



# **Education Health and Care Plans for Adopted and Special Guardianship Children and Young Adults**

**An Enquiry**

**14<sup>th</sup> June 2018**

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## Authorship of report and Acknowledgements

The report is authored by Sylvia Schroer PhD. Sylvia is the elected Chair and co-founder of Special Guardians and Adopters Together. An adoptive parent herself, Sylvia's Health Sciences doctoral research was on the treatment of depression in primary care. Sylvia is an acupuncturist and craniosacral therapist and has an interest in the healing of trauma.

Acknowledgements are due to SG&AT members, to co-founder Janet Barraclough, and to the management committee, which includes Janet, Talib Abdulhussein, Dave Bagshaw, and Donna Lee - for their support in considering the issues under investigation.

We would like to thank all those who participated in this Enquiry through taking part in survey's and sharing their stories and experiences with us in social media groups. Many members of SG&AT are members of POTATO (Parents Of Traumatised Adopted Teenagers Organisation), and More Than Grandparents. Others are members of groups such as UK Adoption Disruption Parents Group and we would like to thank the members of these groups for giving consideration to the EHC Planning process for the purposes of this Enquiry.

We hope that by bringing light onto what is happening in our families, including when our children must re-enter care for no fault of theirs or ours, we can start to find better ways to support them to recover, heal from their losses, and hopefully attain their potential in life. Healing of trauma requires integration. One must look at the past to understand it's impact in a way that does not re-traumatise, live in the present and have hope for the future.

## 1. Summary

More than 500 Adopters and Special Guardians, parenting and caring for more than 700 children and young adults participated in this information gathering process, which included two surveys and the seeking of views and experiences through our own group members and other social media groups we belong to. We have looked at important context issues for this report – in particular where the ‘previously looked after child’ lives, and whether they have re-entered care, in order to give a more comprehensive picture of the EHC Planning process for adopted and SGO children to the Education Select Committee.

Our enquiry submission to the Education Select Committee is beyond the 3k word limit, which was insufficient to disseminate the volume of data and information we have systematically gathered. We hope our efforts, which have not been supported by any charities or funding bodies, can be of help and assistance.

### Summary of findings of the Enquiry

- Attachment Disorder is the most commonly diagnosed condition/problem for adopted and special guardianship children, and Complex Trauma and Anxiety are found at significantly higher levels in one of our surveys amongst adoptees compared to children under SGOs.
- Experiences of the EHC Planning process was mixed but overall more respondents were dissatisfied with the process than those having positive experiences. For those who rated it on a simple three -point stress scale it was considered a stressful process.
- Children who have SEN Plans are those who are excluded from school: we found a significant correlation between children who were frequently excluded, and children having SEN/EHC plans and conversely with children never having been excluded from school and having no SEN/EHC plans.
- Two themes were described from the qualitative survey data – the fact that respondents had to ‘battle and fight’ for support for their children, and the fact that children with social emotional and behavioural problems were harder to achieve EHC plans for than children with more obvious learning disabilities.
- EHC Plans were considered to be a progression from SEN statements with them continuing until 25. However, with the SGO stopping at 18 there is a legislation ‘mismatch’ for special guardianship children. There is also the issue of the EHC Plan and the Adoption Support Fund continuing until 25 if the child is SEN, but children’s services and CAMHS ceasing involvement when the child reaches 18.
- Voices from the social media groups and cases from SG&AT’s membership showed the recognition of disability and the resultant need for an EHC plan was proving a problem. The whole process might resemble a game of ‘Snakes and Ladders’. A lengthy assessment might get rejected by the panel for reasons that made little sense from the perspective of a parent or special guardian, making them fear for the future of their child, and resulting in the process having to start again or go to a Tribunal.
- Post 16 education provision was considered problematic when many of our children are much younger emotionally than their chronological age, and provision of education and support in general may be a postcode lottery.
- Restrictions about which providers could be used meant those who worked hard on the ground to help were not recognised or able to achieve funding and an EHC Plan could not be achieved.

- The re-entering of care of a previously looked after child sometimes saw access to better services but it might also mean the hard won EHC plan was side lined whilst the local authority focused on refuting medical diagnoses such as FASD, and removing children from help seeking parents and grandparents, who were subjected to harrowing court ordeals after seeking help, and then blamed for the child's problems in court. The problems are a legacy of the child's traumatic or abusive past, or a result of in utero damage.
- Adopters and SGs might find themselves marginalised thereafter (when a child re-enters care), when there were disagreements about the approach taken or if there was poor understanding of why a child might reject a parent or special guardian, when the team were child protection social workers, and post adoption teams were no longer involved. The Adoption Support Fund is also not available to these children/families.
- Parents described 'eradication' from their child's life, with no knowledge about education health and care plans – they are not invited to meetings or able to participate in them. SG's alike told us they are not consulted about where the child lives.
- Attempts to expedite an EHC Plan when the child re-entered care, or expedite support may be dismissed using the 'best interests' principle to refuse to meet parents, or the response the child does not meet 'the necessary criteria', or that it will not be funded.
- After care re-entry, and especially after a Section 31 Care Order, therapy provider agencies will not communicate with us so that parents/SGs can self-fund therapeutic help, which all agree is needed. They may also provide therapy to the child but refuse to communicate with the parent striving to achieve support for years, who will be left high and dry when the child reaches 18 and children's services are no longer involved.
- We found evidence that organisations may become defensive and close in on themselves, and there may be a 'closing of ranks' within and between organisations/agencies/charities that give the parent/SG no alternative but court to try and have dialogue about reunification if this is what the child wishes for. Once in court we are treated as the adversary of the child who we sought help for, and made a lifelong commitment to care for. After court, the DCS and senior management may stonewall parents and pass them onto the Complaints Team who refuse to accept complaints as the matter has been to court. But the remit of the court is too narrow to consider the complexities of the case, including the impact of historical negligence, missed opportunities to help, and the human rights of vulnerable children.
- Survey findings (reported elsewhere), and cases from our group, suggest the health and wellbeing of parents and SGs is of little concern to professionals, or the court, who focus on the child in isolation from their family.
- There is an insensitivity to bereavement issues on the part of those working with us, conducting assessments, and supporting or giving voice to our children.
- The permanence of the Adoption Order/SGO is not respected and potentially undermined by Local Authorities/Cafcass Guardians. As has been reported elsewhere problematic language is used to describe the scenario of a child re-entering care – we may find we are called a 'placement' post the AO/SGO, and we are routinely described with loaded stigmatising terminology: 'breakdown'; 'failure' or a 'disruption' – a term that is legally incorrect when used post the AO in the UK, but has regrettably become common parlance after the Selwyn Report (2014).
- We found EHC plans were not done for children living in residential care for whom no foster carers could be identified – their disabilities were simply discounted as non-existent.

- Children put into care under a voluntary Care Order (Section 20), so a respite break might be achieved from the intensity of family life, could get trapped in care with cases allowed to drift.
- No models exist for reunification in our families where parents and special guardians do not need to be reformed due to alcohol or drug abuse or do not suffer with mental illnesses. Proving changed circumstances becomes a virtual impossibility when the family members are kept estranged with contact restrictions that seem designed to give the child a negative view of their adopters and SGs – whilst the system rallies around one foster carer after another until there is only residential care left, and when this fails a Secure Unit.

