



# **Findings of a Peer-led Survey into the Stress, Health and Wellbeing of Adopters and Special Guardians**

[Interim Report - March 2018](#)

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## Introduction

This is an interim report of mostly quantitative data from a peer led survey developed to better understand about the stress factors for Adopters and Special Guardians and appreciate what helps them to better cope.

Reflecting on our own experiences, we designed a comprehensive survey to consider all aspects of stress, as we experience it, including our children's health issues, disabilities, and educational needs, the support we receive and the relationships we have with professionals. We also considered the impact of stress on us and thought about what helps us better cope with stress to improve our resilience and wellbeing, and any barriers to being able to do these resourcing activities. The survey was piloted on group members in December 2017. In covering such a broad range of topics, the final agreed survey was lengthy and 72 questions were asked. However, no questions were compulsory, and we felt the survey could provide an opportunity for self-reflection, launching the survey on New Year's Day, which is a time when one traditionally takes stock, makes resolutions, and thinks about the year that has gone and the year ahead. We had a prize draw for £50 to incentivise respondents to participate in the project.

Our survey was designed to draw out information and many of the multiple-choice questions were open, inviting further comment, with an 'other' box as appropriate. This has yielded a great deal of qualitative data, which we will be reflected on further and will be presented in further reports and analyses – and we emphasise again that this is an interim report. We are hoping that we may secure government funding to develop our work, and collaborate with academic institutions working in this field, to run focus groups to develop the research we have started, and also consider how the Adoption Support Fund (ASF) might be evaluated. Social policy change of this nature requires rigorous evaluation, and as far as we can see, it is not being done. We feel that the voices of those the policy is aimed at helping should be central to any policy evaluation, and the impact of any unintended consequences resulting from policy change on service users must be thought about. It is imperative that policy and infrastructure are ethical and humane in regards to some of our most vulnerable children and young people, and those who parent and care for them.

Data was collected during 1<sup>st</sup> -31<sup>st</sup> January 2018 with one submission per device allowed by Survey Monkey, and respondents were recruited by word of mouth, our website, and various social media platforms. A number of key organisations were supportive and promoted the website on Twitter. At this juncture, we were still called Adopters Together, which we believe may have deterred a number of Special Guardians from taking part. We hope the name change, in February 2018, will help build confidence for Special Guardians in our organisation. The sort of systemic change that we feel is needed, will benefit us all, and having a better understanding of the needs of our Special Guardian and Adopted children and families is what we, as a group, are striving to achieve.

The survey took 24 minutes on average to complete and average completion rate was 65% - although not all questions would have applied to every respondent. We have therefore reported on the number of respondents for each question, on which our calculations and percentage figures are based.

An ethics statement for the survey can be accessed on our website.

Further reports of the findings will be published in due course bringing together the qualitative and quantitative data from the survey and considering topics of particular interest.

The Parents of Traumatized Adopted Teenagers Organisation (POTATO) Group may also publish findings about adopted teenagers and young adults, and we have agreed to share relevant data with POTATO in an anonymised form.

We are really thankful to all those who took part in our survey. Anyone wishing to join our campaigning initiative is most welcome. There is a link to a membership form on our website:

[specialguardiansandadopterstogether.com](https://specialguardiansandadopterstogether.com)

We welcome any donation, no matter how small - donations can be made via our Just Giving page. Donations will be used to cover the costs of this survey, and associated expenses

<https://www.justgiving.com/crowdfunding/adopters-together>

## Authorship of report and acknowledgments

This data in this report was compiled and written up by the chair of Special Guardians and Adopters Together, Dr Sylvia Schroer, who is the author of this report. Acknowledgements for their valuable input and contributions, and/or for help and commitment with getting our new voluntary organisation started, are given to: Jumana and Talib Abdulhussein, Dave Bagshaw, Janet Barraclough, Jane Cross, Denise Dobson, Linda Edge, Sonya Ellis, Dawn Fox, Donna Lea, June Leat, Melissa McDonnell, Janice Storey Kim Undy, Kathi Wilson, and to other contributors and group members who wish to remain anonymous and have offered support and encouragement.

## The issue of respondent bias and negative experiences and views

**This survey does not reflect the views and experiences of all Adoptive parents and Special Guardians and it may be that those with more difficult experiences and journeys were more drawn to completing it. This is known as ‘respondent bias’. However, with 403 respondents, this is a sizeable sample, and we hope it will be considered an important and useful survey.**

**Our survey did not consider the positives of being a Special Guardian or Adoptive parent, or child. This was not the focus of our survey. In considering what needs to change and improve we tried to better understand the problems that need to be addressed – so this survey considers aspects of Special Guardianship and Adoption that aren’t working well. However, we also asked respondents to reflect on good practice, what has been beneficial, and what needs to change. This qualitative part of the survey will be considered in another report.**

**All of us begin our journeys with hope and love, wanting, more than anything, to provide a safe loving permanent home for a child, and this is something that must not be forgotten when reading the survey findings, which paint a pretty bleak picture of our lives, particularly in some sections of the report. We have created this survey and responded to it because we all wish to make things better in the future. This is the spirit in which the difficult messages of this survey should be taken.**

**We hope that we can, as service users, be part of the dialogue about change, that is so much needed.**

## Summary

403 responded to our survey of whom 389 were eligible and included in the statistics – 309 Adopters; 83 Special Guardians (SGs), and 3 respondents who were both adopters and SGs.

Between the 389 survey respondents there are 689 children/adult children (605 aged 18 or under). 47% of adopted children are 12 years or older compared with 21% of SG children. This variance in age is explained by the fact that the Special Guardian Order was only introduced 14 years ago so many Special Guardian children are just approaching their teenage years. SG children are placed younger and 50% were placed before they were 18 months old, compared with 34% for adopted children

37% (213) of 561 children received Disability Living Allowance / PIP or had an application for this benefit pending, with a similar percentage in both groups. In terms of mental health issues, the most common diagnosis for children is Attachment Disorder (303 children) followed by Anxiety (193 children) and Complex Trauma/Developmental Trauma (182 children). There was a different profile of adopted and SG children with adoptive children having slightly higher levels of Depression, and higher levels of PTSD and Complex Trauma and with SG children having a slightly higher incidence of Anxiety, FASD and Alcohol related problems.

In terms of problems caring for children, 'anger and rage meltdowns' was the most common problem for both groups (89%). The incidence of 'Child to Parent Violence' was high in our survey population (69%) and higher for Adopters (75%) than SGs (43%), and so were school refusal problems/school anxieties (65%). Again, the figure was higher for adopted children (71% compared with 43% for SGs). The only problem in caring for children that was higher for SGs, who are most often the child's grandparents (67% in our survey sample are grandparents), was 'problematic relationship with birth family' – 56% of SGs reported this compared with 12% for adopters. Adopters will inevitably have less contact with the birth families of their children and their birth parents than the child's blood relations.

Reasons for adopters having a greater level of difficulty, and more problems and challenges parenting and caring for their children, may in part be explained by the lower proportion of teenagers and young people transitioning to adult life in the SG population sample – because this Order was only introduced 14 years ago. With adopters parenting older children, placed at an older age and with higher levels of trauma that were found in the adoption group, this may also account for some of the discrepancy. It is interesting in this regard that adopters were dealing with higher levels of 'sexually problematic behaviour and acting out of trauma' than SGs (18% vs 6%).

150 respondents (48% and 63% of the adopters and SGs who answered this question), have given up work to care for their children and 145 struggle financially.

The number of adopted children who had re-entered care was much higher for adopters than SGs with 84 adopted children and 12 SG children described as re-entering care in a question about placement stability and breakdown after the child had re-entered care. Only 6 children were living with their family again after a care separation. The rate of re-entering care was 14% for both groups and 15% for adopters, which is higher than previous research has suggested. Children did not cope well with re-entering care and 72% of survey respondents said their children had struggled and become destabilised. 21/49 respondents (43%) said they were 'dissatisfied' or 'extremely dissatisfied' with contact arrangements with their children after they had re-entered care. Given that only 6 children were currently under Section 31 Care Orders (where parental responsibility is shared with the local authority), it seems likely that a proportion of these parents retained parental responsibility for these children. We will look into this matter further for a deeper analysis

of the data when we start to consider the qualitative research findings and develop explanatory accounts for respondent's views.

78 respondents had been involved with care proceedings or Judicial Reviews pertaining to their child. 12 cases were ongoing – 7 adopters and 5 SG cases.

In terms of education 272/572 (nearly 50%) of all children had an EHC plan or one that is pending. The majority of children were in mainstream school but 23 were currently being home educated, with 17 of these children needing to be home educated because of a lack of suitable provision – 13/17 were adopted children.

In terms of support, 240 (73% of respondents), get no respite at all with this figure being similar for both groups. Nearly 60% of respondents (200), had not been able to access counselling or therapy for themselves in regards to their caring role.

In terms of the Adoption Support Fund only 5 (9% of SGs) had accessed it (compared with 144 - 52% of adopters), and 8 SGs said they were not aware of the existence of the fund. Only 10% of respondents considered the Adoption Support Fund to be an adequate amount to meet the needs of their child and family. Comments about the fund suggested serious problems and delays with accessing it and a level of apprehension about dealing with children's services on the part of special guardians.

247 respondents (80% of the 309 respondents answering this question), reported having a 'bad experience' with a social worker, with this figure rising to 84% for SGs. Having a 'bad experience' of an education professional (52%), SENCO (48%), and CAMHS professional (39%) were also common. Respondents had bad experiences of other professionals too including Independent Reviewing Officers (18%).

From the perspective of adopters and SGs, professionals had problems building trust with adoptive and SG children. 179 out of 344 respondents answering this question reported that children's school professionals had trouble building trust with their children. 164 reported that social workers had difficulties and 130 stated that CAMHS professionals had found building trust with their child to be difficult.

146 formal complaints had been made by respondents with 45 of these ongoing. The making of a formal complaint was rated as a stressful experience in and of itself by respondents. This was rated a leading cause of stress or stress factor for respondents, behind 'difficulties in accessing provision'; 'professionals not appreciating your child's needs' and 'tribunals'.

In terms of the stress factors that came directly from caring from a child the profile was slightly different for adopters and special guardians. SGs generally rated stress factors that were asked about as less stressful overall with the exception of 'financial worries'; contact with child's birth family; and dealing with education professionals/school. In terms of financial worries, it is relevant that SGs have lower incomes than Adopters: 40% of SGs had an annual household income of less than £20k

In terms of what gave rise to most stress, 'coping with child's challenging behaviour', 'the impact of the behaviour on siblings' and 'difficulties parenting at a distance' were considered to contribute most to stress, across both groups.

The impact of stress associated with the parenting or caring role or dealing with services, on the mental and physical health of respondents is considerable. 266 respondents are suffering with stress now or have done in the past with 55% of respondents currently diagnosed with stress, 215 have anxiety or had it in the past (48% currently suffer). The figure for those currently suffering with depression and secondary trauma is similar at 29%. 7% of respondents currently suffer with PTSD; 18 respondents currently have PTSD and



a further 23 have had this diagnosis in the past. Only 4 of these respondents are SGs<sup>1</sup>. Over 70% of the 164 respondents to the survey question about NHS care for mental health problems received antidepressants. 2 respondents (1 adopter and 1 SG) reported they had received mental health in patient care.

It should be a matter of very serious concern that of the 323 respondents that answered a question about avoiding seeking help from their GP due to fears that judgements might be made about their capacity to care for an adopted or SG child, nearly 60% of SGs and 42% of adopters reported they had avoided seeking help from their GP for mental health problems

In terms of physical health, pain conditions, Irritable Bowel Syndrome and autoimmune disorders were the most common ailments thought to be exacerbated by the stress of the caring or parental role.

Stress impacted on relationships: 63% reported that their caring role had an impact on their relationship.

The economic impact of adoption and being a SG is considerable: 51% of the 293 respondents answering this question had given up work to care for a child, 44% had reduced their hours and 46% struggled financially. 44% of Special Guardians have an annual household income of £20k or less.

A whole range of factors are shown to help mitigate the impact of stress for respondents, many of them the simple pleasures we asked about. The highest scoring factors for alleviating stress/self-care are: peer support (74%), sharing with others (74%), walking (71%), being in nature (70%) and reading novels/ watching films (67%).

