

Written evidence from SEND Family Voices

Summary

1. This report is submitted by SEND Family Voices, a Parent Carer Forum (PCF) based in 2 London Boroughs. We are run by a steering group of 20 parent carers. Many of our Steering Group members also represent local disability charities. We have around 730 parents who we directly reach through email newsletters, and we are in touch with approx. 500 more through the linked disability charities.

The Key Issues Raised with us by local Parents and Carers

2. The assessment of and support for children and young people with SEND

- 2.1. Poor administration of the EHCP process, leading to very long delays, poor quality plans and inappropriate provision for children. Breaches of statutory duty.
- 2.2. Evidence of Local Authority refusing to conduct needs assessments or setting unlawful hurdles (such as requiring EP reports)
- 2.3. Evidence of watering down of provision or overriding advice from key professionals (or commissioning additional "statutory" reports) to override recommendations from professionals in many cases, leading to poor quality plans and inadequate provision
- 2.4. Compelling evidence that schools are struggling to provide support to SEN pupils because of lack of resources (and sometimes training) – leading to a greater number of children being excluded, placements breaking down or failing to find an appropriate school.

3. The transition from statements of special educational needs and learning disability assessments to education, health and care plans

- 3.1. The LA committed to transferring 900 Statements to EHCPs in 5 months (between November 2017 and end of March 2018) to meet the DfE deadline. In the previous 38 months, since the start of new system approx. 800 statements had been transferred. We are concerned that the pressure on numbers has had a severe impact on quality. Particular concerns are:
 - 3.2. lack of specificity even when this was clear in the statement
 - 3.3. very poor quality reports, when the LA should be carrying out a reassessment (multiple cases of professional reports being submitted without the professional having met the child.)
 - 3.4. provision that was clearly defined in the statement being removed,
 - 3.5. any provision (except SaLT) that is provided by health being either missed, or put in section G
 - 3.6. The process has been opaque, rushed and not at all child-centric

- 3.7. Many EHC plans , that were not properly complete have been finalised to meet the deadline, with vague promises to issue a “final amended plan” later.

4. The level and distribution of funding for SEND provision

- 4.1. Our local authority areas are significantly overspent in their SEN budget, and have had to accept a loan from the DfE to carry them through this year. We expect significant cost savings to be made this year but have yet to hear any detail on what this will look like. However, schools, therapies and LA are already finding meeting demand difficult, as evidenced by this report.

5. The roles of and co-operation between education, health and social care sectors

- 5.1. There is an almost total absence of social care plans included in EHCPs – even for children with significant social care needs
- 5.2. In one borough cooperation with health is very difficult. Health is also a very large entity who don't seem to have EHCPs high on their agenda. Most Plans that have useful health input are based on the parent coordinating this.

6. Provision for 19-25-year olds including support for independent living; transition to adult services; and access to education, apprenticeships and work

- 6.1. Provision post 16 is incredibly disjointed. The small transition team that used to support only parents known to Children's Social Services, was disbanded in 2016 with a promise that it would be rolled out more widely into the SEN/PfA team, but this hasn't happened and consequently this service doesn't exist any more.
- 6.2. The transition between children's and adult social care and paediatric and adult medicine is alarming as they are so different without any clear pathways for transitioning from the children to adult services.
- 6.3. Parents have to find their own options post 16 and post 19 and fight hard for them. There is very little in the way of proper pathways to employment, a handful of supported internships and apprenticeships), with any focus primarily on NEETs and the more able, with only limited, if any, support and opportunities for those with Higher or Complex needs.
- 6.4. Post 16 (and Post 19) education is usually only part time, meaning that vulnerable young people who are not able to be independent when not in a lesson, need supervision or support at these times. This is leading to parents having to stop work to look after them. Or push for far away residential placements, which are often very expensive.
- 6.5. No clear local supported living options available.

Recommendations

7. We believe that to secure positive outcomes for our children an honest debate about the funding for SEN needs to happen. At the moment the LA

and schools have duties, but apparently too little funding, or too little ring-fenced funding to fulfill these obligations in a way that properly supports our children and young people. In particular the extension of the EHCP to 25, without additional funding makes no sense, given the acute lack of resources and funding in adult services. This leads to young people "falling off the cliff"

8. We would also suggest that the sections in the EHCP are overly long and complex, and we suspect that many plans will never be properly read and will be very difficult to keep up to date. We would recommend the adoption of a national EHCP template, based on good practice and what has been proven to work
9. We recommend better oversight of Local Authority and school implementation of SEN policy. Tribunal is a prohibitively expensive and complex remedy for parents who feel that their child is not getting what they need. Further, children who need SEN support but do not have the protection of a statutory plan have nowhere to go for help other than the school. Schools sometimes lack the training or funds to properly assess or support children, leading to a situation where families feel that they have nowhere to turn.

