in a mainstream setting. She was then unable to attend school and missed out on four years of education. When the local authority finally placed her in Specialist provision it cost £80,000 a year for four years.
- There is just not enough by far, it's so, so, so frustrating when you have a child with such low esteem, primary school left everything for high school and by then it's almost too late!!! Nearly every teacher does not read my sons I.E.P so it's a constant call to school all the time reminding them to read it as to know how to educate him.
- Impacted evidence collection, which then has impacted information provided for the Local Authority for EHCP assessment request. Initially this was turned down and we had to go for tribunal.
- Funding for teaching assistants is essential. They are vital to the success of teaching children with special needs. Many SEND children are unable to understand and therefore access the learning provided in a mainstream class lesson without support to understand what is being taught and complete work at a level appropriate for them. Many need help with concentration, hearing or seeing what is being taught and help with assistive equipment as is the case with my daughter. Many other children with behavioural difficulties can be hugely demanding time and input wise. Without the teaching assistant support these children become increasingly distressed which is not fair for them and they can also become increasingly disruptive which is also unfair on the neurotypical children with whom they share a class. Every child is entitled to an education which is becoming impossible with the current funding situation. The additional stress being put on teachers to do more with less resources is causing them to leave the profession. My brother was an excellent teacher who returned to engineering due to this very reason.
- Councils don't want to know. To get anything your turned down and fobbed off and go round in circles.
- There is not enough SEND schools!!! My child needs to go to a special school as he is 5 with a mental age of 2-2.5 but there are no provisions and none within 20 miles!!
- Schools are so short of money they are doubling people up and making groups bigger, they are unable to buy into services that are now traded after being free and our children are suffering.
- The earlier sufficient funding is put in place for these children, I am sure would mean less funding spent later on supporting these same people through their adult life.
- When we got funding ie EHC plan we didn't know or see where they had spent it on our son as his one to one was a TA already within the school with no training on how best to support my son resulting in me having to go into school every day and educational psychologist even stated no support or resources have been put in place for him..
- It seems as though no money is spent on him at all.
- There is not enough funding for support staff in mainstream.
- All funding for schools have been reduced, meaning they are less able to be inclusive. Schools biggest and best resource, manpower, especially TA's has been reduced so there is less support for SEN children.

- Nothing happens until child in is crisis and then it's too late. Mainstream schools are not set up to make allowances for send children or do not want to. Legal jargon can be ambiguous (ie: reasonable adjustments) gets quoted a lot but means little. Academically able young people suffer because they do not always fit profile for special schools and mainstream do not have facilities to adequately meet needs. It seems to the down to schools to decide what they can and can't do and There is no consistency between schools or counties. The only thing everyone agrees on is that the system is failing.
- Not enough is allocated per child.