However, 76% of the 321 respondents that answered this question stated 'not being able to prioritise their own needs as the needs of the child are too great' as the biggest barrier for doing things for themselves that help with stress. The second biggest barrier for doing things for oneself that help with stress identified by SGs is "lack of money" (62%) This was less of an issue for adopters in the survey who have a higher level of household income.

50% of respondents to this question about barriers to doing things that are nurturing, stated that they were 'completely exhausted and suffering with physical and mental burn out'. The fact that 10% of respondents (and 16% of SGs) had care responsibilities for other dependent adults or children may be a significant factor also in the depletion of resources for SGs and adopters that took part in this survey.

**In conclusion, our survey has indicated that the parents and carers of some of our most vulnerable children, who make a lifetime commitment to their care, are dealing with highly stressful family lives and many are struggling to get the support that is needed.**

**Special Guardians and Adopters strive to do their best despite a lack of understanding and support, and despite having to face tremendous challenges and emotional burden. Our survey has revealed a concerning lack of trust in services and it is wrong that parents and carers should be frightened to seek help from their GP when they feel unwell, for fear their capacity to care for their children may then be called into question and judged.**

## Section 1. About Adopters and Special Guardians

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<sup>1</sup>Respondents reported that 68% of the mental health problems they experienced were diagnosed by their GP and a further 24% said the diagnosis was made by another mental health professional. This was 193/211 respondents (N=211).



Demographics: age; where respondents live; gender; ethnicity; relationship to child (for Special Guardians); other care responsibilities

- We had 403 responses to our survey and of these respondents, 389 were eligible. 309 are Adopters (79%) and 83 are Special Guardians (21%). 3 of the survey respondents are both Adopters and Special Guardians (SGs)
- 80% of all eligible survey respondents are 40+ years of age, (See Table 1). 95% of all respondents are female (N=388)
- The age range of Special Guardians tends to be older than Adopters, where 63% are 50+, whereas for Adopters only 38% are 50+ (N=389)
- 86% (333) of respondents identified as white British (see Table 2), and the next largest group identified as white European (4%, 15). Some ethnicities did not wish to be specified as numbers were so low, and there were concerns this might lead to identification. Other ethnicities were poorly represented in our survey population. (N=387). We did not ask about ethnicity of children. This was an oversight on our part and this is something that should be investigated in further research.
- Of the Special Guardians (N=83) two thirds (67%) are grandparents. When respondents ticked 'other' (see Table 3), the relationships included: great aunt/ great aunt and uncle x4; godparent x1; great grandparents x1; Adopter x1; child's birth father's cousin x1; step grandparents x1; parents of birth mother's former boyfriend x1 and one humorous response of 'debt collector'
- 92% of all respondents live in England, 5.6% in Wales and 2.7% from Scotland. There were no respondents from Northern Ireland. (N=386)
- 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. (See Table 4).
- Almost 10% of respondents had care responsibilities for other adults and children who were dependent on them. (See Table 5). The number of Special Guardians with additional care responsibilities was higher (16%) than adopters (8%).

**Table 1: Age Range of survey respondents N=389**

Age Range	All N=389		Adopters N=309		SGs N= 83
<b>20-29</b>	1.54%	6	0.97%	3	3.61%
<b>30-39</b>	11.57%	45	13.27%	41	6.02%
<b>40-49</b>	43.44%	169	47.57%	147	26.51%
<b>50-59</b>	36.76%	143	33.33%	103	49.40%
<b>60-69</b>	6.43%	25	4.53%	14	14.46%
<b>70 plus</b>	0.26%	1	0.32%	1	0.00%

**Table 2: Ethnicity of Survey Respondents N=387**

Ethnicity of Survey Respondents	
<b>White British</b>	86%
<b>White European</b>	4%
<b>White Other</b>	2%
<b>Mixed Ethnicity</b>	2%
<b>White Irish</b>	1.6%
<b>Prefer not to say</b>	1%
<b>Black British, African, Caribbean,</b>	1%
<b>Latin American, Indian Asian, Other</b>	1%

**Table 3: Relationship of Special Guardian to child(ren) N=90**

Answer Choices	Responses N=90
Grandparent	71.08%
Aunt or Uncle	14.46%
Cousin	0.00%
Sister/ Brother	0.00%
Previous Foster Carer For The Child	2.41%
Other (please specify)	12.05%

**Table 4: Single Parent/Carer or Living with Partner N=387**

Answer Choices	Responses N=387		Adopters N=
A Single Parent / Carer	22%	86	20%
Living With A Partner	78%	301	80%.

**Table 5: Care responsibility for others**

Answer Choices	All Respondents N=350		Adopters N=273		SGs N=80
<b>Yes</b>	9.71%	34	8.06%	22	16.25%
<b>No</b>	76.29%	267	79.49%	217	62.50%
<b>If Yes, Please Outline Your Additional Carer Role</b>	14.00%	49	12.45%	34	21.25%

49 Respondents described their additional caring role as: caring for elderly parents x18; caring for birth children x13; caring for husband x7; foster carer x3; adult children x5; brother/sister x2; grandparent x1 and niece x1

#### Household income including benefits; Carers Allowance

- **Adopters tend to be spread across all income groups whereas Special Guardians cluster towards the lower end of the income spectrum. (See Table 6)**
- **Over half of Adopters have household incomes over £40k, whereas for Special Guardians the figure is 2% and 44% have an income under £20K<sup>2</sup>.**
- **32 % of Special Guardians and 18% of Adopters receive Carers Allowance<sup>3</sup>. (See Table 7).**

<sup>2</sup>Adopters may receive an Adoption Allowance, and a support package will be approved by an Adoption Panel before a child is able to be placed. This panel includes adoptive parents who are aware of the challenges of parenting adopted children.

<sup>3</sup>Carers Allowance is a taxable benefit of £62.70 per week. If the child you are caring for must re-enter care, perhaps because of child to parent/carers violence, this allowance ceases, and you may be suddenly left with no income at all.

**Table 6: Showing overall household income, including benefits**

<b>Household Income</b>	<b>All (N=384)</b>	<b>Adopters (=305)</b>	<b>SGs (N=82)</b>
<b>£10k - £20k</b>	20%	14%	44%
<b>£20k - £30k</b>	20%	15%	35%
<b>£30k - £40k</b>	21%	22%	19%
<b>£40k - £50k</b>	12%	15%	10%
<b>£50k - £60k</b>	8%	10%	10%
<b>More than £60k</b>	19%	24%	0

**Table 7: Showing respondents who receive Carer's Allowance**

	<b>All N=342</b>		<b>Adopt N=276</b>		<b>SGs N=69</b>
<b>Yes</b>	21%	71	18%	50	32%
<b>Did Receive Carer's Allowance Until Child Re-Entered Care</b>	1.5%	5	2%	5	0
<b>No</b>	76%	261	79%	218	65%
<b>Pending</b>	1.5%	5	1%	3	3%

## Section 2. About Adoptive and Special Guardian Children

**In this section we will consider the children being parented and cared for by Special Guardians and Adopters**

Children's current age; age when placed

- **Between the 389 survey respondents there are 689 children/adult children of whom 554 are adopted and 135 under Special Guardianship orders<sup>4</sup>. (See Table 8).**
- **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<sup>5</sup>.**
- **Special Guardian children are placed when younger than adopted children – 50% are placed before 18 months old compared with 34% for adopted children. (See Table 9).**

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<sup>4</sup>One child had died since placement. He was an adopted child, and he died at the age of 22 of severe drug addiction problems

<sup>5</sup>The Special Guardian Order was only introduced 14 years ago and it ceases when the child reaches 18.

**Table 8: Ages of children adopted or with SGOs**

	Child1	Child 2	Child 3	Child 4*	Child 6	Total (All)	% Of Total	Adopters	SGs
<b>New-Born - 18 Months</b>	12	7	0	0	1	20	3%	14 (2%)	6 (4%)
<b>19 Months - 3 Years</b>	33	18	4	2	0	57	8%	38(7%)	20 (15%)
<b>4 - 7 Years</b>	104	53	7	2	1	167	24%	129 (23%)	40 (30%)
<b>8 - 11 Years</b>	87	47	17	4	3	158	23%	114 (20%)	46 (34%)
<b>12 - 15 Years</b>	71	51	12	2	1	137	20%	121 (22%)	16 (11%)
<b>16 - 18 Years</b>	38	22	4	2	0	66	10%	65 (11%)	1
<b>Older Than 18</b>	42	26	10	3	1	82	12%	80 (14%)	6 (4%)
<b>Total</b>						689		554	135

\*32 respondents (28 Adopters and 6 Special Guardians), responded to the option about 'further children' with responses about adult children (total =48 adult children), and two children aged 11. The two 11 year olds are added to the figures above under child 6

\*We did not ask about Child 5 on this question – this was due to human error

**Table 9: Age when child was placed with family**

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	All (%)	Adopters (%)	(SGs %)
<b>From Birth</b>	20	8	5	1	1	1	36 (5%)	18 (3%)	19 (14%)
<b>1 Month-18 Months</b>	118	76	17	9*	1	0	221 (32%)	173 (31%)	49 (36%)
<b>19 Months To 3 Years</b>	115	79	14	2	0	0	210 (30%)	183 (32%)	31 (23%)
<b>4-5 Years</b>	79	44	7	1	0	1	132 (19%)	120 (22%)	12 (9%)
<b>6-8 Years</b>	50	12	6	4*	1	0	73 (11%)	57 (10%)	15 (11%)
<b>9-11 Years</b>	5	2	4	0	0	0	11 (2%)	6 (1%)	5 (4%)
<b>11 + Years</b>	3	1	1	1*	0	0	6 (1%)	1	4 (3%)
<b>Total</b>	390	222	54	18	3	2	689	558	135

\*These figures include 4 Special Guardian children – 4 Special Guardians responded to the question about further children/ comments by giving ages of their children. There were no more than 4 children placed with any Special Guardian under a Special Guardian Order. The children in columns Child 5 and Child 6 are all adopted children.

- Numbers of children receiving Disability Living Allowance, or with applications pending were broadly similar, at 35% for Special Guardians and 38% for Adopters with 344 respondents answering this question (See Table 10).
- There was a slightly different profile of Adopted and Special Guardian children with adoptive children having slightly higher levels of Depression, PTSD and Complex Trauma and Special Guardian children slightly higher incidence of Anxiety, FASD and Alcohol related problems. (See Table 11)<sup>6</sup>.

**Table 10. Children receiving Disability Living Allowance/Personal Independence Payment**

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	All (%) N=344	Adopt (%) N=275	SGs (%) N=72
<b>Yes</b>	107	67	11	3	1	1	190 (33%)	156 (34%)	36 (32%)
<b>No</b>	196	125	30	5	0	0	356 (63%)	289 (62%)	71 (64%)
<b>Application Pending</b>	16	6	0	1	0	0	23 (4%)	19 (4%)	4 (3%)
<b>Total</b>	<b>319</b>	<b>198</b>	<b>41</b>	<b>9</b>	<b>1</b>	<b>1</b>	<b>569</b>	<b>464</b>	<b>111</b>

<sup>6</sup>Some explanation for the differences might be that Adopters and Special Guardians are parenting children/young people of a different age profile. Special Guardian children tend to be placed younger than adoptive children. Special Guardians are more likely to be aware of drug and alcohol problems of family members/children's parents, whereas adopters and those diagnosing adoptive children must rely on secondary information sources



**Table 11. Children's mental health diagnoses**

Child's Mental Health Diagnoses	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	All (%) N=264	Adopt (%) N=225	SGs (%) N=42
<b>ADHD</b>	56	32	6	4	0	1	99 (9%)	85 (10%)	15 (9%)
<b>Autism (ASD)</b>	43	25	3	3	1	1	76 (7%)	63 (7%)	15 (9%)
<b>Foetal Alcohol Syndrome</b>	22	15	3	1	0	0	41 (4%)	31 (3.5%)	10 (6%)
<b>Alcohol Related Neurological Disorder</b>	14	10	2	0	1	0	27 (2.5%)	21 (2.5%)	6 (3%)
<b>Anxiety</b>	110	62	14	5	1	1	193 (18%)	156 (18%)	39 (24%)
<b>Depression</b>	34	19	4	1	1	1	60 (6%)	54 (6%)	7 (4%)
<b>PTSD</b>	34	19	6	3	1	1	64 (6%)	61 (7%)	3 (2%)
<b>Complex Trauma/Developmental Trauma</b>	103	61	12	4	1	1	182 (17%)	163 (18%)	22 (13%)
<b>Attachment Disorder/ Pattern</b>	178	96	24	5	0	0	303 (29%)	257 (29%)	47 (29%)
<b>Total Diagnoses</b>							<b>1045</b>	<b>891</b>	<b>164</b>