A Note on the Evidence

10. This section contains the evidence that we have relied upon for this report. It is based on case studies submitted to the Parent Carer Forum by parents for a meeting with local MPs. It also contains some data extracted from the SEND Family Voices issues tracking log, which is compiled from contacts that the PCF has with parents, carers and sometimes SENCOs and other professionals. The data is a by-product of supporting parents but the PCF logs each individual case so that they maintain an overview of what the community is contacting them about as feedback to decision makers and service providers.
11. Each issue / question / comment / request is logged only once (even though there may be multiple contacts through email or phone with the family).
12. All names in the case studies have been changed.

Summary of Issue Log Data:

13. The issues are categorized into topics and logged as either an issue (when there is a problem), or a comment, question or request.

SCN0290

Regarding	Total Raised in 2016-2017						Total Raised in 2017-2018					
	Comment	Issue	Question	Request	Overall	%age	Comment	Issue	Question	Request	Overall	%age
EHCP Implementation	3	41	4	2	50	10%	6	97	18	5	126	32%
Request for information		15	7	56	78	15%	2	6	4	65	77	20%
School placement issue	1	48	5	8	62	12%		19	10	6	35	9%
Post 16 provision		18	2	4	24	5%	1	19	2	5	27	7%
Families supporting families		15	1	44	60	12%	1	1	1	14	17	4%
Reasonable Adjustments	2	6	2	3	13	3%	1	11	2	2	16	4%
Short Breaks / Aiming High	5	47	3	8	63	12%	1	5	3	6	15	4%
Thank you	19				19	4%	14				14	4%
SEN Support		5		2	7	1%		10		1	11	3%
Social Care	4	31		3	38	7%		9		2	11	3%
Transport	1	22			23	4%		5		1	6	2%
Non provision despite plan					0	0%		5			5	1%
Annual Review		3			3	1%		3		1	4	1%
CAMHS				1	1	0%	2		1	1	4	1%
Health / Therapies		12	1	3	16	3%		3	1		4	1%
Other	3	47	1	7	58	11%	0	12	1	4	17	4%
Totals	38	310	26	141	515	100%	28	205	43	113	389	100%
	7%	60%	5%	27%			7%	53%	11%	29%		

EVIDENCE

14. The assessment of and support for children and young people with SEND

14.1. Poor administration of the EHCP process

Date	Contact how?	Details
09/08/17	email copied to SFV	Complaint sent to Councillor that The LA have failed to manage the transition of 11 primary school children to secondary, partly due to failures in EHCP process. Feels that the current situation is unacceptable and that the case load for EHCP Case workers is too high to provide a decent service
01/07/17	call to SFV	Parent of a child not in school needing support. Wanted to go to tribunal but busy so deadline lapsed
17/11/17	transfers workshop	Parent stating that the EHCP plan has been issued - with the wrong school - even though she has never seen a draft. The process seems to have got completely messed up, as there have been a number of changes in case officers and information doesn't seem to have been passed on. Parent is wondering what to do as the EHCP issued is clearly incorrect
16/01/17	Web form	Parent complaining that she has had 3 case officers since August and none of them have done anything.
26/06/16	call to SFV,	Parent called with query about EHCP process - is far in excess of statutory time limit (30+ weeks so far) and was concerned that LA could remove the child's support since plan not finalised.
04/05/16	email to SFV SG member	EHCP Process started July 2015 and still not finalised. Multiple changes of case officer. No one returning calls or emails or acknowledging family feedback
20/11/16	reply paid card	Parent has an EHCP for child - transitioning from mainstream infant to special school junior. Found process appalling. 5 changes of case officer. Wrong information given by case officers regarding schools to consider. Paperwork not sent to out of borough schools requested. Parent had to repeatedly chase over a period of 10 months. Paperwork arrived just before deadline at schools, which are already over-subscribed. Social care and health aspects of EHCP have been dismissed despite the fact that the child sees several specialists for a variety of difficulties

A KNOCK DOWN, DRAG OUT FIGHT

14.1.1. ***We wish that politicians would understand that the fight that parents have to go through to get their children's needs understood and provided for is far, far worse than the realities of raising our disabled children***

14.1.2. ***A KNOCK DOWN, DRAG OUT FIGHT - The costs in terms of time spent trying to get responses, disdain and unpleasantness experienced from those who are specifically tasked to support our children's needs and us, ignorance, dishonesty, unkindness, lack of empathy, being fobbed off, and all the emotions raised in the process, just to get our children's needs understood and adequately provided for - is far, far worse than the realities of raising our disabled children.***