## Suggestions for a way forwards/Recommendations

We suggest:

- Those with 'lived experience' of providing a nurturing family environment need to be involved at a decision making level with shaping legislation and policy.
- The setting up of a Commission to allow dialogue with parents of children with disabilities, adoptive parents, special guardians and kinship carers – basically all those who provide a safe nurturing family environment for children to grow and thrive.
- We have previously proposed a new childcare role – the Independent Guardian' who can safeguard permanence for previously looked after children, working with children *and* families whether the child lives at home or re-enters care. We suggest this new role could perhaps be expanded to oversee and support EHC Planning and make this a less stressful process for families.
- A more open, less defensive approach to legislative review in regards to the Children's Act 1989, which is causing harm because of its implementation, particularly in regards to the threshold of Beyond Parental Control for children with poor mental health. Section 20 is also problematic - it carries too high a risk of re-traumatising our previously looked after children, and de-stabilising any child, when it is the only way to access respite. There is no effective scrutinising of Section 20 when Independent Reviewing Officers either do not, or cannot bring cases to court and cases are allowed to drift. We cannot see how the getting rid of IRO's can do anything but harm, as they need to be more independent rather than dispensed with.

## 2. Introduction

Special Guardians and Adopters Together are a peer led, peer supported campaigning group. The aim of SG&AT is to provide an authentic collective voice, which is necessary to protect identities, and to raise awareness of issues that affect our respective communities. We seek to work together with government, researchers and relevant organisations/charities to find workable solutions to extremely complex multi-layered social problems. We believe dialogue with us, with those with 'lived experience' is vital to bring about beneficial change. We seek understanding of problems and underlying reasons for them first and foremost – because solutions to problems will always elude without this. We hope this report will be of value to the House of Common's Education Committee.

The Committee is considering the following areas:

- Assessment of and support for children and young people with SEND
- The transition from statements of special educational needs and Learning Disability Assessments to Education, Health and Care Plans
- The level and distribution of funding for SEND provision
- The roles of and co-operation between education, health and social care sectors
- Provision for 19-25-year olds including support for independent living; transition to adult services; and access to education, apprenticeships and work

The information in this Enquiry is based on two surveys and supported by further input from parents and special guardians, who make use of closed Facebook Groups for support and community. Our Survey of Stress and Wellbeing suggested parents and carers found these groups a valuable resource<sup>1</sup>.

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<sup>1</sup> <https://specialguardiansandadopterstogether.com/interim-report-of-a-peer-led-survey-on-stress-health-and-wellbeing-of-special-guardians-and-adopters-march-2018/>

### 3. Methods

We have conducted two surveys and the information in this report comes from these surveys, and from our own closed Facebook group. Members of the Facebook group of POTATO (Parents of Traumatised Teenagers Organisation), and a group entitled 'UK Adoption Disruption Parents Group' were also invited to provide input to the report. We chose these groups because we were especially interested to learn about children who leave the adoptive and special guardianship family home prematurely, and wanted to consider how EHC plans were working for this population, which receives scant research attention. A maximum variation criterion sampling method<sup>2</sup> was used to select cases for presentation from our own group's membership to give examples ranging from children just starting their formal education to post 16's, and include the experiences of both adopters and special guardians whose children had remained at home and re-entered care. This is a type of purposive sampling method. Participants/SG&AT members created narrative summaries. Vignettes of cases were created from these summaries by the report author, which were subsequently verified with the participants/members, as reflecting an accurate summary of events.

The Stress and Wellbeing Survey of Adopters and Special Guardians was piloted on group members during December 2017 and conducted anonymously (using Survey Monkey), to enable respondents to feel able to answer questions freely. No questions were compulsory and 72 questions were asked. Email addresses were provided, if wished, by respondents for a prize draw, to incentivise participation, and were used solely for this purpose. We explained how the data would be considered and used to participants, and put a statement of confidentiality and ethics on our website in February 2018, to keep respondents updated and informed. Data was collected from 1<sup>st</sup>-31<sup>st</sup> January 2018 and is stored anonymously in accordance with GDPR on Survey Monkey. The survey was promoted using social media platforms of Facebook and Twitter. Qualitative data was extracted from Survey Monkey, and analysed thematically. Respondents were asked about their children's medical diagnoses and disabilities. Most questions were asked per child, which made looking at correlations and associations too complex – we do not have the resources or expertise to conduct this statistical analysis. In terms of EHC plans we asked about whether a plan was in place or pending, and invited further comments to this question. We also asked what respondent's experiences were in regards to achieving the plan requesting experiences to be rated according to whether they had been very positive, positive, acceptable, dissatisfied, or extremely dissatisfied.

The Partnership Working, School Exclusion and School Refusal (Self-Exclusion) Survey was developed at the beginning of May 2018. Sylvia Schroer, the report author, put the survey together and two group members, one adopter and one special guardian piloted it, and made suggestions for improvements. The survey went live from the afternoon of the 2<sup>nd</sup> May 2018 to 5pm on the 5<sup>th</sup> May 2018, and was promoted using social media platforms of Facebook and Twitter. For this survey we were interested in exploring associations and correlations with EHC plans and school exclusion/self-exclusion, with this information being used for an earlier report, prepared for the DfE's call for evidence on school exclusions. We did not ask respondents about individual children or invite or ask for comments on this survey. The design of this survey enabled us to explore statistical associations using Survey Monkey, without the need for statistical support.

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<sup>2</sup> Patton MQ (2002) *Qualitative Research and Evaluation Methods*, Thousand Oaks, Sage Publications

## 4. Findings

There is a dearth of comparative data for adopted and special guardianship children so we begin by discussing some findings in regards to this, which may be pertinent to education, health and social care support planning for previously looked after children.

### 4.1 Stress and Wellbeing of Adopters and Special Guardians Survey

We had 403 responses to our survey and of these respondents, 389 respondents were eligible and included in analyses. 309 are Adopters (79%) and 83 are Special Guardians (21%). 3 of the survey respondents are both Adopters and Special Guardians (SGs). Not all questions were answered so we have reported the number of respondents answering each question separately.

#### 4.1.1 Demographics and background information about respondents/children including comparative data for Adopters and Special Guardians

- The age range of Special Guardians tends to be older than Adopters, where 63% are 50+, whereas for Adopters only 38% are 50+
- Of the Special Guardians (N=83) two thirds (67%) are grandparents.
- Just over a fifth (22%) of all respondent are single parent/ carers. One fifth (20%) of Adopters in the survey are single parents and this rises for Special Guardians where 30% are single carers. (=387)
- Adopters tend to be spread across all income groups whereas Special Guardians cluster towards the lower end of the income spectrum. Over half of Adopters have household incomes over £40k, whereas for Special Guardians the figure is 2% and **44% have an income under £20K.**
- 32 % of Special Guardians and 18% of Adopters receive Carers Allowance

Between the 389 survey respondents there are 689 children/adult children of whom 554 are adopted and 135 under Special Guardianship Orders. Respondents currently parent and care for 605 children and young people aged 18 or under.

- 47% of adopted children are 12 years or older, whereas 21% of Special Guardian children are 12 years or older.
- Special Guardian children were placed when younger than adopted children – 50% were placed before 18 months old compared with 34% for adopted children.

#### 4.1.2 Children's disabilities and health issues

- Numbers of children receiving Disability Living Allowance, or with DLA/PIP applications pending were broadly similar, at 35% for Special Guardians and 38% for Adopters with 344 respondents answering this question.
- There was a different profile in terms of mental health diagnoses of children: proportionally higher numbers of adopted children were diagnosed with Depression, PTSD and Complex Trauma and the converse was true for special guardian children in terms of an Anxiety, FASD/AND diagnosis – see Table 1 (N=264).

**Table 1. Children's mental health diagnoses**

Total respondents N=264	Number of children with diagnosis	Adopters Respondents N=225	SGs Respondents N=42
<b>ADHD</b>	99	85	15
<b>Autism</b>	76	63	15
<b>Foetal Alcohol Syndrome</b>	41	31	10
<b>Alcohol Related Neurological Disorder</b>	27	21	6
<b>Anxiety</b>	193	156	39
<b>Depression</b>	60	54	7
<b>PTSD</b>	64	61	3
<b>Complex Trauma/Developmental Trauma</b>	182	163	22
<b>Attachment Disorder/ Pattern</b>	303	257	47
<b>Total Number of Diagnoses</b>	<b>1045</b>	<b>891</b>	<b>164</b>

#### 4.1.3 EHC Plans in place or pending

Nearly 50% of respondent's adopted and Special Guardianship children have an EHC Plan or one pending (See Table 2). 223 children had EHC Plans and 49 children had a plan pending.