## Other health issues or disabilities

- **114 of all survey respondents reported that their children had other mental health diagnoses and 183 respondents said that their children had other disabilities and health conditions, as follows:**

## Adopters

91 Adopters reported that children had other diagnosis and 158 said that they had other disabilities and health conditions. These included:

- Sensory processing disorder (39) and another 6 with sensory issues
- Dyscalculia, Dyslexia, dyspraxia (30)
- Learning difficulties/ disabilities (26)
- Developmental delay/ Global/ severe development delay (17)
- Asthma (21)
- A range of genetic disorders and conditions (13)
- Eczema (11)
- Hypermobility (11)
- Oppositional defiant disorder (11)
- Self-harm (11)
- Visual impairment (11)
- IBS/ Bowel problems (10)

- Borderline personality disorder/ personality disorder/ Anti-social personality disorder (10)
- Hearing impairment (8)
- Bipolar (5)
- Eating disorders (5)
- Heart/ cardiac problems/conditions (5)
- Nocturnal enuresis (bed-wetting and soiling) (5)
- OCD (5)
- Reactive/ Persistent defiance disorder (5)
- Speech and language delays/ issues (5)
- Suicidal tendencies (5)
- Down's syndrome (3)
- Epilepsy (3)
- Kidney problems (3)
- Tourette syndrome (3)

## Special Guardians

24 Special Guardians reported that children had other mental health diagnosis and 27 that they had other disabilities and health conditions. These included:

- ODD/ PDA/ RAD (7)
- Sensory Process disorder (5)
- Eczema (5)
- Visual impairment (5)
- Learning disability/ difficulties (5)
- Speech and language problems/ delays (4)
- Dyslexia/ dyspraxia (3)
- Heart defects (3)
- Thyroid (3, same family)
- Asthma (2)
- Eating disorder (2)
- Global development delay (2)
- Eating disorder (2)
- OCD (2)
- Tourette syndrome (2)

Problems and issues encountered in caring for adopted/Special Guardian child(ren)

- In this population sample the children of Adopters are more difficult to parent and care for than the Special Guardian children<sup>7</sup>. See Table 12.
- For both Adopters and Special Guardians anger and rage meltdowns and emotional dysregulation are the most common problems
- For Special Guardians “problematic relationships with birth family” is far more common than for Adopters, with well over half (56%) experiencing this.

**Table 12. Problems Special Guardians and Adopters experience in caring for their children (N=321)**

	All N=321		Adopters N=263		SGs N=60
Child to Parent Violence	69%	221	75%	197	43%
Emotional Dysregulation	88%	283	94%	247	63%
Anger and Rage Meltdowns	89%	286	95%	246	70%
Stealing	45%	146	51%	135	21%
School Refusal/School Anxieties	65%	210	71%	186	43%
Drug and Alcohol Problems	14%	46	17%	44	5%
Social Anxieties, Agoraphobia	44%	142	46%	120	38%
Suicidal Ideation or Suicide Attempts	24%	76	27%	70	10%
Being Bullied at School or On Social Media	33%	107	37%	96	2%
Being Groomed for Sex	11%	35	13%	33	5%
Targeted by Drug Dealers	10%	32	12%	32	1%
False Allegations Made About You, Your Partner or Other Family Members	24%	77	25%	66	18%
Sexually Problematic or Harmful Behaviour - Acting Out Their Own Trauma	18%	57	21%	55	6%
Problematic Relationships With Birth Family	20%	64	12%	31	56%
Going Missing or Running Away Whilst in Your Care	24%	76	28%	73	6%
Going Missing from Care	8%	26	10%	25	3%
Child Being Arrested	12%	38	14%	38	1%
Child Being Arrested After Re-Entering Care	6%	20	8%	20	0
Sibling Trauma Bonds/Aggression and Violence Towards Siblings	43%	140	45%	118	37%
Other	9%	28	7%	19	15%
Other (Please Specify)		56		43	

<sup>7</sup>Reasons for the discrepancy might be due to Special Guardians caring for children from a younger age group and/or caring for children who have experienced less trauma and abuse in early life, who were placed when younger. It is interesting, in this regard, that the level of sexually problematic behaviour and acting out early life trauma is greater for Adopters than for Special Guardians

Other problems specified by respondents included (Adopters): self-harm; sleep problems; agoraphobia; intense fear (of birth family); food issues and eating disorders; playing with fire; lying; criminality; being exploited by 'friends'; destruction of the house; early pregnancy; emotional detachment; learning difficulties and poor working memory. One Adopter reported having 'no issues' and several commented how things had improved as their child got older, or, conversely, worsened. One respondent commented that problems had only started after her child had re-entered care.

Special Guardians also commented that their children had sleep problems; anxieties; difficulties at school; fixations and needing routines; destruction of the house; defiance; disrespect and disobedience.

## Section 3. About Family Life

Our section on family life includes families where children have re-entered care under a voluntary Section 20 Care Order or a Section 31 Care Order<sup>8</sup>.

- In terms of contact/connection with birth family, the majority (68%) of Special Guardians had Contact Orders in place for contact with the child's birth parents and in 74% of cases this was supervised by the Special Guardian. In 8% of cases the contact was unsupervised as the parent was not 'deemed to be a risk' to their child.
- The percentage figure for adopted children and children under Special Guardian Orders having contact with birth siblings was broadly similar 48% and 47% respectively, although the nature of this contact was not specified by our survey. It may have been letter box contact rather than meetings. This requires further investigation.

### Assessment of family life

- The majority of respondents said there were 'ups and downs but managing' with more Special Guardians in this category (51% compared with 36%). 27% of all survey respondents described their family life as "more downs than ups" (See Table 13).

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<sup>8</sup>An Adoption Order, once made, is permanent in the UK. The fact that adopted children must live apart from their parents, often during adolescence, does not mean their parents will cease to play a significant role in their lives. Adopters call this role, when a child re-enters care, 'parenting from a distance'. It is not supported by legislation or policy and these families and children are not eligible for the Adoption Support Fund if the local authority decides they do not intend to reunify the child with their adoptive parents, when they would otherwise be eligible for support until the age of 25 – if they had an EHC plan in place. The Adoption Support Fund is often the only route to accessing the specialist therapies that are often needed by these extremely vulnerable young people who have experienced the most difficult of starts in life – beginning it with the trauma of immense loss. In our survey there is only one Special Guardian who reported that a child has re-entered care under a Section 20 and only one Adopter and one Special Guardian who reported their children had been reunified.

**Table 13. Adopters and Special Guardians' assessments of their family life N=372**

Answer Choices	All N=372	%	Adopters N=294	%	SGs N=81	%
Really Positive	13	3%	10	3%	3	4%
Mostly Positive	51	14%	36	12%	15	19%
Ups and Downs but Managing	145	39%	105	36%	41	51%
More Downs Than Ups	99	27%	81	28%	19	23%
At Risk of A Child Re- Entering Care	27	7%	25	9%	2	2%
Child Re-Entered Care	21	6%	21	7%	0	0%

#### Living arrangements and legal status of Adopted and Special Guardian children/young adults

- **6% of Adopters said their child(ren) have currently re-entered the care system and a further 9% of Adopters said that their child(ren) are at risk of re-entering care system, as compared with only 2% of Special Guardians<sup>9</sup>. (See Table 13).**
- **We found that 5% and 2% of adoptive parents reported children were under Section 20 Care and Section 31 Care Orders respectively (See Table 14).**
- **1% (6 children), are living with their family again after a care separation. Most children re-enter care under a voluntary Section 20 Care Order<sup>10</sup>. Reasons for adopted and special**

<sup>9</sup>Special Guardians may be much less likely to flag up difficulties if they fear the consequences of doing so may be removal of the child. The route to Adoption and Special Guardianship is quite different. Special Guardians are often family members who are told that unless they take on the care of their child they will never see them again because the child will be placed for adoption.

<sup>10</sup>A Section 20 Care order may be the only way an adoptive parent, or Special Guardian, is able to access respite (especially in a crisis), when it is not safe for parents and children, including siblings, to live together. When understanding of the family's support needs is poor or lacking, and provision of support is not forthcoming it may be that the short break becomes a long or permanent one. It may also be that without timely or adequate support that family life has deteriorated to a degree where parents, siblings and/or children feel unable to be safe to live together again, and the adopted or special guardian child must live away from their family. These children are arguably the most vulnerable in the care system and transitioning to adulthood is likely to be challenging for them – especially when relationships with their family are not well supported by those with a duty of care. This scenario can come about, in our experience, because social care professionals and agencies prioritise the stability of the new placement over family (usually foster care but frequently residential care), imposing contact restrictions that parents and special guardians find unacceptable and difficult – see Table 17. Without specialist help that local authorities are not required to provide, and which parents and guardians may struggle to achieve when a child re-enters care (the Adoption Support Fund cannot be accessed in this scenario if there is 'no intention to reunify' on the part of the local authority), these children may never be able to return home. In adoption cases this scenario is often described as a 'disruption', a term that should technically only be used before an Adoption Order is made. Using this term after the Order is made, as has happened since Selwyn (2014), has created serious problems for families where they would like work to be done to help reunification. This has been an unintended consequence of the Selwyn report. The terminology used of 'breakdown', 'failure' and 'disruption' post the Adoption Order, is too loaded and can condone the fact there is little no work done to support the child in the context of their family who then find themselves being replaced by other forms of care. Local authorities may also put a great deal of effort into reunifying a child with birth family – even when parents present a grave risk to the child (see case number 2. In the cases we presented to the SCIE for our consultation with them in October 2017 <https://adopterstogether.org/cases-for-scie-project-on-mental-health-and-well-being-of-children-in-care/> . The recommendation of Selwyn et al that 'reunification never be ruled out' (with adoptive families), does not

guardian children not returning home, and families not being supported towards this, when this is a wished for outcome, need further investigation. The permanence of adoption and special guardianship are undermined if children are unable to return to their families and prevented from doing so by those who should be providing support.

**Table 14. Living arrangements/legal status for Adoptive and Special Guardian Families (N=367)**

	Child1	Child 2	Child 3	Child 4	Child 5	Child 6	All N=367 (%)	Adopt N=288 (%)	SGs N=82 (%)
<b>Living with Family</b>	317	195	42	13	3	1	571 (87%)	445 (84%)	132 (97%)
<b>Living with Family but Attends A Residential School</b>	4	1	1	0	0	0	6 (1%)	6 (1%)	0
<b>Living with Family After A Care Separation</b>	4	2	0	0	0	0	6 (1%)	5 (1%)	1
<b>Re Entered Care Under Section 20 Care Order</b>	9	7	1	0	0	0	17 (2.5%)	16 (3%)	1
<b>Re Entered Care Under Section 31 Care Order</b>	5	1	0	0	0	0	6 (1%)	6 (1%)	0
<b>Living Independently</b>	25	11	7	3	1	1	48 (7%)	48 (9%)	2
<b>Total</b>	364	217	51	16	4	2	654	526	136

24 respondents (all Adopters) ticked the further children/ 'other' box in response to where their child(ren) live, and provided further comments. Responses included: child in supported living; homeless after assaulting care home staff and not engaging with services; emergency B&B accommodation; unsupported and unplanned reunification after court proceedings ended 3.5 year care separation; living in own accommodation but requiring daily parental support; sleeping rough; in prison (x2); child had died as a young adult of drug addiction; living part time independently but mostly with family; Section 25 (Scotland) in semi secure residential unit; living with ex-partner (adoptive father); family had many previous Section 20 care separations for three eldest children.

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necessarily lead to work being done to achieve it. It can be put aside in the LAC review with no discussion achievable by parent or child. When local authorities concede to an application for the discharge of a Care Order or Supervision Order there are no Judgments to be published - so no learning from these cases. Despite our best efforts (this is why we formed Special Guardians and Adopters Together – originally Adopters Together), no one is tackling these issues and we have struggled to draw attention to them. We introduced the idea of the Adoption Guardian (to distinguish this role from the Cafcass Guardian), on national television in a programme with the Children's Commissioner, in November 2017 <https://www.youtube.com/watch?v=t1GKBwPwuE&t=12s> The name needs rethinking as special guardians and kinship carers need to be included, and know they are included. We believe this role needs to be independent of the LA and have called it the Independent Guardian in our recommendations and suggestions at the end of this report.