14.2. **Evidence of Local Authority refusing to conduct needs assessments or setting unlawful hurdles (such as requiring EP reports)**

Date	Contact how?	Details
03/09/17	email to SFV	Parent very angry at what perceives as "systemic failings" and managing a budget rather than providing a service to our children. Had a 2 year battle to convince the LA to assess for need as they repeatedly said school was meeting need - where parent is clear the school was not (and they child now has an EHCP - so that must be the case) Also there was no attempt to put any meaningful social care assessment into the plan. Parent firmly believes that this is all a tick box exercise to meet statutory deadlines and has nothing to do with producing a good quality plan for the child.
10/05/17	web form	Parent of a child with HFA / Anxiety who would like to see more support for child - and medical pathway have suggested that a LSA may be appropriate- but has been told by the school that LSA only provided when EHCP in place - and not seeming to want to assess at the moment. Parent confused as to what she needs to do to ensure that the child is properly assessed and supported
21/02/17	call to SFV	Parent of a reception child who submitted a needs assessment request personally, as school did not support, and has been rejected and very upset. Also was told by SEN team that a MAM meeting would happen but this was cancelled and parent does not know why. Wanted to know

		what can do next.
14/06/16	email to SFV	Young person with a statement turned down for transfer to an EHCP by LA. Looking for advice as parents strongly believes that the YP needs support post 16
08/10/16	email to SFV	Email thread copied to SFV detailing an email from the SEN team EHCP coordinator rejecting a request for a needs assessment - based on the fact that professional reports were submitted (i.e. as based on school based evidence) and that it was just before the summer holidays. the person forwarding the email suggested that this has been in more than one case and suggests that the SEN team are not following the code of practice and using the 6 weeks to investigate the request for a needs assessment

14.2.1. ***The LA sacrificed any chance of early intervention to save money***

14.2.2. ... they instigate procedures that are illegal, without fear of come back from Ofsted, the LGO or the Government. And it's me, Sam's only parent & carer, who bears the personal, professional and financial brunt of it all. But it is Sam who potentially loses all chance of a socially and economically productive life.

14.2.3. Sam was 2.5 when I realised his speech wasn't developing like other kids his age. By the age of 3 he'd had Speech and Language assessments and begun group therapy. It wasn't until he was 4 that he was referred to Occupational Therapy and within 6 months 'Autism' was first mentioned.

14.2.4. But due to limited capacity it would take a year for a full diagnostic assessment. An EHCP was suggested, but both LA and school said no, through false pretences and ignorance respectively as I later discovered. Sam by this time was 5 and a half.

14.2.5. Then his therapies were stopped because he didn't have an EHCP. His behaviour deteriorated dramatically. He regressed alarmingly. The school applied for an EHCP. It was refused. After many requests for clarification the LA said their refusal was on procedural grounds. The wrong forms had been used. Not a single mention of my boy's needs.

14.3. **Evidence of watering down of provision or overriding advice from key professionals**

Date	Contact how?	Details
05/10/17	email to SFV	Parent complaining that the draft EHCP has been "watered down" from what is written in the reports and is wholly inadequate.
08/03/17	email to SFV	Parent asking for advice about a new EHCP. Hours support have been reduced - less than that requested by family and school - and also therapies are specifying a package of visits per term rather than tailored support.
18/03/16	email to SFV	Parent has been allocated less support time in the draft EHCP than she, the SENCO and the Ed Psych feels are necessary. Looking for support to resolve this
10/06/16	web form	Parent wishing to appeal the provision in the EHCP - considers it completely inadequate.

- 14.3.1. ***Documentation is extremely poor and sections are incomplete or missing...***
- 14.3.1.1. ***We had no OT or SLT commissioned for Oliver despite the school, ourselves, and EP saying it was necessary***
- 14.3.1.2. ***The documents used vague and unspecific language "Oliver will receive advice and support from language professionals as deemed appropriate"***
- 14.3.1.3. ***They used responsibility passing phrases "Oliver will have use of strategies and support from Occupational Therapy for sensory and motor issues if deemed appropriate by the service"***
- 14.3.1.4. ***And finally they did not reflect the original submission or statements from a subsequent review meeting and minutes***
- 14.3.2. ***An inadequate report will be crucial in determining the support my child receives***
- 14.3.2.1. ***A week or so ago I was out shopping and got a call out of the blue from an Educational Psychologist from The LA. The EP said that she needed to submit a report by tomorrow so it was important that we talk. During the call I did discuss my concerns and then at the end we summarised together what she'd put in the report. I was still not happy and asked that we speak the next day. I have just received a copy of the report – and it makes no mention of the key issues that I was at pains to communicate to the EP. The EP has never met my child.***