**Table 2. EHC plans in place or pending for child**

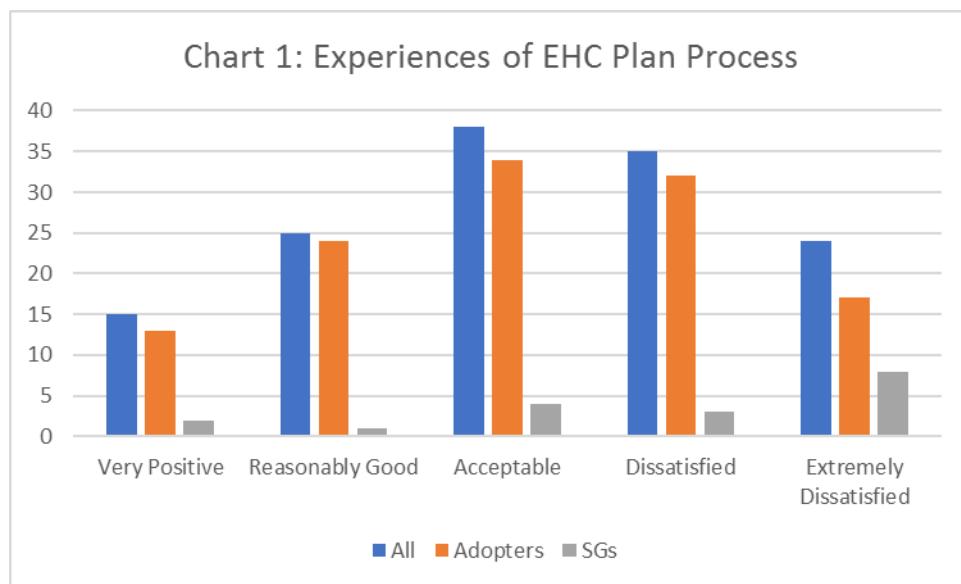
	All (%) N=340	Adopt (%) N=275	SGs (%) N=68
<b>Yes</b>	223 (39%)	189 (40%)	35 (32%)
<b>No</b>	300 (52%)	241 (51%)	64 (58%)
<b>Pending</b>	49 (9%)	37 (8%)	12 (10%)
	<b>572</b>	<b>467</b>	<b>111</b>

#### 4.1.5 Experiences of ECH Plan Process

The ratings were not asked on a per child basis but according to the respondent's overall experience of the EHC Process. 267 Respondents answered this question. Of these, 137 rated their experiences, and 130 ticked 'Not Applicable'. Experiences are shown in the Table 3 and Chart 1

**Table 3. Experiences of EHC Plans**

	All	N	Adopters	SGs
	%		N	N
<b>Very Positive</b>	11.00%	15	13	2
<b>Reasonably Good</b>	18.00%	25	24	1
<b>Acceptable</b>	28.00%	38	34	4
<b>Dissatisfied</b>	26.00%	35	32	3
<b>Extremely Dissatisfied</b>	18%	24	17	8
		<b>137</b>	<b>120</b>	<b>18</b>



#### 4.1.6 The EHC Plan process as a 'stress factor' for parents and carers

We asked respondents to rate various aspects of parenting/caring for a child or young person in terms of the following rating scale: 1= slightly stressful; 2= stressful; 3= extremely stressful (see Table 4)

in relation to the EHC process: 311 responded to this question of whom 127 said the question was not applicable. The weighted average score for the remaining respondents who rated the EHC process was 2.05 (2.01 for adopters N=148; 2.13 for Special Guardians N=38).

**Table 4 Ratings of aspects of parenting/caring for a child in terms of stress**

	All N=336			Adopt N=270			SGs N=69	
	Total	Answered N/A	Weighted average	Total	Answered N/A	Weighted average	Total	Answered N/A
Supporting Your Child in Family Home	331	9	2.36	265	6	2.44	68	3
Difficulties Parenting from A Distance	279	212	2.48	226	168	2.5	55	45
Coping with Your Child's Issues/ Problems or Challenging Behaviours	331	14	2.5	267	8	2.59	67	6
Impact of Child(ren)'s Challenging Behaviours Upon Their Siblings	319	90	2.45	256	63	2.46	65	28
Dealing with Your Child(ren)'s School	325	49	2.15	262	26	2.2	66	23
Home Schooling	272	243	1.97	225	200	2.08	49	44
<b>Education Health and Care Plan Process*</b>	<b>311</b>	<b>127</b>	<b>2.05</b>	<b>250</b>	<b>102</b>	<b>2.03</b>	<b>63</b>	<b>25</b>
Family Time/Contact Arrangements If Child Is Living Away from You	290	243	2.34	237	196	2.37	55	48
Child's Contact/Meeting with Birth Family*	304	181	2.08	239	177	1.81	67	4
Child's Contact/Meeting with Birth Siblings Who Do Not Live with You*	298	197	1.65	239	159	1.64	61	38
Demands of Multiple Caring Roles (Other Than Your Adopted Or SG Children)	296	191	2.09	237	163	2.14	62	29
Differences with Partner	315	97	1.97	254	76	1.99	63	22
Worries About the Future	333	11	2.3	269	7	2.31	67	4
Financial Worries*	319	50	2.11	254	46	2.04	67	4
Lack of Support and Understanding From Friends/Family/Community	325	37	2.02	260	25	2.03	67	12
Other	115	78	2.57	87	59	2.61	30	20
Other (Please Specify)	33			27			7	

\*these aspects of parenting/caring for a child were rated as more stressful by Special Guardians than adopters

#### 4.2 Findings of the Partnership Working, School Exclusion Self-Exclusion Survey

The survey had 148 respondents of whom 145 were eligible. 96 were Adopters and 50 were Special Guardians. One respondent was both an adopter and a special guardian. Findings were similar to the larger survey.

##### 4.2.1 Demographics and background information – comparisons between adopted and Special Guardianship children

Findings reported below showed significant differences/associations between Adopters and Special Guardians 95% confidence level (p=0.05)

- More Special Guardians cared for children under 4, and 4-7 years.
- More Adopters parented children who were 12-15, 16-17 and 18+ years.
- Special Guardians were less affluent than Adopters and more struggled to cope financially: more Special Guardians had an annual household income of £20k or less and more Adopters had an annual household income of £40+K.
- More adopted children had re-entered care compared with Special Guardianship children: 12 adopted children had re-entered care compared with only one Special Guardianship child.
- More Special Guardianship children were in mainstream school up to 16 (86% compared with 61% adoptees). More adopted children were in a special school up to 16 (14 adoptees compared with 2 SGO children), a special school or educational programme for 16-19 year olds (7 adoptees compared with 0 young people under an SGO), or NEET (18 adoptees compared with 1 young person under an SGO).
- More adopted children were on DLA/PIP, or with applications pending, than Special Guardianship children (58% compared with 22%).