- 96 children (84 Adopted children and 12 Special Guardian children), were described as re-entering care in response to a question about Foster Care and Residential Care placement stability (after re-entering care). See Table 15. This figure suggests a total rate of re-entering care of 14% in our respondent sample (96/689), 689 being the number of children placed – see Table 9. The rate for Adopters is  $84/558 = 15\%^{11}$ .
- In terms of placement stability as reported by respondents (N=64), 47/96 children had not had a placement breakdown; 22 had experienced at least one placement breakdown and of these 22 children, 16 had experienced more than two placement breakdowns.
- 40 Respondents (all Adopters and one also a Special Guardian) answered a question about their children coping with re-entering care (See Table 16). The majority of children (72%) were considered to have become destabilised by their parents and carers.

**Table 15. Residential or Foster Care placement breakdown if Adoptive or Special Guardian child has re-entered care? (N=64)**

	Child1	Child 2	Child 3	Child 4*	All N=64	Adopt N=53	SGs N=12
No	32	10	4	1	47	35	13
Yes	12	9	1	0	22	22	0
Once	4	1	1	0	6	6	0
Twice	3	1	1	0	5	5	0
More Than Twice	10	4	2	0	16	16	0
Total	61	25	9	1	96	84	13

\*Respondents had not reported 5<sup>th</sup> and 6<sup>th</sup> children as having re-entered care

<sup>11</sup>Information on whether children starting to be looked after had previously left care under a permanence arrangement (that is adoption, special guardianship order or child arrangements order) was collected for the first time in 2014. In the year ending 31 March 2017, of the 32,810 children starting to be looked after, 86% had had no previous permanence arrangement and 620 (2%) were known to have had a previous permanence arrangement; 240 had had a special guardianship order, 200 had been adopted and 180 had a residence order or child arrangements order. It is difficult to read too much into these numbers given they are small, and that in nearly 4000 cases (12% of children starting to be looked after in 2017) the information is not known. Source SSDA903

**Table 16. Parent/Guardian's assessment of how child coped if re-entered care**

Child coped well	Child was OK		Child struggled and became destabilised		
12.50%	5	15.00%	6	72.50%	29

All of the respondents in Table 16 are Adopters although one is also a Special Guardian. This variance in numbers may in part be explained by the younger age profile of Special Guardian children who have not yet hit the turbulent years of adolescence. Further comments were invited for this question and there were 22 responses. One respondent reported that her son was in a hotel with 2 to 1 support when Local Authority were unable to find a suitable placement; another reported one child being in a psychiatric hospital and the other finally able to access therapy in care that had been identified as needed years previously; one respondent said 'it was the best thing' that their child had been able to re-enter care and live apart; two respondents reported children being kept away from their families against their wishes with one child left suicidal and self-harming (this removal was reported as against the wishes of the Adopter and her child); one respondent reported that the child's care home had been shut down due to illegal activities of staff and residents; another reported her child as doing well in residential care after unsuccessful foster care placements; one respondent reported her child having 4 unsuccessful foster care placements interspersed with inpatient psychiatric care resulting from drug induced psychosis; one respondent reported her child being removed after being placed in two 'abusive' placements and no placement found for her sibling who moved back with birth family (a second cousin) where she was abused and raped; one respondent reported her son being made homeless upon re-entering care and another had avoided her son being made homeless at 17 only because of her appreciation of the legislation – she had worked in fostering and adoption for 15 years – this respondent pointed out that the emotional age of adopted children may be far younger than their chronological age and they may need support well into adulthood and throughout their adult life. One respondent commented on the destabilising impact of re-entering care on their adopted child and the other siblings in the family. One respondent, gave a lengthy response, which paints a vivid picture of the difficulties for this young man faced, and demonstrates the enduring commitment of loving parents when a child leaves home prematurely:

*"He is very resentful of us "throwing him out" of the family home. He says "what kind of people do that do an adopted child?" He felt and still feels very rejected by that. We have given him our perspective many times, and explained about the pressures on us, the need to work, the need for respite that was never provided etc, but he says he feels that when the chips are down he is alone in the world. Although there is a great deal of evidence to the contrary - which we sometimes point out - as do others! He knows he is loved. But what we give and have given - at great costs to our own health and wellbeing - are never enough. We have worked via our GP and mental health services to get him referred to ..... regional centre for neuropsychiatry. However, despite being a centre for neuropsychiatry they seem to struggle with the fact he has ASD and has difficulty communicating exactly why he often feels so anxious and why he sometimes won't go to appointments. He also struggles to accept responsibility for his own actions/responses to events and so therapy based on principles of CBT have been deemed unsuitable. When he first re-entered care, for the first six months there was a huge dip in his health and well-being. He continued to go missing, abuse substances etc - just there was nobody out looking for him at nights. He was beaten up several times. We worked with his carer/landlord, who after about three months of finding that the usual methods didn't work, came to trust us, and often rang us to ask us to pick him up and take him to college, collect him, or just to discuss next steps. Children's Services seemed focused on securing him welfare benefits, which was disastrous as he received a huge initial "back" payment, which resulted in more extreme abuse of drugs and increased vulnerability in the community. This levelled off somewhat after six months, when he asked us for help to manage his money, with his carer/landlord, and a new girlfriend who didn't do drugs led to a reduction in his drug use. There have been peaks and troughs during the last four years. He had to move out of his supported accommodation when his host sold his house to move abroad with his new wife. Our son, then 19 nearly 20, couldn't face dealing with new carers and more social workers, whom he now loathed as "worse than useless - they make things worse". So he moved into an independent flat, which we set up - furnished, decorated etc with him. It has been a mixed bag for the first two years. At times when he has been lonely, he has sought out drugs and the wrong kind of people. His girlfriend of the last 3 years has helped in some*

*ways to keep him away from criminality - but her severe mental health problems have been impossible for him to cope with. She has physically attacked him on several occasions when she has lost control. Recently, he has moved, again with significant practical and emotional support from us. He is settling well".*

We asked respondents to tell us if they were satisfied with contact arrangements in the event their child had re-entered care. 49 responded, 40 of whom were Adopters and 10 Special Guardians (1 respondent is both). 27% of the 49 respondents were 'extremely dissatisfied' although the majority (31%), found arrangements acceptable.

**Table 17: Parent/Guardian's views about contact arrangements if child not living with family N=49**

<b>Extremely satisfied</b>	N=7 (14%)
<b>Good</b>	N=6 (12%)
<b>Acceptable</b>	N=15 (31%)
<b>Dissatisfied</b>	N=8 (16%)
<b>Extremely Dissatisfied</b>	N=13 (27%)

## Care proceedings and judicial reviews

- We asked about participant's involvement with care proceedings and judicial reviews pertaining to their Adopted or Special Guardian child. 13% of Adopters had been previously involved with 7 ongoing cases at the time of the survey. The figure for Special Guardians was much higher, with 40% involvement and 5 (7%) ongoing cases<sup>12</sup>.

**Table 18. Adopters and Special Guardians involved in care proceedings or Judicial Review**

	<b>All N= 338</b>		<b>Adopt N=271</b>		<b>SGs N=70</b>
<b>Yes, In the Past</b>	19.53%	66	10.70%	29	57.14%
<b>Yes, On Ongoing</b>	3.55%	12	2.58%	7	7.14%
<b>No</b>	76.92%	260	86.72%	235	35.71%
<b>Please Say More About This, If You Wish</b>		29		18	

<sup>12</sup>The route to becoming a Special Guardian is that it may begin with care proceedings, Court involvement will also be needed for Contact Orders with the child's birth parents.

## Section 4. About Children's Education

- **72% of respondents reported that the school received Pupil Premium Plus for their children, with levels being broadly similar for Special Guardians (67%) and Adopters (73%) N=301. The remaining respondents either did not know (15%) or reported that no Pupil Premium Plus was received for the child (13%).**
- **Respondents were asked about the utilisation of Pupil Premium Plus and if they considered that it was used to address their child's specific social and educational attainment and wider needs. 50% of Adopters responded No, 27% said Yes, and 23% did not know. The figures were 28%, 30% and 42% respectively for SGs with 246 respondents answering this question in total.**
- **73% of 324 respondents had never accessed information or advice from the 'virtual school head' about their child, with a higher percentage of Special Guardians (80%), not accessing the virtual head than Adopters (70%).**
- **School exclusions were slightly lower for Special Guardian children (19%), than adoptive children (29%) (N=331)**

### Where child receives education and training

- **The majority of children (324 respondents; 540 children) are in mainstream school although the figure is higher (90%) for Special Guardians than Adopters (69%). (See Table 19)<sup>13</sup>**

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<sup>13</sup>Some of the disparities between Adopters and Special Guardian's children in Table 19 may be accounted for by differences in age of the children being parented/cared for. Adopters in our survey were parenting older children than Special Guardians – few children under Special Guardianship will be of university age given the Order was introduced 14 years ago.

**Table 19. Education and training of children**

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	All (%) N=324	Adopt N=262	SGs N=65
16 Or Under and In A Mainstream School	217	129	34	10	2	1	393 (73%)	300 (69%)	97 (90%)
16 Or Under and In A Special School	28	18	5	0	0	0	51 (9%)	45 (10%)	6 (5%)
Full Time Education (16 To 19)	16	11	3	0	0	0	30 (6%)	29 (66%)	1
16 To 19 In A Special School or Education Programme	7	4	0	0	0	0	11(2%)	11(3%)	0
Apprenticeship Scheme	1	0	0	0	0	0	1	1	0
University	8	2	1	0	0	0	11 (2%)	11 (3%)	0
Home Schooled	7	6	0	0	0	0	13 (2%)	10(2%)	3
NEET	18	11	1	0	0	0	30 (6%)	30 (7%)	1
<b>Total</b>	<b>302</b>	<b>181</b>	<b>44</b>	<b>10</b>	<b>2</b>	<b>1</b>	<b>540</b>	<b>437</b>	<b>108</b>

#### Respondents views about school support

- Respondent's views about school were rather mixed (See Table 20)

**Table 20. Adopters and Special Guardian's satisfaction with school**

Excellent support		Good support		Acceptable		Dissatisfied		Extremely Dissatisfied	
All respondents									
9.12%	26	27.37%	78	32.28%	92	22.81%	65	8.42%	24
Adopters									
7.83%	18	27.39%	63	31.74%	73	24.78%	57	8.26%	19
Special Guardians									
13.79%	8	25.86%	15	34.48%	20	15.52%	9	10.34%	6

## Home schooling

- 18 respondents reported home schooling 23 children with three of these being Special Guardian children. For the majority this was not out of choice but because there was no suitable provision.

**Table 21. Number of children home schooled**

	All N=18	Adopters N=14	SGs N=4
Home Schooled Out Of Choice	6	6	0
Due to Lack of Suitable Provision	17	13	4

4 respondents commented on the question about home schooling as follows:

*"Not formally home-schooled as would not accept education from parents. minimal tutor education. lack of suitable provision locally.*

*Needs a nurturing, attachment and trauma aware environment. No school can provide this: mainstream can only provide separate containment; special needs schools oversubscribed and focus on SALT or SLD; behavioural schools overuse restraint and inappropriate behaviour / anger management frameworks.*

*I would have home Schooled if only 2 children. 4 with complex needs impossible*

*Did not manage school from year 9 due to anxiety, trauma etc. Out of education for 3 years until I found a specialist school providing online education for traumatised children"*

## EHC plans

- Nearly 50% of children have an EHC Plan or one pending.