14.4. **Compelling evidence that schools are struggling to provide support to SEN pupils because of lack of resources**

No .	Date	Contact how?	Details
813	03/11/17	call to SFV	Parent of a child who needs OT / Physio equipment in school and school is saying they have no funding so is asking the parent to fund it. Wanted to know whether this is appropriate and also if she were to do so whether this would set a precedent for more expensive pieces of equipment
786	21/09/17	email to SFV	Parent of a child at primary with ASD diagnosis in mainstream concerned that the school is going to suggest that they can no longer meet the child's needs (there has been an incident of the child hitting the LSA during a meltdown).
686	24/06/17	conversation with SG member	Parent of a child at mainstream secondary. Child gone from A/B grades to failing. EP diagnosed dyslexia, anxiety and a range of other things. Parent requested meeting with SENCO to discuss provision - nothing for 10 months. Then went to head. Had a meeting within a week (involving SENCo also). For the week after the meeting lots of extra provision put in place and since then nothing
610	22/03/17	email to SFV	Parent looking for support with finding a suitable school for a primary child with complex learning difficulties. The schools that they were recommended to contact all say that they are full - parent doesn't know where to go
352	04/07/16	web form	Child at secondary school with a range of issues, including undiagnosed ADHD (waiting since Jan 2015! for diagnosis) Child has been excluded from school for much of the year. EHCP process started but Ed Psych & School report didn't arrive and LA closed the file with no EHCP. School now keen to permanently exclude the child. Parent not sure what to do. Have resubmitted paperwork for EHCP.

14.4.1. ***They are failing to provide education for our children, either in a school or home schooling***

- 14.4.1.1. We moved to the Borough on 1st July 2017. At the beginning of September we had a meeting with the caseworker of our twin boys, 9 years old both diagnosed with ASD. We had 4 preferred schools. On a second meeting in October we found none of the 4 schools

would offer our boys a space. The caseworker named 6 other schools she would forward our boys papers to. At this point (end November) we still don't have a school for our children

EVIDENCE

15. The transition from statements of special educational needs and learning disability assessments to education, health and care plans

31/03/18	Email to SFV SG member	Parent received final plan even though requested amendments had not been incorporated. When queried with case officer was told that it was to meet the deadline and not to worry the amendments would be incorporated after the deadline. Hasn't heard anything since
23/03/18	email to SFV	Parent forwarding email trail to SFV detailing a long list of issues with the EHCP draft, including lack of specificity of OT / SaLT provision, out of dates being used, reports not being appended to the plan, ambiguous phrase in the provision section "would benefit from", no social care assessment etc.
16/01/18	email copied to SFV	Parent complaining that in draft EHCP quantified hours have been removed, some provision from statement is missing (Physio) and all equipment has been moved to health - even though plainly for allowing access to education
12/1/17	email to SFV	Parent complaining because child has been in transfer process for around 8 months and nothing has happened. Child needs an EP assessment, probably a referral to a psychologist, sensory integration therapy. Case worker appears to be off long term sick. Parent is not called back and is not getting and follow up from team - seems to have been forgotten. Meanwhile child is not getting provision needed
09/02/18	Email to SFV SG member	Parent going through transfer for a child with MLD, "they've tried to remove Xxx's full time one-to-one (slashing funding by a whopping 70%), the report is full of generalisations, lack of specificity and also an intent to withdraw any therapy; S&L & OT"
04/02/18	email to SFV	Parent contacting us about an EHCP transfer. 2 major issues. Firstly provision in current statement not being provided - already in dispute about that. Also SEN team pushing for (unsatisfactory) EHCP to be finalised for 15th Feb to meet statutory deadline. Not happy with the quality of the document or the way that provision is currently working