#### 4.2.2 Mental health diagnoses of children

- In this survey Adopters parented more children diagnosed with Anxiety and Complex Developmental Trauma: 42 adopted children had Complex Developmental Trauma compared with only four special guardian children. (see Table 5)

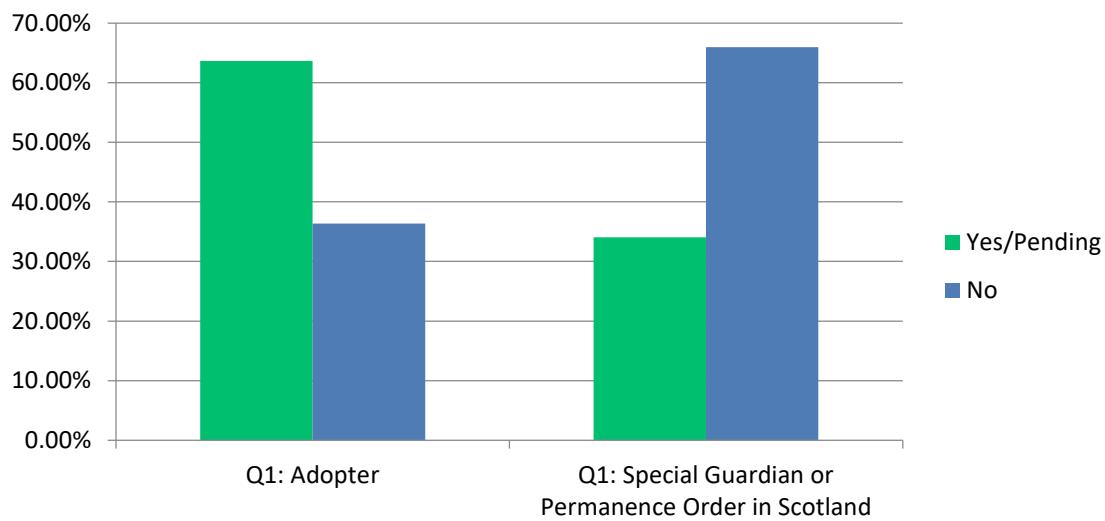
**Table 5: Mental Health diagnoses of respondent's children**

Answer Choices	All %	All N=111	Adopt N=76	SG N=35
<b>ADHD</b>	28.83%	32	26	6
<b>Autism (ASD)</b>	23.42%	26	19	7
<b>Foetal Alcohol Syndrome/Alcohol Related Neurological Disorder</b>	14.41%	16	13	3
<b>Anxiety*</b>	42.34%	47	38	9
<b>Depression</b>	18.02%	20	16	4
<b>PTSD</b>	13.51%	15	13	2
<b>Complex Trauma/Developmental Trauma*</b>	41.44%	46	42	4
<b>Dissociative Identity Disorder</b>	5.41%	6	5	1
<b>Attachment disorder/ pattern</b>	71.17%	79	54	25
<b>Other mental health condition/diagnoses</b>	22.52%	25	18	7
<b>Total diagnoses</b>		312	244	68

\*significantly greater for adopted children than Special Guardianship children

More adopted children were described as SEN or had an EHC plan pending than Special Guardianship children 56 (64%) Adopters compared with 16 (34%) SGs.

## Chart 2: Does your child have special educational needs and/or an EHC Plan?



### 4.2.3 SEN/EHC Plans and school exclusion

We found a significant correlation between children who were frequently excluded, and children having SEN/EHC plans in our population sample and conversely with children never having been excluded from school and having no SEN/EHC plans.

### 4.3 Qualitative Data – from the Stress and Wellbeing of Adopters and Special Guardians Survey

This survey was done prior to the call for evidence to the Education Committee and we did not ask questions in regards to the headings that policy makers have requested. Our qualitative responses are very broad in regards to SEN/EHC plans as we had just invited general comments and observations. We have considered two emergent themes, which are discussed below:

#### 4.3.1 'Battling and Fighting'

Obtaining the right educational provision for an adopted or Special Guardianship child with mental health problems that lead to behavioural difficulties is evidently not straightforward. Help did not seem to be offered by professionals and to the contrary, parents were deterred from putting in applications and described having to '*battle and fight*' for support. With Attachment Disorder, a common diagnosis that can have serious ramifications for a child's learning needs, two respondents reported having difficulties. One parent reported being deterred from putting in an application on the basis this would 'label' their child and another reported they were never made aware that they could make an application with this condition despite there being obvious difficulties. Parents and Special Guardians repeatedly reported that their children had obvious difficulties, but they were not statemented, had no EHC plans and it was a battle to achieve one. The local borough also made a difference and there was an element of a postcode lottery in terms of provision.

Opting out through home education was one solution, but this would not suit every child or family.

#### 4.3.2 A lack of recognition of the impact of social emotional and behavioural problems

A Virtual Head had informed one respondent that obtaining support for mental social, emotional and behavioural problems was much harder to achieve than for children with more obvious learning disabilities. This was also the observation of a Welsh adopter: *“we still have Statements of Special Educational Needs in Wales. Our daughter had one when she was just 3 years old. Her journey to adulthood (including special school and hopefully specialist residential college placement) has been far, far smoother than that of our son who is academically very able but mentally and emotionally unable to cope with everyday life”*.

A barrier to accessing an EHC plan, when a child had obvious difficulties in terms of education, was *‘not meeting the criteria’*

#### 4.4 Cases and comments from the social media groups

The cases and comments we received are described according to the main areas of concern for the Education Committee and requested by this Committee. Six cases or vignettes are provided to offer context information as well as show divergences in approach when previously looked after children re-enter care, compared with remaining at home. These are: Robert age 8; Lucy age 14; Ali age 14; Jimmy age 5, Liam age 18 and Emma age 17. Robert and Jimmy are under Special Guardian Orders and Lucy, Ali, Emma and Liam are adopted. Robert, Ali and Lucy have re-entered care, Jimmy and Emma live with their families, and Liam lives at home after reunification.

##### 4.4.1 Assessment of and support for children and young people with SEND

- Eligibility to be assessed was challenging for different reasons (see Liam’s, Roberts’, Ali’s, Emma’s and Jimmy’s stories). Parents and Special Guardians might be thwarted in their efforts to be considered and/or achieve an assessment for years, until finally it became so obvious that it was desperately needed because the school could not cope and the child was getting excluded or was dropping out of education altogether. At this stage there was no guarantee of success and the whole process might, having got to the panel stage, have to start again, as if it were a game of ‘Snakes and Ladders’ for reasons that made little sense to parents and Special Guardians and left them in no doubt the consequences could be severely detrimental. Reasons given for the panel rejecting the assessment/application seemed petty and obstructive: the wording on the application’s title (see Robert’s story), or the application being considered ‘ambiguous’, (see Jimmy’s Story).
- Denial/discounting of problems and disabilities. A child’s disabilities might not be recognised as such by a Local Authority to avoid a CIN approach (see Liam’s story), which might have led to better recognition of educational support needs. When a child re-enters care their disabilities may also not be recognised by the Local Authority (see Robert’s, Ali’s and Liam’s stories). Diagnosed conditions such as FASD, with obvious characteristics, may also be challenged by Local Authorities who do not accept the diagnosis – see Robert’s story.
- Local authorities under pressure are overly focused on meeting the EHC Plan timetable and legal obligations (see Liam’s story). This can impact on relationship building as parents and carers feel the needs of the child become secondary to the Local Authority, when for them, living with the child under stress on a daily basis, these timetables seem to add more pressure – as one has to endure the crisis for longer until the assessment is done, and then the panel, which may or may not be successful. All the while the crisis deepens.
- When an organisation closes in on itself and views the parents as adversaries with a Section 31 Order made, and an application for its discharge attempted, the playing of the ‘best interests’ card was a way to control and subjugate parents and Special Guardians who were left feeling disempowered and immensely frustrated on top of the bereavement issues they

had to deal with (see Ali's story). This made any kind of partnership working impossible and parents and Special Guardians were unable to contribute. When a child re-entered care this was seen as the work of professionals. The making of a Section 31 Care Order, child protection investigations, and being in court were all barriers to good relationships with those who make a lifelong commitment to permanence.