**Table 22. EHC plans in place or pending for child**

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	All (%) N=340	Adopt (%) N=275	SGs (%) N=68
Yes	135	72	14	2	0	0	223 (39%)	189 (40%)	35 (32%)
No	165	103	27	4	1	0	300 (52%)	241 (51%)	64 (58%)
Pending	25	17	2	3	1	1	49 (9%)	37 (8%)	12 (10%)
	325	192	43	9	2	1	572	467	111



## Section 5. Support for Special Guardians and Adopters

In this section we will look at respite and therapy provision, as supported via the Adoption Support Fund<sup>14</sup>

### Support for parental/caring role in terms of respite

**Respite is hugely important for anyone parenting or caring for a child with disabilities and mental health issues.**

- **Almost three quarters of all survey respondents get no respite at all (73%), there is little variance between the two groups.**
- **Only 5% of survey respondents get short-break respite from their Local Authority for their caring role and the rate is even lower for Special Guardians (1%).**
- **For just over a fifth of survey respondents who do get respite (21%) it is informal respite from friends and or family members. Special Guardians are less likely than Adopters to get informal respite (22% and 16% respectively).**

**Table 23. Respite for parental/caring role**

Answer Choices	All Responses N=326		Adopters N=260		SGs N=69
Short break respite (LA)	5%	16	5%	14	3%
Informal respite from friends/family members	20%	67	22%	56	16%
Respite provided by voluntary organisation	1.5%	5	1%	3	3%
Other support from voluntary organisations	1.5%	5	1.5%	4	1%
Other support from LA	2%	6	1.5%	4	2%
Have had to use S20 to access respite	2%	6	2%	6	0
None	73%	240	73%	189	78%

<sup>14</sup>The Adoption Support Fund does not fund respite unless it has a therapeutic component/aspect. It may therefore be impossible to access respite without a child re-entering care, under a voluntary Section 20 Care Order, when re-entering care carries a high risk of destabilising Adopted and Special Guardian children – see Table 16. A third of Adopted and Special Guardian children in our survey receive Disability Living Allowance/PIP (See Table 10). Our experience is that these disabilities, which are often 'hidden' disabilities are not factored in or taken into account by local authorities – as this would make our children being considered as 'Child in Need' and necessitate a higher level of statutory support.

Nearly 60% of Adopters and Special guardians had not been able to access therapy/counselling for themselves in the light of their caring role: 58% had not been able to access it but 42% had (N=330). Figures are 17% accessed and 53% not accessed for Special Guardians (N=70), and 123 accessed, and 139 not accessed (N=263) for Adopters

#### Accessing the Adoption Support Fund and views about this fund

- Only 9% of Special Guardians had accessed the Adoption Support Fund compared with 52% of Adopters (N= 344) See Table 24)
- Approximately 10% of respondents considered the Adoption Support Fund sufficient to meet the needs of their child and family, whilst 50% considered it inadequate (See Table 25).
- 73% of Special Guardians said they did not know whether the fund was sufficient (See Table 25)
- Experiences of accessing the ASF were rather mixed and knowledge about match funding is poor amongst respondents about this issue. 315 respondents answered a question on match funding of whom 59 were Special Guardians. Most respondents (71%) say they do not know if the Local Authority match funds. Only 14 (4.4%), of respondents say their Local Authority does match fund.

**Table 24. Accessed Adoption Support Fund**

Accessed ASF	All N=344	Adopt N=279
<b>Yes</b>	43.60%	51.61%
<b>No</b>	47.38%	39.43%
<b>Pending</b>	9.01%	8.96%

**Table 25A. Views about Adoption Support Fund limits/cap<sup>15</sup>**

Is ASF Sufficient for your Child and Family's Needs?	All N= 259	Adopt N=220
<b>Yes</b>	9.27%	10.91%
<b>No</b>	50.97%	55.00%
<b>Don't know</b>	39.77%	34.09%

**Table 25B. Experiences of accessing Adoption Support Fund**

	<b>Extremel y positive</b>	<b>Good</b>	<b>Acceptable</b>	<b>Dissatisfied</b>	<b>Extremely Dissatisfied</b>	<b>Tot al Nu mb er</b>
<b>All</b>	15.52%	25.86%	28.74%	20.69%	9.20%	174
<b>Adopters</b>	16.46%	25.61%	29.27%	20.73%	7.93%	164
<b>SGs</b>	0.00%	27.27%	18.18%	27.27%	27.27%	11

**113 respondents commented about the Adoption Support Fund (in response to the question about the £5k cap being sufficient to meet the needs of their child and family). Several were unequivocally positive about the Fund, but many were concerned that the limit would not be sufficient:**

*Accessed therapeutic life story work which has been really useful, excellent independent worker*

*My daughter accessed ASF before the limit was in place and received about £15k which has helped her considerably. My son's needs will not be met by the £5k limit.*

*We have had funding for child to have weekly play therapy at School for the duration of the previous and current academic year. The application was processed by our supervising Social Worker and very straightforward. We hope to continue with this on an annual basis whilst our child is at School. We are in the process of making a further application for a specialist assessment of her attachment needs to assist the School, and ourselves, in providing support appropriate to her needs.*

*Our therapist works independently. Application for funds has become increasingly difficult. We hope we can continue with therapy as it is needed.*

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<sup>15</sup>A limit/cap of £5k per child per annum, and £2.5k per child for assessment was introduced by the government in 2016. If further support is needed the local authority is required to match fund. There is little transparency about which local authorities match fund and which don't. The Adoption Support Fund is only available in England.

*Does not cover one month's worth of ..... We were having therapy with ..... and now the limit has come in the LA refused to match fund*

*As neither of my children are in education we do not qualify in spite of our needs in being parents to two young people with very complex needs.*

*My son has many complex needs and 5k is not sufficient to provide the therapy and support we need as a family.*

*Funding just secured. My son is having an attachment and sensory assessment next week with the funding, I don't know whether it will provide payment for any necessary treatment at this stage.*

*My daughter accessed the ASF before the limit was in place and received about £15k which has helped her considerably. My son's needs will not be met by the £5k limit.*

*Only because our therapist fits her work to this budget. We have been lucky.*

**There were a number of respondents that the gatekeeping to the fund was poor and commented the application process was lengthy and distressing:**

*The gate keeping around accessing ASF is appalling. We are in a complaints process.*

*I had to petition the DofE direct for funding and make formal complaint to LA to get funding for therapy started to continue. The stress of getting the funding each term has been awful*

*We had to fight for over a year to get assessments and now the LA are refusing to match fund the therapy so we can't access it. I now have a solicitor!*

*The LA conducted an assessment that we did not consent to and submitted this without our knowledge. This was accepted by Mott MacDonald instead of an assessment done for court. It was inaccurate and caused hurt and offence to the degree that I felt the police should be informed - and I informed them, as well as our MP. There was a Supervision Order in place at the time and this was discharged by the court before it ran out when the LA did not meet statutory obligations in regards to Pathway Planning.... £5k is ridiculous - it cost £5k PER WEEK to keep my son in care - against his wishes. Our LA do not match fund at all I have been told. The D of E is a shut door and does not deal with complaints or individual cases. The police have been to see the DCS but said there was nothing 'criminal' just distorted reports*

*Has been an appalling experience.....Recently, we have experienced appalling delay, lack of decision making and grip. LA trying to coerce us to accepting the support they provide - parenting training - using ASF to fund their own services rather than enabling us to access support we identified would be helpful. Taken us a year of meetings and having to contact DCS to access what we asked for - and this is minimal support for v complex child. After years of asking - we are finally accessing a specialist assessment.LA worried that the care plan following on from this will be more than £5k - already talking about making priorities. We are saving them thousands – parenting our son.*

*We applied in February (2017) and we are still waiting (January 2018).*

*It is difficult to access as it is dependent on social workers who do not understand the complex needs of the children and what is required.*

*It took 9 months to even be assessed then another 3 through internal LA panels. The agreement was very short term and piecemeal.*

*Taken far too long. Request to LA made in May, actual therapy starts in January. Meanwhile there's been 2 School exclusions & now facing permanent exclusion for violence (in the words of the School).*

*Applied in March, got told in November we are successful by social worker, silk waiting in January for paperwork to be able to access anything. Almost a year wait is ridiculous.*

*I applied for ASF funding 2 years ago to pay for play therapy for child 1, but after 15 months slow assessment, we were turned down. No reason was given.*

*5K limit has led to loss of specialist trauma informed therapy for our children; CAMHS, even tier 4, lacks specialist knowledge, appropriate attachment / family-based approach; doesn't understand impact or trauma and CPV; unable to provide level of support needed for all family.*

*The Fund was also rather limited in scope and some therapies that were considered beneficial, with good evidence, were not covered at all*

*I am appalled that Sensory Integration Occupational Therapy isn't always funded by ASF which has a scientifically recognised benefit*

*As ASF is very specific unfortunately it would not cover a mentoring programme which would have been very positive for older AS*

**Some respondents spoke of being a drain on the public purse when therapy was not provided leading to returns to care for a child that might have been prevented. Providing support was also considered to have saved parents from a stress breakdown:**

*I paid for an assessment at Family Futures which outlined a three-year intensive therapy programme for me and my son when he was aged 7. It would have cost £73,000 and the LA refused to pay. In the end they paid up to £750,000 for the special school where he receives no therapy or healing.*

*We got funding for DDP but part of whole plan was for us to have respite. LA refused. things got worse and they eventually took her into care on section 20 but LA were very aggressive to us in their attitude and told daughter untrue things which meant she wouldn't speak to us for months so DDP didn't really get started*

*It saved us from breakdown and by limiting it you are risking individuals not getting the support they actually need costing more money in the future*

**Several respondents reported being too worn down by battles to achieve support or daily struggles to apply:**

*If I had more emotional energy I would make further use of the fund. That we don't use it more does not mean we don't need more support, it is just that I am utterly worn out from holding things together day to day.*

*Accessing SEN support in school is so stressful - don't wish to embark upon another stressful process, even though feel we need support. Support is not supportive if you have to fight to receive it.*

*Respondents were disappointed about the lack of support for aspects of adoption that were not covered by the fund, with no other provision either:*

*My children, after 8 years, have recently made contact with an older birth sibling who is still in care. It would be lovely to access funding for them to spend time together, perhaps in a residential setting, with therapeutic support.*

**A number of respondents were disappointed that the fund was not available in Scotland and Wales, and it was pointed out that children adopted from these nations could not access funding pre the Adoption Order:**

*No ASF in Scotland - any amount would be good :)*

*We cannot access this until post AO because our child placed from Scotland and pre-AO.*

**Eight Special Guardians reported not knowing of the funds existence at all and two Special Guardians spoke of their wariness and inability to trust social care and adoption social workers.**

**The reasons for this are explained in this quote, where the respondent emphatically suggests a renaming of the fund to make it clear it is for Special Guardians:**

*I find it very difficult - as a Special Guardian who, in common with many other SGO holders, has had a very negative family experience of the "permanency" team within Children's Services - that it is the local authority adoption team who are the gatekeepers for this support fund. It is easy for the Government to decree that children who are ex-LAC and now under SGOs are now able to access this fund. However, the practicality is that many, possibly most, SGO holders will have had horrendous experiences - often in court and at huge personal financial and emotional cost - with the very social workers and their managers who hold the key to the door to therapeutic support. This reality will no doubt deny access to many many children in need. Many families have fought local authorities to prevent their children being adopted out of the family - so it is highly inappropriate to require them to contact the authority's adoption team to access therapeutic support for their child. We have asked about the possibility of accessing the Fund for filial therapy for our child - via his Social Worker - and, four months later - haven't even had a response to the basic question. We are wondering if the slow response is a result of us currently having a formal complaint in to the local authority (the second complaint - the first being found in our favour) and have also just informed the authority that we intend to report the social worker who assessed us for fostering/Special Guardianship to the HCPC for unacceptable practice. Adoption teams in local authorities tend to be small and social workers tend to be close and very supportive of each other. Families who have fought colleagues in court - or are perceived to have caused colleagues and friends distress - may well be resented. And families will feel that they will be judged harshly if they seek help - and that there may well be other consequences to seeking support (the previously-experienced horror of child protection investigations may well be a great fear). The last people they will want to disclose difficulties to is the team who wanted the child to be adopted anyway. The Government needs to be lobbied on this as a matter of urgency - there needs to be another "way in" to the Fund (which also needs to be re-named) other than through local authority adoption teams.*

*Another Special Guardian raised the issue of fear of social services being a barrier*

*Too much fear of Child Protection threats if contact Children's Services*

**Adopters and their children also found the prospect of dealing with children's services off putting:**

*We didn't even apply because have to go via social services, and my daughter refuses to have anything more to do with social services and would not have co-operated. I also never want anything more to do with them, after being failed by them, support wise, for years.*

**There were concerns raised that Local Authorities were using the funding to pay for statutory services and not reunifying children living apart from families:**

*The cap is too low, and LAs are using it for everything, including to pay for things they are obliged to pay for under post adoption support*

*Application for £19,000 prepared while S20 but never submitted as social worker. unilaterally decided there was no plan for rehabilitation.*

**The price of assessments was considered too high and seen to benefit organisations, but the fund did allow access to these costly assessments – however this was not done retrospectively when parents had self-funded assessment work:**

*Due to poor care by SW wasn't assessed for ASF for a course so self-funded and then was told ASF assessment couldn't be done retrospectively. Met many other adoptive parents on PAC courses who self-fund as not able to be supported by ASF.*

*We asked the LA for access to ASF. A SW visited once but then left and was never seen again and no-one picked up the work. Only when we entered crisis and we had to find my daughter somewhere else to live were social services involved and we now have an assessment done (which was incomplete) and sent in with an ASF application. We will*

*see if the money is enough. However, organisations are using the rules to their advantage - it does not cost £2500 to assess a child but that is what they charge the LA. It's a disgrace.*

*We accessed 7.5k to have a family assessment at the .....*

*We accessed it before the cap. The assessments alone for our 2 children came to around 3k*

**Concerns were raised about how the therapies the fund pays for are being evaluated. It seems compromises are being made in the provision of therapy that need to be considered and properly evaluated in terms of their impact on the child and family:**

*It's a fantastic provision but what thought is given to the evidence base of therapies available? How is that being collected since the fund was made available? Very slow process which means the help can't be joined up with existing health care provision (which I have had to fight to access also, in particular OT) and too short term for my child's needs. A sense that 'match funding' unlikely to be successful. Lack of expertise within post adoption social work with regards to effective therapies? No consideration of the impact on children with attachment problems to the short-term nature of the relationships they make with therapists via ASF. Good therapists very aware of this and therefore cautious in how they deliver the therapy leading me to question the validity of the therapy? (We are getting a watered-down version of evidence-based therapy because my daughter's needs are complex and therapists cautious to fully engage her for fear of implications when the money runs out).*



## Section 6. About Special Guardians' and Adopters' Views and Experiences of Professionals

In this section we describe the views and experiences of Special Guardians and Adopters in regards to the statutory and independent professionals that provide health, educational and social care support and safeguarding to children – and who conduct assessments. Views of legal professionals are also considered.