- 15.1. ***It is so emotionally draining knowing I am going to have to go into battle with the LA in order to secure a place that meets the needs that I know she has but that the LA refuse to identify on her EHCP***
- 15.1.1. ***.... Firstly, timing issues. It has taken in excess of 2 years to transfer from statement to plan. I initially requested that the plan be transferred in April 2015. During this time I have dealt with 8 different co-ordinators. I have had at least 6 drafts issued. On reflection, knowing what I do now I should have appealed a long time ago but naively held faith that we could get a workable plan.***
- 15.1.2. ***Section B in my daughters plan is crucial as in order to inform provision in F it is vital that needs are clearly identified. Obviously this is not in the LA's interests so it has been a battle***
- 15.1.3. ***Preparing for Adulthood has been a joke.***
- 15.1.4. ***Sections C, D, G and H state 'none identified' Why not? Reports should have been requested surely. My daughter has a social worker and a psychotherapist working with her.***
- 15.1.5. ***A couple of weeks ago I was told by my current caseworker that his supervisors had stated that there would be no further placements at this school from the borough due to costs – how can this possibly be the case when the needs assessment has yet to be done???***
- 15.1.6. ***I now believe that my daughter's primary need is SLT. The borough currently gives her 6, yes 6 sessions a year. This is totally budget not needs driven.***
- 15.1.7. ***It is so emotionally draining knowing I am going to have to go into battle with the LA in order to secure a place that meets the needs that I know she has but that the LA refuse to identify on her EHCP.***

EVIDENCE

16. The roles of and co-operation between education, health and social care sectors

16.1. Almost total absence of social care plans included in EHCPs – even for children with significant social care needs.

Date	Contact how?	Details
07/11/17	email copied to SFV	Complaint to The LA regarding the refusal of The LA Social Care to assess her child as part of the EHCP transfer social care assessment. Parent believes that The LA are acting unlawfully
03/11/17	email to SFV	Parent requested a social care assessment via the SPA for her child. Timing wise is linked to the EHCP transfer - but child needs the assessment anyway. SPA told her that the child didn't need one (having phoned the EHCP coordinator for some reason) - even though it has nothing to do with the EHCP coordinator. Finally persevered with the "Education and Early Help" person in the SPA and they have agreed to go ahead with the assessment
14/09/15	email to SFV	Parent forwarded correspondence from SEN case officer who was being extremely inflexible and pushing to meet deadline even though no social work input was in the plan (despite there being a named social worker) and Case officer had not attended meetings

16.1.1. ***Care part still blank despite the fact my son goes to a specialist residential school and will need care all his life***

16.1.2. ***I've been through about 10 people. The care part still blank despite the fact my son goes to a specialist residential school and will need care all his life.***

16.1.3. ***Social care team has used their part of the EHCP form to link to the local offer. No words and no interest (even though they pay 1/3rd of the fees)***

16.1.4. ***I have advised already I will never sign it off with such a woeful contribution to a document that will need to be valid for 12 years.***

EVIDENCE

17. Provision for 19-25-year olds including support for independent living; transition to adult services; and access to education, apprenticeships and work

11/01/18	email copied to SFV	Parent, having attended a legal workshop states that the EHCP she has received from The LA falls well short of what the law requires (outcomes only for a year, for post 16 takes no account of training / work outcomes / funding only covers part time in education etc. etc.) Highlighted all this in November. Had no response to emails until January and escalated.
17/11/17	transfers workshop	parent expressing anger and frustration (suffers from depression as a result of the stress) of the system having consistently let her daughter down. EHCP has never been finalised - and she is unable to find a suitable educational or work experience placement for her child. Many people have offered to help but she has been let down by all of them. Very emotional
13/05/17	email to SFV	young person taking GCSEs this summer. Absolutely no plan for what should happen next. No one in The LA (or anywhere else) has provided actual support with what to do just post 16. The signposting received to date has been a "roundabout" with no one actually doing anything. The LA were not even aware that the young person was about to leave school - as there was a mix up and the records showed the child being in year 10. Parent worried, frustrated and at a loss as what to do
14/05/17	email to SFV	Comment from parent following dear all that the Jobs Page on future hub is always empty - so doesn't really help
20/11/17	call to SFV	Parent trying desperately to find a suitable college placement for her YP - needing a higher level of support than any of them seem to offer
26/02/18	email to SFV	parent raising the issue of a work experience placement (Balance) which falls under social care and not education and therefore the young person has to pay to go there - whereas if it were considered education or training provision it could be considered education and would therefore be free. This seems unfair and an anomaly. Parent believes that the LA have been seeking legal clarification over this

17.1. ***Even with an EHCP at 16+ it is very difficult***

17.1.1. ***This is a young person who has an illness and consequently missed a lot of schooling – and also has severe anxiety. The EHCP has made no difference to the support she's been given at college. Last year she attended x college but was asked to leave for poor attendance. I attended various meetings and requested extra help – but none was forthcoming. There were no funds available via the college and LA said nothing available as she was already at college. A no-win.***

17.1.2. ***No 6th form would give her a place as she didn't have the requisite 5 GCSEs even though "reasonable adjustments " should be made – she has 4 including Maths and English.***

June 2018