- Relationships could work however after care re-entry. An example of a relationship that was working post a Section 31 Care Order was provided by a member of the UK Adoption Parenting Disruption Group – this is discussed below in the section on the level and distribution of funding.
- One of the consequences of not achieving educational support that met the child's needs was school exclusion, school refusal and re-entering of care (see Robert's and Liam's stories). School exclusions came up frequently as being an area of serious concern for parents and special guardians.
- Parents and Special Guardians of children who re-enter care are marginalised and feel 'persecuted' (see Robert's, Lucy's, Ali's and Liam's stories). For parents who were able to be involved with the application (when a child had not re-entered care or had been reunified), there were many battles along the way that led to delays (see Jimmy's, Liam's and Emma's stories).

#### 4.4.2 The transition from statements of special educational needs and Learning Disability Assessments to Education, Health and Care Plans

- One adopter commented that the EHC Plan was a progression from SEN statements, with it continuing to the age of 25, but there were no other remarks or comments made in relation to the change. There is however a legal mismatch with the SGO ending at 18.

#### 4.4.3 The level and distribution of funding for SEND provision

- It is not clear whether going into care made things better or worse, and three of our cases suggest the latter with the Local Authority not recognising the child's disabilities in two cases (Ali and Liam); and even refusing to accept the medical diagnosis of FASD (Robert's case). Re-entering care potentially had catastrophic negative consequences. For Ali it meant losing his faith, connection with community and his only UK family as well as numerous school exclusions. For Robert, who is only 8, his education is side lined and his connection with his family is in peril. For Lucy, the family is broken, Lucy's mother cannot expedite therapy she is willing to pay for, and the respite break under Section 20 became a permanent one with the approach taken. For Liam, who is reunified, his time in care meant his education was better but he twice tried to take his life when he wished to go home but could not achieve dialogue about it.
- Adopters in the 'Adoption Disruption' Group described being 'eradicated' from the life of their adopted child by Local Authorities who did not seem to appreciate that an Adoption Order, once made, is permanent, and cannot be revoked. One parent in this group described how services they had previously struggled to achieve had 'kicked in' after their teenage child (the middle of three adopted siblings), had to re-enter care because the family, including his siblings, could not cope and it was too unsafe to live together. It was interesting because this adopter had established a very positive working relationship with the local authority, albeit after a change of team and a more sensitive approach. Court followed and the Section 31 Care Order went through smoothly. What makes this case so different to those we have described from our group is that the parents were not in opposition with the

Local Authority about services and support by the time the case went to court and all agreed that the child should be in care and could not come home. Another parent, previously a teacher, commented that Looked After Children were able to access better services. However, cases such as Lucy's, Roberts and Ali's suggest that support for education and therapy does not always kick in. Lucy's mother could not even self-fund Lucy's therapy in care, when she heard Lucy was not doing well, because no agency would deal with her due to there being a Section 31 Care Order, which she had applied for hoping it would bring better services and therapeutic support.

#### 4.4.4 The roles of and co-operation between education, health and social care sectors

- There was variability in cooperative working between agencies. In Robert's case the local authority's lateness meant the application missed the panel, which had a knock on effect on their child. When the EHC plan was finally achieved, it was side lined by social care. In Liam's case excellent cooperation had been achieved through the involvement of the Virtual Head, a psychologist who became involved through a Criminal Injuries Compensation Award assessment and who struck up a positive relationship with the child, and Adoption Support Fund specialist providers.
- One family were coming to the end of an appeal process for an EHC plan for their home schooled 17 year old daughter, and described "*zero cooperation*" between education and social care teams, although their post adoption social worker had been supportive. A Formal Complaint had resulted in a positive meeting with an SEND senior manager. They are hoping to achieve an EGC plan with 4 education providers named in Section 1, suggesting this was an unusual case.

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

- Post 18 provision of education was a major concern for Special Guardians in our group (SG&AT), when the SGO ends at 18 but the EHC plan continues to the age of 25.
- Special Guardian's spoke of how their children will need life-long support in some cases but they are not able to protect them, care for them, or look out for them
- One Special Guardian, who has an EHC plan for her youngest grandchild, was deeply concerned about what would happen after 16, and the fact the Local Authority did not seem to be meeting their statutory obligations in terms of reviewing the plan. The post 16 provision was described as "*absolutely appalling*".
- One of the challenges for young people who cannot access education is they feel very stuck in their lives whilst their peers move forwards. This exacerbates depression and low mood and it becomes a vicious cycle with a parent or Special Guardian trying to keep their child's spirits up at the same time as having battles, which may be futile, to get them the support they need (see Liam's story).
- One adopter described how her 19 year old son, who was placed at 2, had found school a 'nightmare' and been labelled a 'naughty boy' rather than get the help he really needed. A highly intelligent young man who had been predicted high grades, he had re-entered care at 15. Since then he has been groomed by drug gangs, had a gun found at his 'supported living' flat', and has numerous criminal convictions. His mother was expecting him to be given a prison sentence this week. This story echoes many that we hear on our social media forums. Parents feel education is key in cases such as this.
- One adoptive parent made the following submission on 13.6.18, which we have included verbatim, as received: "*The EHC plan is welcomed as a way to describe a young person's*

*special educational health and social care needs. It explains the help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in life. It incorporates the three elements but it seems health and care are subsidiary to education so is not really a holistic approach, yet still a progression from a statement of SEN, and can be available until the age of 25. For one young person seeking to move to post 16 education - educational psychologist and other reports were compiled, and a draft plan in preparation when things came to a halt. No LA post 16 provision felt able or was willing to offer a place. The only available offering came from a charitable organisation founded by someone who had been homeless, been in care, but had turned life around and on gaining a degree determined to help others facing similar problems and built a team with similar commitment. Not being a LA approved provider, despite several awards, there could be no EHC plan. However, they don't give up: their motto 'Change a young person's life today, and they may change the world tomorrow,' So for several years a non-approved provider aided a young person let down by the structure and attitudes within the organisations supposed to be offering help."*

### *Robert's Story*

Robert is 8 years old and lives in residential care. His Special Guardians are not consulted about the placement and are unable to discuss their grandson's care needs. Robert's behaviours were too difficult for a mainstream school setting to cope with. An EHC plan was finally achieved in February 2018 after many years of struggle to get there by his grandparents. The application process began when Robert was in Key Stage 1, but it was initially declined by the panel because of the 'wording' of the title. This application was put forward by a 'Nurture Group' providing Robert's education alongside mainstream school. The Nurture Group claimed they never excluded children but excluded Robert on numerous occasions. Robert's grandfather explains what happened with the EHC plan:

*"When we first applied for the EHCP it was turned down as the title did not meet the criteria for panel, we then had to reword the document and obtain a new panel date and extra evidence was required from the Nurture Group, which we got in time for the panel date - but we also needed evidence from social care. This was provided late so we missed the panel date we then had to apply for a new date which took a couple of weeks. In the meantime my Grandson was due to go from Key stage 1 to Key stage 2 and the Nurture Group would no longer be able to have him - it was for Key stage 1 only, so a link school was looked at while the plan process continued, but he was turned down for the link school leaving us with no education provision for the next academic year with only 1 week left before the summer break"*

The EHC plan was finally achieved in February 2018 but Robert re-entered care in March 2018 and the plan is now side lined. Robert's grandfather, who had asked for help and support to care for him, described how he 'faced persecution', in court at the hands of those with a duty of care for the family. He is very shaken by the blaming approach taken when his grandson has a lifelong medical condition that cannot be cured, and requires environmental support. Although a diagnosis of FASD was made at the beginning of March and it appears from his physical appearance and features that Robert has FASD, the Local Authority do not accept this diagnosis. It appears to his grandfather that Robert, an extremely vulnerable boy, is being deprived of his right to family life by the State and he feels very concerned about this when Robert's FASD, a condition which benefits from environmental support, means that he is likely to require care and support long after the Special Guardian order ends at 18. Robert's Special Guardian Grandfather feels the Special Guardian Order has not been properly thought through by legislators and policy makers. *"I think this Order needs extending particularly when most SGO's are because of removal from parents so those children are damaged in some way physically or mentally- in our case FASD which does not end when he turns 18 - it is a life-long condition that will require some form of support for his lifetime. You have to draw the line somewhere but it (the SGO), should be increased from 18 to at least 21 and there should also be a case by case approach as those with disability/lifelong condition need longer term looking after and support"*