### Views about current situation

- Table 26 shows high levels of dissatisfaction with social workers, Independent Reviewing Officers, Cafcass Guardians, and CAMHS professionals. Non-statutory therapists, legal professionals and court and tribunal judges fared better but there were still a number of respondents that are 'extremely dissatisfied' with their current treatment<sup>16</sup>.

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<sup>16</sup>We have more work to do to analyse the qualitative data to better understand what the problems are for Adopters and Special Guardians that they are left feeling so 'extremely dissatisfied' by current treatment.

**Table 26. Views of Special Guardians and Adopters vis a vis present treatment/situation**

All Resp onde nts N=33 5													
		Extremely Positive		Mostly Positive		Satisfactory		Dissatisfied		Extremely Dissatisfied		N/A	
<b>Social Worker</b>		7.29%	24	11.85%	39	20.97%	69	13.98%	46	18.24%	60	27.66%	91
<b>Independent Reviewing Officer (IRO)</b>		4.10%	12	5.80%	17	6.83%	20	4.44%	13	6.14%	18	72.70%	213
<b>Cafcass Guardian</b>		3.46%	10	1.73%	5	2.42%	7	2.77%	8	2.42%	7	87.20%	252
<b>CAMHS Professional</b>		2.88%	9	8.65%	27	7.05%	22	14.42%	45	10.26%	32	56.73%	177
<b>Mental Health Professional</b>		4.41%	13	6.10%	18	7.46%	22	5.08%	15	5.42%	16	71.53%	211
<b>Education Professional</b>		10.94%	35	18.75%	60	27.19%	87	18.44%	59	7.19%	23	17.50%	56
<b>SENCO, Teacher</b>		12.14%	38	18.21%	57	18.21%	57	17.57%	55	10.86%	34	23.00%	72
<b>Independent Assessor</b>		1.07%	3	2.14%	6	3.20%	9	1.78%	5	2.14%	6	89.68%	252
<b>Non-statutory Therapist</b>		12.23%	34	10.43%	29	6.12%	17	2.52%	7	1.08%	3	67.63%	188
<b>Legal Professional</b>		4.23%	12	4.93%	14	4.58%	13	1.76%	5	2.11%	6	82.39%	234
<b>Court or Tribunal Judge</b>		5.67%	16	5.32%	15	3.55%	10	1.06%	3	3.55%	10	80.85%	228
<b>Other</b>		4.35%	7	3.11%	5	1.86%	3	1.24%	2	1.24%	2	88.20%	142
<b>If You Ticked Other, Please Specify</b>													
Adopt ers N=26 8													
		Extremely Positive		Mostly Positive		Satisfactory		Dissatisfied		Extremely Dissatisfied		N/A	
<b>Social Worker</b>		6.44%	17	12.50%	33	22.73%	60	14.02%	37	17.80%	47	26.52%	70
<b>Independent Reviewing Officer (IRO)</b>		3.80%	9	4.64%	11	6.75%	16	5.06%	12	5.91%	14	73.84%	175
<b>Cafcass Guardian</b>		0.86%	2	0.43%	1	1.29%	3	1.72%	4	1.72%	4	93.97%	218
<b>CAMHS Professional</b>		2.73%	7	9.77%	25	7.81%	20	14.84%	38	10.94%	28	53.91%	138
<b>Mental health Professional</b>		4.60%	11	6.28%	15	7.53%	18	5.44%	13	5.86%	14	70.29%	168
<b>Education Professional</b>		10.04%	26	20.46%	53	27.41%	71	18.92%	49	6.95%	18	16.22%	42
<b>SENCO, Teacher</b>		12.16%	31	21.18%	54	18.04%	46	18.04%	46	10.98%	28	19.61%	50
<b>Independent Assessor</b>		0.86%	2	2.16%	5	3.88%	9	1.29%	3	2.16%	5	89.66%	208
<b>Non-statutory Therapist</b>		13.54%	31	12.23%	28	6.55%	15	2.62%	6	0.87%	2	64.19%	147

<b>Legal Professional</b>	3.45%	8	3.02%	7	4.31%	10	1.29%	3	1.29%	3	86.64%	201
<b>Court or Tribunal Judge</b>	4.37%	10	3.06%	7	2.62%	6	1.31%	3	3.06%	7	85.59%	196
<b>Other</b>	5.56%	7	3.97%	5	2.38%	3	1.59%	2	0.79%	1	85.71%	108
<b>If You Ticked Other, Please Specify</b>												
Special Guardians N=69												
	Extremely Positive		Mostly Positive		Satisfactory		Dissatisfied		Extremely Dissatisfied		N/A	
<b>Social Worker</b>	10.45%	7	8.96%	6	13.43%	9	14.93%	10	20.90%	14	31.34%	21
<b>Independent Reviewing Officer (IRO)</b>	5.17%	3	12.07%	7	8.62%	5	1.72%	1	6.90%	4	65.52%	38
<b>Cafcass Guardian</b>	13.56%	8	8.47%	5	6.78%	4	8.47%	5	5.08%	3	57.63%	34
<b>CAMHS Professional</b>	3.45%	2	3.45%	2	3.45%	2	15.52%	9	6.90%	4	67.24%	39
<b>Mental health Professional</b>	3.45%	2	5.17%	3	6.90%	4	5.17%	3	3.45%	2	75.86%	44
<b>Education Professional</b>	15.87%	10	11.11%	7	26.98%	17	15.87%	10	7.94%	5	22.22%	14
<b>SENCO, Teacher</b>	13.33%	8	5.00%	3	18.33%	11	15.00%	9	11.67%	7	36.67%	22
<b>Independent Assessor</b>	1.96%	1	1.96%	1	0.00%	0	3.92%	2	1.96%	1	90.20%	46
<b>Non-statutory Therapist</b>	5.88%	3	1.96%	1	3.92%	2	1.96%	1	1.96%	1	84.31%	43
<b>Legal Professional</b>	7.41%	4	12.96%	7	7.41%	4	3.70%	2	5.56%	3	62.96%	34
<b>Court or Tribunal Judge</b>	12.73%	7	14.55%	8	9.09%	5	0.00%	0	5.45%	3	58.18%	32
<b>Other</b>	0.00%	0	0.00%	0	0.00%	0	0.00%	0	2.78%	1	97.22%	35
<b>If You Ticked Other, Please Specify</b>												

## Professionals building trust with children

- With such a high proportion of our children suffering with attachment issues and potentially having problems building relational trust we thought it vitally important to ask respondent's views about the abilities of professionals to build trust with our children. Results are shown in Table 27

**Table 27. Showing reported frequency of professionals having difficulty building trust with Special Guardian and Adopted children N=344**

<b>All N=344</b>	<b>Yes</b>		<b>No</b>		<b>N/A</b>
<b>Social Worker</b>	50%	164	28%	93	22%
<b>CAMHS Professional</b>	43%	130	12%	36	45%
<b>Child(ren)'s School</b>	55%	179	37%	123	8%
<b>Specialist Agency Therapist</b>	27%	78	33%	96	40%
<b>Other</b>	20%	35	10%	18	70%
<b>Adopt N=278</b>	<b>Yes</b>		<b>No</b>		<b>N/A</b>
<b>Social Worker</b>	53%	140	28%	73	19%
<b>CAMHS Professional</b>	46%	117	12%	29	42%
<b>Child(ren)'s School</b>	61%	160	33%	87	6%
<b>Specialist Agency Therapist</b>	29%	68	35%	84	36%
<b>Other</b>	22%	29	8%	11	70%
<b>SGs N=68</b>	<b>Yes</b>		<b>No</b>		<b>N/A</b>
<b>Social Worker</b>	40%	26	30%	20	30%
<b>CAMHS Professional</b>	26%	14	14%	8	60%
<b>Child(ren)'s School</b>	29%	19	58%	38	13%
<b>Specialist Agency Therapist</b>	20%	11	22%	12	58%
<b>Other</b>	16%	7	16%	7	68%

## Experience of discrimination

- Being subjected to any kind of discrimination can be an enormous stress factor and we wanted to find out about perceived discrimination amongst Special Guardians and Adopters. Results can be seen in Table 28.

**Table 28. Adopters' and Special Guardians' experience of discrimination in accessing services on the basis of age, race, gender, faith disability etc**

<b>Answer Choices</b>	<b>All N=333</b>		<b>Adopt N= 268</b>		<b>SGs N=67</b>
<b>Yes</b>	13.51%	45	13.81%	37	13.43%
<b>No</b>	86.49%	288	86.19%	231	86.57%
<b>Please say more about this, if you wish</b>		47		38	

## Bad experiences of professionals in the past or present

- We are aware that Adopters and Special Guardians report having bad experiences of dealing with professionals and wanted to find out how many had experienced difficulties. Social Workers, CAMHS professionals, Education professionals and SENCOs have all given respondents bad experiences in our population sample (N=309). 80% of respondents had a bad experience with a Social Worker (See Table 29).

**Table 29. Adopters' and Special Guardians' 'bad experiences' of professionals**

	All N=309		Adopt N= 250		SGs=62
Social Worker	79.94%	247	78.80%	197	83.87%
Independent Reviewing Officer (IRO)	16.50%	51	18.00%	45	9.68%
Cafcass Guardian	7.77%	24	4.80%	12	20.97%
CAMHS Professional	39.48%	122	42.80%	107	27.42%
Mental Health Professional	21.04%	65	23.20%	58	12.90%
Education Professional	52.10%	161	57.60%	144	30.65%
SENCO, Teacher	47.90%	148	52.00%	130	33.87%
Independent Assessor	3.56%	11	3.20%	8	4.84%
Non-Statutory Therapist	3.88%	12	4.00%	10	3.23%
Legal Professional	5.50%	17	5.20%	13	6.45%
Court of Tribunal Judge	6.15%	19	6.00%	15	6.45%
Other	5.50%	17	6.00%	15	3.23%
If You Have Ticked Other Please Describe	14.89%	46	14.00%	35	17.74%

## Formal complaints, in the past, or ongoing

- 146 Formal complaints had been made or are ongoing by Special Guardians and Adopters - the percentage figure being equal amongst the two groups. (See Table 30 N=341).