### *Lucy's Story*

Lucy is 14. She was taken into care under Section 20, when she was 9. Family life had become too intense due to child to parent violence, for which her mother could not access the right support and a respite break was required. Her mother battled for therapy for her in care under Section 20 to no avail. No suitable foster carers could be identified to care for Lucy and she was sent to live in a children's home. The case drifted with many social worker changes. No effort was made to support Lucy to be reunified and she was then sent to live with foster carers originally deemed unsuitable. She has lived there for three years. Lucy does not wish to see her mother and the Local Authority, who do not allocate specialist social workers to the case, misunderstand the reasons why and do nothing to support a positive relationship. Lucy's mother's solicitor wrote to the Local Authority about concerns under the Section 20 Care Order. The local Authority instigated care proceedings and a Section 31 Care Order was made. Since then Lucy's mother is marginalised, increasingly estranged from her daughter, and unable to attend LAC reviews when her daughter does not wish for her to be there. The social worker visits her at her home and reports that Lucy is not doing well at the moment. Lucy's mother has offered to fund therapy herself. The Social Worker agrees it is needed but will not fund. No therapy providers will deal with Lucy's mother because of the Care Order, and with no 'intention to reunify' there is no possibility to access the Adoption Support Fund. The family are in a stuck place with a divisive approach taken even though Lucy's mother is a loving committed parent desperate to help her daughter. Lucy is statemented and attends a special school but her mother has not been invited to an education meeting for many years and has no idea if Lucy has an EHC plan or not

### *Ali's Story*

Ali is 14. He is diagnosed with complex trauma and his mother, who suffers from epilepsy, took harmful medication during pregnancy in Ali's country of origin. He is a kinship adoptee. He came to the UK the year he turned six having been cared for by wider family because of our immigration laws making it too hard for him to come earlier. Ali was adopted in February 2013 after a harrowing 2 year removal from his family, and he re-entered care again in 2015. He received Disability Living Allowance but his disabilities are not recognised by the 'family friendly' Local Authority and all attempts to get the Local Authority to work in partnership with his Muslim parents have failed. Unable to make any progress for Ali, an application for discharge of the Care Order was put in by his parents in June 2017 when Ali wished to go home. But in March 2018, when care proceedings had concluded, the Local Authority and Cafcass Guardian had successfully undermined a positive outcome two of reunification as Ali no longer wished to come home and also rejected his faith, which has been unsupported by the State. The 'system goal' had been to replace his family with foster carers, who offered a different 'parenting style' to his loving committed adoptive parents. No foster carers of Ali's faith or nationality could be found so this was an inter-racial placement. His parents' attempts to support their child's faith was considered to be 'backdoor contact' and the psychologist in charge did not realise Ali was adopted due to poor communication. He believed the adopters were birth parents. A month before care proceedings concluded, a sixth foster carer who the 'system' had rallied to support instead of his adoptive parents, handed in her notice. Not informing Ali of this, the Cafcass Guardian used the child's contact time with his parents to visit the boy and ascertained he wished to remain in a foster care placement, where he had struck up friendships, but had to shortly leave. The LA and Cafcass Guardian successfully thwarted all attempts to involve a Muslim psychologist and an adoption expert to consider the complex case when Ali's parents had no legal representation. This independent assessment done for court would have been funded by Ali's mosque who remain deeply concerned about the case and the impact of all this on Ali who grows up estranged from family and community. Ali who is now addicted to tobacco, in residential care as no foster carers can be identified to care for him. The Independent Reviewing Officer obstructs Ali's parents continually and says it would not be in the child's 'best interests', whatever it is they suggest.

In terms of education, a statement of special educational needs was discussed first in a Child In Need meeting in 2013 but dismissed as it would 'label' the child. Ali's father raised the matter again in November 2014 but Ali was deemed as 'not meeting the criteria'. A referral was made for him to see an educational psychologist but he was then considered 'not stable' enough to proceed in February 2015, shortly before he was removed from the family home. An EHC plan was discussed in numerous LAC reviews since care re-entry, as Ali was so often getting excluded from school in years 7-9, but an EHC plan was always considered 'not necessary'. Parents are unable to attend PEP meetings or education meetings about their child. In the most recent LAC review on 6/6/18 the Local Authority appear to have altered their intransigent position on the EHC plan. They have said the father will be sent a form to complete and an education meeting will happen in August. Ali's parents are informed it will be a 26 week process. Ali receives education in a PRU.

### *Jimmy's Story*

Jimmy is almost six and under a Special Guardianship Order since the age of two. Court documents revealed a diagnosis of Global Developmental Delay, which the social worker had not shared with his grandmother special guardian, informing her Jimmy was just like any other boy of two. At almost five Jimmy was assessed at 22 months across every domain of the test. Jimmy's preschool said they would begin the ECH plan process to ensure he would be ready when he started with school, but the pre-school SENCO left and the work was not done when the new SENCO did not understand how to do it. Once in mainstream school, the forms were filled in and assessments were carried out with the process taking seven months to complete. Despite the assessment showing he is unable to read, write, draw, recognise numbers or letters, have good relationships with his peers, concentrate for any period of time, or follow basic instructions, as well as having an attachment disorder, his assessment was rejected by the Local Authority, as it was deemed 'ambiguous'. Jimmy's grandmother, a single carer, was told to begin the assessment process again from the beginning, and advised not to appeal as it would be too 'distressing for her' and would include legal proceedings. An appeal will be made because Jimmy starts another school year in September having made no progress at all. Jimmy's grandmother feels her grandson is being set up to fail in life. Jimmy's grandmother had spent her life savings to pay legal costs to achieve a Special Guardian Order for Jimmy and his older brother, to prevent them being put up for adoption by the Local Authority. She says: "*The school Senco has been great and has tried to give him as much support as possible, but he needs more specialist help. Without this I despair about how he will cope with the curriculum without any basic literacy or numeracy skills. This will impact his learning in every subject and will have an effect throughout the whole of his school life unless specialist support is put into place now*"

### *Liam's Story*

Liam is 18 and reunified for 2 years after his adoptive mother battled alone, without legal assistance, to get him back home, for 3.5 years. He was taken into care and a Care Order given in 2013, when he was 13, due to him meeting threshold for Beyond Parental Control as a result of school refusal, which was anxiety related. The Care Order was finally discharged in 2016 when an adoption specialist was instructed by the court to re-assess the case. No dialogue was achievable about reunification and the DCS gave no alternative but court to Liam's mother and has stonewalled her since October 2014. Liam, who wished to go home for the entire time, attempted suicide twice in care. He is diagnosed with ADHD; PTSD; Reactive Attachment Disorder; Depression; Anxiety, Dissociative identity Disorder and Complex Trauma. A Supervision order was sought by the Local Authority when the Care Order was discharged. In order to expedite a swift much longed for reunification, and avoid a costly contested hearing where she would have no legal help, Liam's mother agreed to this. Thus Liam came home with no rehabilitation plan and funding for support was refused until it could be accessed via the Adoption Support Fund some months later. The Supervision Order was discharged before it expired with the Local Authority not meeting its statutory obligations in respect of Pathway Planning. Liam's mother is directed to the Formal Complaints team by the Deputy DCS in respect of the approach taken, which saw Liam's rights of a child violated, but the Complaints Team refuse to discuss a complaint because the matter went to court. The remit of the court was too narrow to properly consider the impact of negligence in terms of early risk assessment, missed opportunities to help, and the human rights violations of this case - but through the organisation closing in on itself Liam and his mother receive no apologies and must absorb the condemnation that has been heaped upon them both when a child protection approach was taken instead CIN. Liam has been in receipt of Disability Living Allowance/PIP since 2007 but his disabilities are not recognised by the Local Authority and Liam's mother could not get him assessed as having special educational needs in 2012 or 2013 before he re-entered care. Liam started receiving home tuition in the children's home in 2014 through the Virtual Head/and a PRU. He achieved 7 GCSEs. He began mainstream sixth form when he returned to the family home but could not cope and stopped attending. The following academic year the Local Authority tried a novel educational approach for 4 young people of university potential, which Liam is. Liam was the only young person who could not manage to attend, and the Local Authority decided to put in for a post 18 EHC plan. Liam's mother was asked to request the plan by his education providers who took two months to develop a preliminary support plan with Liam and his mother. This was submitted to the Local Authority on 16.5.18. Liam's mother was contacted on 6.6.18 to be informed that the LA had 20 weeks to complete the assessment from when 'the clock started ticking' but the educational psychologist who made contact has no idea when this was/is. Cooperation between education and health professionals (who are funded by the Adoption Support Fund with CAMHS no longer involved), has been good since the therapy began four months after reunification. Liam is a Care Leaver as he was in care on his 16<sup>th</sup> birthday and the leaving care team are able to be contacted if needed. If Liam is successful to achieve the EHC plan he will be able to access therapy until he is 25 through the Adoption Support Fund and avoid becoming NEET. He struggles to leave the house due to anxiety issues being quite severe, possibly exacerbated by the approach taken of rescuing him from his adoptive mother to whom he was securely attached, instead of supporting the family. The educational psychologist informed Liam's mother that the Local Authority are currently re drafting the criteria for social, emotional and behavioural problems as they had placed too much emphasis on children who 'acted out' through behaviour and not enough on those who shut down and withdrew, of which Liam was a good example.

### *Emma's Story*

Emma, who is 17, has very high anxiety, due to the developmental trauma she went through in her early years. Through her secondary years, she was home educated by her adoptive parents who were able to tailor the education to match her unique needs. When she reached 16, they wished wanted to allow her to broaden her educational horizons, but were aware that she wouldn't cope with a normal college, due to her anxiety issues. So they approached the Local Authority to seek an assessment of her needs, and to ask what alternative education providers were available in our area.

Emma's parents appreciated this was an unusual case as no school was involved in the EHCP application process, but had not anticipated the adversarial reaction they received from the LA SEN team from the moment they applied for an EHCP assessment. They did their best to put them off, but with persistence they agreed to do an assessment. The educational psychologist did an excellent job, and recommended that Emma go to a small alternative college for just one day per week. Her parents realised that a variety of educational settings were required to meet her needs, and asked for these to be recognised in the draft EHCP.

This was obviously an unusual request for the LA, who repeatedly tried to steer the parents towards a full-time registration at the college, despite the clear recommendation from the psychologist that their daughter would not cope with this. This was the start of a long-drawn out fight from to get the LA to recognise all of the different providers. They had to appeal to the SEN Tribunal, and during this process had good support from a Post-Adoption Social Worker. In the end the LA conceded the appeal just before the hearing was due. So now, 18 months after first applying, the parents have agreed an EHCP that includes specific provision from several different providers in Section F, and names them all in Section I.

## 5. Discussion

### 5.1 Summary of findings

We sought to offer respondents/participants in this process of systematic information gathering, an opportunity to have their voices and experiences heard, and to contribute to the Education Select Committee in a way that meant our concerns would be taken seriously, whilst respecting the anonymity and privacy of our families and children.

We have reported on relevant findings of two recent surveys conducted by our group. We have also ascertained the views and experiences of adoptive parents and special guardians through social media groups that we are members of ourselves. Our surveys are anonymous so there may be participants taking part in both surveys, but notwithstanding this, we have, in a systematic manner, ascertained the views and experiences of 500+ individuals who parent 700+ previously looked after children and young people. With the survey's there is obviously the issue of respondent bias since participants self-selected to take part. One must consider that their motivation for participation may have been to be heard about difficulties they experienced. Whilst we do not know how representative our population is of the wider communities we hope to better understand, the themes we have uncovered and discussed have been described by numerous other researchers (Selwyn et al 2014; Neil et al 2018), and in other reports. What is new is the comparison of adopters with Special Guardians and the comparison of cases where children remain in the family home or re-enter care.

Our findings suggest a high level of need in terms of medical diagnoses and health conditions particularly Attachment Disorder, but also ADHD, Autism, FASD/AND, Complex Trauma and PTSD, which may all impact on learning, behaviour, cognitive functioning and an ability to relate to and connect with others.

In both surveys, adopted children were more likely to have a diagnosis of Complex Trauma. Adopted children also had more diagnoses given to them, a higher level of disability and more EHC plans than special guardianship children.

We have found experiences of educational support for previously looked after children and young people to be very mixed but overall there were more negative experiences than positive of the EHC plan process. The EHC Plan process was considered to be stressful by parents and carers.

Two emergent themes were described from the report author's analysis of comments made by survey respondents. These are the 'battling and fighting' of parents and special guardians to achieve support and secondly the challenge to have social emotional and behavioural issues recognised as a barrier to education and learning requiring additional support and a collaborative working approach.

Comments from the social media groups and six cases from the SG&AT membership were discussed according to the themes of interest for the Education Committee. We have highlighted a number of areas of concern that need to be given serious thought:

- Achieving recognition of the child's difficulties as warranting an EHC plan presented a significant challenge.
- Cases/vignettes, to look at context factors, showed that a child's disabilities and medical diagnoses were not accepted by local authorities.

- The process of achieving an EHC plan can be stressful, lengthy, burdensome and challenging for parents and carers and can at times resemble a game of 'Snakes and Ladders' with unexpected setbacks and obstructions.
- School exclusions are a major source of concern for both adopters and Special Guardians and there is a significant association between children who are excluded from school and children who have EHC Plans.
- Post 16 provision can be a postcode lottery and may not meet the needs of our children, who are often behind their peers in terms of development.
- Within the EHC process it seemed health and care became subsidiary to education and the approach was not holistic.
- Collaborative working between agencies was not always achievable and agencies might also close in on themselves to protect their reputation and interests.
- The system does not support providers who make be able to help on the ground through an appreciation of the problems faced from personal experience.
- Disparities increase between our children and their peers and there is a risk they will fall under the influence of the wrong people or become socially isolated and stuck in a vicious cycle of loneliness/social isolation and unable to access education or therapy at different times on their journey through childhood to adult life.
- There are disparities of education provision when a child re-enters care. Educational support that was previously unavailable can 'kick in', or conversely, hard won EHC Plans are side-lined.
- Parents and special guardians are not being used as a resource by agencies when children re-enter care. Parents and Special Guardians feel blamed not supported when they ask for help and describe being 'persecuted' by local authorities.
- The local authority makes decisions in an autocratic manner. Parents and SGs may not be consulted at all about the child's education or where the child lives.
- Achieving therapeutic support for a child poses a significant challenge when a parent/special guardian cannot make headway with providers who refuse to communicate with them.
- Parents and special guardians feel powerless to protect, support and advocate for their 'rescued' children who re-enter care following help seeking.
- Children who suffer with loss and deprivation are further deprived. The request for help is considered a 'child protection' issue. The short break becomes a long one. Children lose touch with family and community, and their faith/religion may be unsupported in care.
- There are no models of rehabilitation/reunification for blameless parents and carers who find that their child's difficulties, a legacy of their pre-natal environment or early life abuse, neglect and immense losses, are being attributed to their lack of capacity, or 'parenting style', after they were rigorously assessed in the first instance.
- The protective benefits that a loving stable family environment, community, and long childhood friendships can offer, to buffer adopted and SGO children from the impact of trauma and early life abuse/neglect – are not being thought about enough by local authorities and the wider State. The child protection approach that is often used is overly focussed on 'risk'. Families in crisis, with children on the edge of care, are not receiving the help they need in a timely manner – including EHC Plans.