**Table 30. Formal complaints made by Special Guardians and Adopters, or ongoing**

	All respondents N= 341		Adopt N=272		SGs N= 72
Yes, In the Past	29.62%	101	29.78%	81	27.78%
Yes, On Ongoing	13.20%	45	13.60%	37	13.89%
No	57.18%	195	56.62%	154	58.33%
Please Say More About This, If You Wish		96		80	

## Section 7. About Stress Factors for Special Guardians and Adopters

**In this section we consider the views of Special Guardians and Adopters in regards to their personal experiences and individual assessment of what they find most stressful. We asked survey respondents to score a range of statements using a three points rating scale rating each statement as 1 = 'slightly stressful'; 2= 'stressful' and 3 = 'extremely stressful'. If there was no stress involved the respondent could tick 'not applicable'.**

#### **Main stress triggers associated with parental caring role**

- **Among the 5 highest scoring stress triggers for both groups who responded to the survey are: 'supporting your child in the family home'; 'difficulties parenting at a distance' – although 212 respondents rated this stress factor not applicable; and 'coping with your child's issues'.**
- **Many of the stress triggers arising from family situation/ caring role are slightly lower for SGs than they are for Adopters, with the exception of: 'financial worries', 'child's contact/meeting with birth family' and 'education health and care plan processes'.**

**Table 31. Special Guardian and Adopters' assessment of stress triggers associated with parental/caring role N=336**

	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
Education Health and Care Plan Process	311	127	2.05	250	102	2.03	63	25
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	

33 respondents used the 'other please specify' box to describe a range of other personal stresses that had affected them including: obtaining visas for children adopted from abroad – one partner had to remain abroad caring for the children single handed whilst the other worked in the UK; Looked After Child reviews; court proceedings; 'family in crisis'; 'everything'; social isolation; work stress with lack of understanding from employers; worries about secondary school; dealing with the child's birthparents as a Special Guardian grandparent and getting time off to attend meetings about the child. Several respondents also commented how life was not stressful for them, that they felt fortunate, or fortunate to have a good relationship with their partner.

Main stress triggers that have arisen from accessing services and dealing with professionals/ agencies

- The three greatest stress factors for both groups were ‘difficulties and obstacles in accessing provision’; ‘professionals not appreciating your children’s needs’ and ‘tribunals’, although 236/268 respondents said that this last stress factor was not applicable to them.
- Almost all of the stress triggers arising from accessing services and dealing with professionals/ agencies are slightly lower for Special Guardians than they are for Adopters, with the exception of legal issues which is slightly higher.

**Table 32. Special Guardian and Adopters’ assessment of stress triggers arising from accessing services and working with professionals N=329**

	All Respondents N=329			Adopt N=265			SGs N= 67	
	Total	Answered N/A	Weighted average	Total	Answered N/A	Weighted average	Total	Answered N/A
<b>Professional(S) Finding It Hard To Build Trust With Your Child(ren)</b>	313	100	1.89	254	71	1.9	61	29
<b>Professional(s) Not Appreciating Your Child(ren)'s Needs</b>	324	40	2.45	261	22	2.48	66	18
<b>Difficulties and Obstacles In Accessing Provision</b>	317	38	2.56	257	22	2.56	63	16
<b>Being Discriminated Against When Trying to Access Services/ Support</b>	300	194	2.31	242	164	2.35	60	31
<b>Lack of Understanding From Professionals</b>	324	40	2.39	262	24	2.4	65	16
<b>Legal Issues</b>	296	205	2.31	237	181	2.25	61	25
<b>Formal Complaints</b>	295	167	2.41	238	138	2.42	59	30
<b>Court Proceedings</b>	291	213	2.27	233	196	2.32	60	17
<b>Tribunals</b>	268	236	2.44	223	202	2.52	47	35
<b>Other</b>	139	127	2.92	110	100	2.9	30	28
<b>Other (Please Specify)</b>	11			10			2	

11 respondents provided comments about other stress factors. These included: applying for PIP and having to go through mandatory reconsideration and then a tribunal; dealing with schedule 1 offenders, criminals and drug addicts to keep children safe from being groomed and child sexual exploitation; countering misinformation and inaccuracies in reports; dealing with abusive treatment in schools; and feeling judged and blamed. One respondent explained that due to the catalogue of errors the placing local authority had paid their barristers fees for court proceedings.



## Section 8. About the Impact of Stress on Adopters and Special Guardians

In this section we look at the impact of stress on Adopters and Special Guardians

### Mental and emotional health problems

- **Table 33 shows the mental health difficulties experienced by Special Guardians and Adopters, which are believed to be associated with their caring/parenting role. Stress, Anxiety and Depression are reported at high levels with 50% of respondents experiencing stress and anxiety.**
- **35 respondents are currently having a stress breakdown with another 50 having experienced one in the past. 18 respondents are diagnosed with PTSD**
- **There are also high levels of secondary trauma amongst respondents.**
- **45% of respondents had avoided seeking help from their GP for mental health problems for fear this would lead to judgements being made about their capacity to parent/care for their child. This figure rises to nearly 60% for Special Guardians (See Table 34). Comments made indicated active threats of removal and fears being justified on the basis of experience of care proceedings to become a Special Guardian. Parents seeking GP advice for injuries inflicted by their children had not spoken about the impact this might have had on them with their family doctor and respondents indicated being too preoccupied with the needs of their children to focus on their own health needs – which might open a “floodgate”.**
- **More than 70% of respondents reported using antidepressants in answering the question about NHS treatment for their problems. Nearly 60% had accessed counselling. See Table 35.**

**Table 33. Mental health difficulties for Adopters and Special Guardians experienced as arising from parental/caring role**

<b>All Respondents N= 331</b>							
		Yes, at present		Yes, in the past		No	
<b>Stress</b>		55.11%	178	27.24%	88	22.91%	74
<b>Depression</b>		29.41%	90	29.74%	91	42.81%	131
<b>Anxiety</b>		47.59%	148	21.54%	67	33.76%	105
<b>Stress/ Mental Health Breakdown</b>		12.64%	35	18.05%	50	71.12%	197
<b>PTSD</b>		6.79%	18	8.68%	23	85.66%	227
<b>Secondary Trauma</b>		29.21%	85	20.62%	60	52.23%	152
<b>Blocked Care</b>		14.66%	39	18.05%	48	69.17%	184
<b>Other (please specify)</b>							
<b>Adopt N=265</b>							
		Yes, at present		Yes, in the past		No	
<b>Stress</b>		54.65%	141	28.29%	73	23.26%	60
<b>Depression</b>		30.04%	73	30.04%	73	42.39%	103
<b>Anxiety</b>		49.39%	122	19.03%	47	35.22%	87
<b>Stress/ Mental Health Breakdown</b>		13.18%	29	17.73%	39	71.36%	157
<b>PTSD</b>		7.98%	17	9.39%	20	84.04%	179
<b>Secondary Trauma</b>		32.35%	77	24.37%	58	45.80%	109
<b>Blocked Care</b>		17.35%	38	21.46%	47	63.01%	138
<b>Other (Please Specify)</b>							
<b>Special Guardians N=68</b>							
		Yes, at present		Yes, in the past		No	
<b>Stress</b>		56.72%	38	23.88%	16	20.90%	14
<b>Depression</b>		27.69%	18	29.23%	19	43.08%	28
<b>Anxiety</b>		40.91%	27	31.82%	21	27.27%	18
<b>Stress/ Mental Health Breakdown</b>		11.86%	7	20.34%	12	67.80%	40
<b>PTSD</b>		1.85%	1	5.56%	3	92.59%	50
<b>Secondary Trauma</b>		14.55%	8	3.64%	2	81.82%	45
<b>Blocked care</b>		2.04%	1	2.04%	1	97.96%	48
<b>Other (please specify)</b>							

Respondents reported that 68% of the mental health problems they experienced were diagnosed by their GP and a further 24% said the diagnosis was made by another mental health professional. This was 193/211 respondents (N=211)

**Table 34. Avoidance of help seeking from GP for mental health problems due to fears judgements might be made about capacity to care for an Adopted or Special Guardian child N=323**

	<b>All N=323</b>		<b>Adopt N= 258</b>		<b>SGs N=67</b>
<b>Yes</b>	45.51%	147	42.24%	109	59.70%
<b>No</b>	54.49%	176	57.75%	149	40.30%
<b>Please Say More About This, If You Wish</b>		42		32	

42 Respondents commented on this question. Special Guardians reported fearing to seek advice from their GP as a result of the care process, and the fear of losing their children, when they saw no one else to care for them, was very severe. During the Special Guardian assessment process GP consultations were avoided and another respondent spoke of waiting for the Adoption Order to go through before seeking advice. One respondent spoke of a fear it might open a floodgate if she spoke to her GP. One respondent (adopter and Special Guardian), described active threats to remove children if she was diagnosed with a mental health problem. An adopter described seeing the GP for physical injuries inflicted by her children but not formally speaking about her own mental health. Time constraints were also factor that prevented some respondents seeking GP advice – and several also reported being too preoccupied with the needs of their children to care for themselves.

**Table 35. NHS Treatment for mental health problems felt to be related to stress of caring role N=154**

	<b>All N=154</b>		<b>Adopt N=119</b>		<b>SGs N=36</b>
<b>Medication Such as Anti-Depressants</b>	72.08%	111	69.75%	83	80.56%
<b>Counselling/ Talking Therapies</b>	57.79%	89	61.34%	73	47.22%
<b>Mental Health Day Care</b>	0.00%	0	0.00%	0	0.00%
<b>Mental Health Inpatient Care</b>	1.30%	2	0.84%	1	2.78%
<b>Other (Please Specify)</b>	12.99%	20	14.29%	17	11.11%

### Physical health problems

- **Pain and Irritable Bowel Syndrome were the two most common physical ailments/conditions to be exacerbated by Special Guardian and Adopters' parental/caring role. See Table 36.**
- **Almost a quarter are suffering from auto immune disorders, this is consisted for both groups**
- **3% attribute serious illnesses such as cancer and heart attacks to the strain from their caring role.**

**Table 36. Physical health problems that are thought to be exacerbated by parental caring role**

	<b>All N=165</b>		<b>Adopt N=129</b>		<b>SGs N=38</b>
<b>Cancer</b>	3.64%	6	3.88%	5	2.63%
<b>High Blood Pressure</b>	24.85%	41	25.58%	33	23.68%
<b>Stroke</b>	0.00%	0	0.00%	0	0.00%
<b>Heart Attack</b>	3.03%	5	3.10%	4	2.63%
<b>Fibromyalgia</b>	6.06%	10	3.10%	4	15.79%
<b>Auto-Immune Disorders</b>	23.03%	38	24.03%	31	21.05%
<b>Irritable Bowel Syndrome</b>	37.58%	62	37.98%	49	36.84%
<b>Any Pain Conditions, e.g. Back Pain</b>	55.15%	91	53.49%	69	60.53%
<b>Other (Please Specify)</b>		57		40	

Giving up work/ reducing income to care for children

The impact of stress is far reaching and may mean that Adopters and Special Guardians must give up work, or careers, altogether or take on less stressful and less well-paid jobs.

- Over half of survey respondents have given up work all together to care for their children (51%). The rate for Special Guardians is higher, almost two third (63%) and for Adopters just less than half (48%).
- Adopters in the survey are more likely than Special Guardians to have changed to a less paid/ less stressful job (16% against 5%).
- Just less than half all respondents struggle financially as a result of caring for children (46%). The rate is higher for Special Guardians (57%).

**Table 37. Showing rates of those who have given up work, reduced hours/ income etc.**

<b>Answer Choices</b>	<b>All N=294</b>	<b>Adopters N=231</b>	<b>SGs N=66</b>	<b>Variance</b>
<b>Given Up Work</b>	51%	48%	63%	15%
<b>Reduced Your Hours</b>	44%	49%	25%	-24%
<b>Changed to A Lower Paid Job</b>	17%	21%	6%	-15%
<b>Changed to A Less Stressful Job</b>	14%	16%	5%	-14%
<b>Struggled Financially</b>	46%	44%	57%	13%

Almost two thirds of survey respondent's relationships have suffered as a result of their caring role (63%). The rate is slightly higher for Adopters compared to Special Guardians, 64% and 58% respectively.

**Table 38. Showing relationship suffering as a result of caring roles**

<b>Answer Choices</b>	<b>All N=330</b>	<b>Adopters N=273</b>	<b>SGs N=70</b>	<b>Variance</b>
<b>Yes</b>	63%	64%	58%	-6%
<b>No</b>	22%	23%	22%	-1%
<b>N/A</b>	15%	13%	20%	7%

## Section 9. About what helps Adopters and Special Guardians to better cope with stress

### Assessment of current social support network

- Table 39 shows how Adopters and Special Guardians assessed their social support network. Whilst more Special Guardians felt 'extremely isolated', more Adopters felt themselves to be 'somewhat isolated'. Approximately 60% of both groups felt their social support network was 'OK', 'Good' and 'Excellent'.