## 5.2 Consideration of our findings in the context of related research

Our findings are consistent with the findings of other researchers from the field of social care, for example, the BASW enquiry on the role of the Social Worker in Adoptions<sup>3</sup> has described many of the themes we have also found in our surveys and cases, including the challenges of parenting a child with complex needs/multiple diagnostic labels and then being viewed through a “prism of risk” and “constructed as part of the problem” when seeking help. The BASW Enquiry has also highlighted the impact of austerity measures and service cuts leaving social workers under great pressure with a necessity to meet deadlines and suggested that fragmented roles could lead to fragmented approaches rather than a unified holistic approach.

A recent study by Neil et al (2018), using a survey methodology, has considered whether adopters' expectations matched with their experiences of the adoption, dividing survey participant's into three groups: more rewards/less challenges; fewer rewards/greater challenges, and greater rewards/greater challenges. For the middle group whose challenges outweighed the rewards a recurring theme to emerge was education provision “The final recurring theme amongst this group of parents was that they had found accessing services for their child (education being mentioned often here) much harder than expected. In some cases, the responses (or lack of) of others were seen as the main area of challenge: ‘Negotiating the education system for a child with additional needs has been more stressful and time consuming than I could ever have imagined.’ ‘The challenges have not come from my child - who would be expected to pose challenges given his past - the challenges have come from accessing services, ghastly court proceedings...’”<sup>4</sup>

Finally, we consider the case of Connor Sparrowhawk. Connor was a young autistic man suffering with epilepsy who died in a bath in a STATT Unit due to serious failings. His mother's moving account of the inquest process in her book 'Justice for Laughing Boy', describes how she was put under severe duress at a time of bereavement: “The portrayal of me and so many other women as unbalanced troublemakers (at best) throughout this process demands critical reflection by those directly involved in the mother blame game, and who stand by and witness it happening without comment. Mother-blaming is a form of suppression and silencing in the UK. A colleague of mine said that, in Greece, parents would be vilified for not complaining about poor services and support for their children. She could not understand what we were being subjected to”.

These are all important context issues for legislators and policy makers to consider when reviewing the EHC Plan process.

Our Enquiry adds to the knowledge gained by these far more comprehensive and well-resourced research studies, in that we have been able to draw comparisons between adopters and special guardians, and consider the impact of a child re-entering care on the child and on the relationship with parents and carers.

We feel our work is just beginning and that the understanding that can be gained by providing us with resources and enabling us to work with other researchers could be of great assistance to those who develop services, legislators and policy makers.

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<sup>3</sup> Featherstone et al (2018), The Role of the Social Worker in Adoptions – Ethics and Human Rights: An Enquiry

<sup>4</sup> Neil et al (2018), The Joys and Challenges of Adoptive Family Life: A Survey of Adoptive Parents in Yorkshire and Humberside

Despite it being a recommendation of the Selwyn Report (2014), that reunification is never ruled out we are finding that it is very rarely considered and almost impossible to discuss. Removing disabled children from loving families and blameless parents who cannot be reformed, with no way for them to get home, and then not supporting the relationship with family or community and leaving the children, adopters and special guardians bereaved and blamed, and still struggling for support but now marginalised and potentially set up for estrangement if there is disagreement about the approach taken. This is surely not the way forwards.

The Care Crisis Review, which had just come out as we were finalising this report (and have not had the chance to properly consider), has shown how there are no models for reunification for our previously looked after children who re-enter care (Section 5.3). This is a problem that must be addressed otherwise the permanence of adoption and special guardianship are undermined and there is a risk of exploitation - when services are unavailable under austerity, and children are removed instead of the child being helped in the context of their family. When a family member must live apart it does not mean they cease to be a member of the family.

What is needed, going forwards, is a better understanding of what makes relationships between professionals and parents/carers striving to provide a loving nurturing family environment work well or fail. We need to understand what creates pressure and stress for adopters and special guardians, many of whom are already beyond the limits of what can be realistically expected of any parent or carer.

### 5.3 Suggestions for a way forwards

We believe that the recommendation to allow local authorities to dispense with Independent Reviewing Officers, put forwards in a recent review on foster care<sup>5</sup>, as a cost saving exercise, could potentially put previously looked after children at grave risk. The problem is that these IROs cannot and do not bring cases to court – and this is surely a result of independence being compromised when they work for the local authority in question. Thus we have previously proposed a new childcare role – the Independent Guardian<sup>6</sup> who can safeguard permanence for previously looked after children, working with children *and* families, whether the child lives at home or re-enters care. The set up costs for a national service of 50 Independent Guardians is less than £500k. We suggest, as a result of conducting this Enquiry, this new role could perhaps be expanded to oversee and support EHC Planning and make this a less stressful process for children/families. The role, which we envisage might be attachment based in its conceptual underpinnings, would be about relationship building between family members and also between children, families and services where, as we have reported elsewhere<sup>7</sup>, trust is poor and much compromised by the pressures on social workers and other services under austerity. Where the child protection approach that is used can cause unintentional harm and has done so.

We do feel that the 1989 Children's Act is letting us down badly with how it is being applied. It is hard to know whether legislation change will improve matters but we think it is wrong to rule it out,

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<sup>5</sup>[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/679320/Foster\\_Care\\_in\\_England\\_Review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/679320/Foster_Care_in_England_Review.pdf)

<sup>6</sup> <https://specialguardiansandadopterstogether.com/the-independent-guardian/>

<sup>7</sup> <https://specialguardiansandadopterstogether.com/professional-trust-building-with-special-guardianship-and-adopted-children/>

as the Care Crisis Review has just done. To suggest it has “stood the test of time, as has its underpinning principle of partnership with families to promote their children’s well-being” makes little sense in the context of our experiences and the cases we have described in this report. Even in their own survey of family members it was reported that 84% of 654 respondents said they felt unable to have their voice heard by the local authority in decisions affecting their children or family. This is not partnership working by any stretch of the imagination and the basis for the review’s conclusion, as stated above, is unclear.

We think that there is nothing wrong with being open to reviewing the problematic aspects of the act, which we feel are undermining permanence and cause so much grief for us and our children: the threshold of Beyond Parental Control and the lack of scrutiny under Section 20, a piece of legislation we have endured for 30 years, which was never designed for our children and can destabilise them through making them relive earlier traumas of removal – as the only way that respite can be accessed when the intensity of family life becomes too much.

As a group we have created a petition to review the Children’s Act 1989 – see Appendix.

As a way forwards, we very much hope this call for evidence about EHC Plans might lead to a Commission and a more comprehensive consultation process that could involve dialogue that parents and carers could contribute to.

Those with ‘lived experience’ need to be more greatly involved in shaping the design of services and support that are intended to help and benefit our children and families, at a decision making level.

## Appendix

### Petition to Parliament

#### *Changes to Children’s Act 1989*

Urgent action is required to give more rights & protection to parents/carers & also vulnerable children in care

Sections 20 & 31 of Children Act are currently unworkable, resulting in a care crisis. We call on government to take urgent action to make changes to legislation & guidance to protect the parenting/caring role from a distance by:

- A more humane ethical family centred approach where birth & adoptive parents & special guardians can be seen as part of the solution & not part of the problem, in striving to do their best caring for their children.
- Safeguarding vulnerable children with new legislation & legal frameworks that also supports parents/carers when children are ‘beyond parental control’ which may be related to poor mental health, disabilities, early life trauma, abuse or neglect.