**Table 39. Social support network for Special Guardians and Adopters N=326**

<b>All Respondents N=326</b>	<b>Excellent</b>		<b>Good</b>		<b>OK</b>		<b>Somewhat isolated</b>		<b>Extremely isolated</b>
	10.74%	35	28.53%	93	25.15%	82	28.83%	94	6.75%
<b>Adopters N=261</b>	<b>Excellent</b>		<b>Good</b>		<b>OK</b>		<b>Somewhat isolated</b>		<b>Extremely isolated</b>
	9.58%	25	29.50%	77	24.14%	63	31.03%	81	5.75%
<b>Special Guardians N=68</b>	<b>Excellent</b>		<b>Good</b>		<b>OK</b>		<b>Somewhat isolated</b>		<b>Extremely isolated</b>
	14.71%	10	25.00%	17	30.88%	21	19.12%	13	10.29%

### Supportive factors and activities

- A whole range of factors are shown to help mitigate the impact of stress of Adopters and Special Guardians, many of them the simple pleasures we asked about.
- The highest scoring factors for effectively alleviating stress for Adopters and Special Guardians are: peer support (74%), sharing with others (74%), walking (71%), being in nature (70%) and reading novels/ watching films (67%).

- Most of the percentages are lower for Special Guardians, with the exception of “campaigning - trying to make a difference” where this way of putting energy into something positive for others to come out of personal difficulties, is just over a third for both groups.
- The highest variances between groups are “religion and personal faith,” two thirds of Adopters (66%) and one third of Special Guardians (35%) and Yoga/Pilates/TaiChi (40% and 12% respectively).
- There are also variances (not shown), around “spending time with partner” and “socialising with friends” both of these categories are around half of Adopters and one quarter of Special Guardians.

**Table 41. Supportive and resourcing factors that potentially alleviate stress for Adopters and Special Guardians**

	<b>All N=325</b>	
	Yes, this helps and I can do it	Would help but I can't do this because of constraints of caring role
Sharing With Others	211	75
Peer Support	192	67
Being In Nature	176	97
Walking	165	75
Reading Novels/Watching Films	159	81
Holidays	124	41
Socialising With Friends	116	85
Spending Time With Partner	106	65
Meditation And Mindfulness	105	117
Music And Singing	94	77
Making Art And Crafts	76	149
Have Hobbies	72	119
Exercise And/ Or Going To The Gym	64	126
Swimming	61	83
Campaigning - Trying To Make A Difference	58	68
Religion And Personal Faith*	58 (60% Adopt vs 35% SGs)	90
Yoga/Pilates/Taichi*	45 (40% Adopt vs 12% SGs)	87
Learning Something New	43	89
Other	9	11

\*These two beneficial/stress protective factors showed the most variance with fewer Special Guardians

## Barriers and obstacles to doing things for oneself that help with stress

- 76% reported not being able to prioritise their own needs “as the needs of the child are too great” as the biggest barrier for doing things for self that help with stress
- Also included in the in the top barriers identified by all those who responded to the survey are “lack of respite” and “lack of energy/ motivation” both scoring 56%
- Almost two thirds (64%) stated that they did not have enough time.
- Half of all respondents (50%) stated “completely exhausted/physical and mental burn out”
- The second biggest barrier for doing things for self that help with stress identified by Special Guardians is “lack of money” (62%) this was less of an issues for Adopters in the survey who have a higher level of household income (38%)

**Table 42. Barriers and obstacles for Adopters and Special Guardians to doing things that potentially help with stress (N=321)**

	%
Not Able To Prioritise Own Needs As Needs Of Child Are Too Great	76.01%
Not Enough Time	63.55%
Lack Of Respite	56.39%
Lack Of Energy/ Motivation	55.76%
Completely Exhausted/Physical And Mental Burn Out	50.47%
Lack Of Money*	42.37%
Demands Too Great	37.69%
No Energy	31.15%
Demands Multiple Caring Roles (Other Than Adopted Or SG Children)	17.13%
Lack Of Transport	5.92%
Other (Please Specify)	6.85%

\*lack of money was second biggest obstacle for Special Guardians



Support from charities, voluntary organisations, peer support groups, self-help groups and community groups

**We asked respondents whether they received useful support for their parenting/caring role from self-help groups, community groups, peer support groups, voluntary agencies or charities. 147 responded to this question.**

A number of respondents were members of POTATO Group and this closed social media group was considered to be a support for many Adopters who answered this question with numerous citing and positive mentions. Respondents described finding other groups and associations beneficial including: local Adoption support groups, Twitter, local authority Adopter chat groups, SGO groups, AUK magazine and online forums, PAC UK, Coram, We Are Family, Little Miracles, the SEN Revolution, Women of Fenland, local church (an opportunity to get out), Kinship care UK, Attachment Disorder FB group, Parent support groups, NVR parent support groups, Unconventional Mamma, Adoptive Parenting, Therapeutic Parents, NATP, Scottish Adoption Association through Barnardo's, CAMHS Adoption group, Caritas Care, FASD UK and other FASD groups, Sure Start, More Than Grandparents (Sunderland), an NVR WhatsApp group, Open Nest, Kinfest Skegness, Northamptonshire Kinship group, Leicestershire Adopters Group, LGBTQ Adopters group, North Tyneside Special Guardian's group, More Than Grandparents, One Adoption, the Lucy Faithful Foundation, MOSAC, Brighton and Hove Families Through Adoption, Faith in Families, Catchpoint and Family Futures. Two respondents had set up their own support groups and one of these had been a trainer for Adoption UK. Our own group was mentioned also, although we are not a support group. We do provide support however, and a collective voice, for those who would like to see something positive come out of their difficulties, for others in future.

More about coping with stress and reflection on what needs to change

**We invited respondents to tell us more about what helped them cope with stress and let us know if there was anything that they thought had been missed out in the survey in regards to stress and coping with it. These questions generated 102 and 82 comments, respectively. Questions about examples of good practice and thoughts about what needs to change generated 83 and 197 comments respectively. Reflection on the themes that emerge from qualitative data and producing a sound and robust mixed methods evidence synthesis are beyond what we are able to manage within the timescales, given our work and care commitments and capacity to undertake the analysis without additional support. We did not want such an analysis to delay the release of the quantitative data.**

Taking the survey project further

**We would like to reflect more deeply on our qualitative data and develop our research, ideally working with key research partners to support us. These will be researchers and clinicians who we**

feel have an understanding of the problems we face, funding permitting for this<sup>17</sup>. We hope the government might see the value of our work, and fund this important research, helping us to develop the project.

We envisaged that perhaps focus groups might be an appropriate methodology to further explore the views of Special Guardians and Adopters, particularly in regards to what needs to change and how this change might come about. Focus groups enable a depth of thought to be given to a topic and this method allows for interaction between research participants, which survey questionnaires do not permit. These are complex social problems with no easy answers or solutions and it is important that there can be discussion and reflection on our experiences together and hopefully this can also be with policy makers and legislators, so they might better appreciate the impact of their policies.

The co-production model used by the SCIE in their recent project on mental health of children in care, including adopted and special guardian children was one we considered helpful as a way of working together, depending on how it is implemented, and it felt very positive that we were considered 'experts by experience'. We were pleased to have been able to have been given a consultation with the SCIE, although this was after the final report was written and we were thus not able to feed into the report. Our consultation can be seen on the SCIE website.

<https://www.scie.org.uk/children/care/mental-health/findings/adopters-together-summary>

We see this survey as a starting point to developing much needed research. We would also like to see our research leading to or feeding into the development of some sort of practice based evidence for the Adoption Support Fund.

We draw attention to the fact that research on adopter's experiences and views of their support is lacking<sup>18</sup> particularly in regards to the Adoption Support Fund, whilst we could find no research at all on the experiences of Special Guardians of their support.

We are also not in a position to continue alone (most of this report was written by one person, the chair of Special Guardians and Adopters Together), and support is felt to be needed to progress the analysis, and evidence synthesis, with the volume of qualitative data our survey has generated.

Many of the interventions the Adoption Support Fund pays for have a poor evidence base, or interventions have not been tested on adopters and special guardians in the UK context. However, a lack of evidence does not equate with a lack of effectiveness. This is where practice based evidence can help inform decisions about what the Fund should pay for, and which providers are considered to be of most help. We need a better understanding of what service users find beneficial in regards to the Fund, and what we experience as helpful. We also need a better understanding of 'effect modifiers' – these are aspects of educational, social or therapeutic care interventions that can improve uptake and success. The evaluation of complex interventions is different from a simple intervention. Consideration could be given to component efficacy for complex interventions and in this regard, process evaluation methods can be very helpful – looking at what factors support the

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<sup>17</sup>We are meeting with the Chief Social Worker for Children and Families on 7/3/18 and hope we might discuss funding to complete our analysis with the research partners.

<sup>18</sup>We could only find one small questionnaire study (N=20) by Benfield (2017), who concludes that larger studies, such as ours, are needed. We note with some disappointment tone of the 4 LAs contacted by Benfield assisted with recruitment of participants. Benfield concluded that timely effective support and training, and changes in approach along with attitudinal shifts (listening to concerns without judgement or blame), towards adopters, rather than policy change, would prevent children re-entering care and would not involve additional resources.

**intervention to have successful outcomes – or impede it. There is no reason why such research could not be conducted with or by recipients of the Fund.**

**The advantage of peer led research such as this survey, is that it enables issues that service users' concerns and experiences to be the central focus of investigation. There are significant power disparities for us as parents and guardians with those who support, assess and even research us<sup>19</sup> and having our voices heard is not without challenge, because of our need for anonymity and confidentiality – especially in respect of the children we parent and care for.**

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<sup>19</sup>Benfield who was trying to conduct 'emancipatory' research follows Selwyn et al (2014) in his use of the term 'disruption' pre and post the Adoption Order. Researchers seem unaware of the possibility for detrimental impact of this term on those they research in terms of causing distress or preventing efforts being made to reunify children with their families and we feel it would be beneficial for others to work with us in a more collaborative way. Their use of the term 'disruption' is used as justification for others, notably the BBC's recent File on 4 team who we asked not to use the term before they went ahead with a questionnaire that used the term – justifying their usage and dismissing our concerns on the basis that Selwyn used the term and there was no 'intention' to cause harm or distress. Many adopters, it seems, are unaware that the term disruption should technically only be used pre the Adoption Order being made and use the term themselves – such is the level of power imbalance in modern UK adoption. The term is imposed and those that feel upset by it for very good reason, because of the detrimental impact its usage has on them and their children, cannot have influence. We discussed this issue within our group and decided we would like the scenario of an adopted child re-entering care to be known as just this – 'a child re-entering care'. This was before Special Guardian's joined our group and it may be that this more neutral and technically accurate description is not acceptable to Special Guardians as they come on board – but we cannot imagine they would wish to be described as 'disruptions', 'breakdowns' or 'failures' or made to feel their care was the reason for the child needing to be accommodated when many SGs face similar challenges to adopters, and they must care for children with significant needs, and face many challenges.

## Suggestions for Improvements

This is an interim report and as such we feel it is too early for recommendations, especially with data analysis not being complete. We have not had time or the capacity to consider what respondents themselves believe needs to change properly at this juncture and would like to be able to reflect on this with others – with the various boards governing adoption and special guardianship locally and nationally, with other researchers and organisations, and with policy makers and legislators. However, we will struggle to take this project further without resources and support. So we feel now is the time to take stock. In our view the figures and statistics we have presented should be more than sufficient cause for concern and action. So we would like to present some suggestions for improvements. These suggestions also come from our own thinking and reflection, as a group, about the problems we face.

We put forward our suggestions in the context of the recent case of a child suicide in Powys, of an adopted child (Child A), who re-entered care at the age of 10. The young man, who lived in foster care, took his life three months before his 18<sup>th</sup> birthday because of fears about transitioning to adult life.

<http://www.bbc.co.uk/news/uk-wales-mid-wales-43049144>.

We offer our sincere condolences to his family, and parents, who it seems struggled in vain to build a positive working relationship with agencies and services for the child they had parental responsibility for.

It should not be that services that are supposed to help us, and help our children, let us down so badly as with this tragic case, or, as our survey has shown, cause us to fear seeking medical advice, lest the consequences are removal of our children because our parental capacity may be called into question and considered inadequate (Table 34). We need to be able to trust those we turn to for help when caring for extremely vulnerable children and young people. We need assistance, empathy and support when we are under extreme duress, dealing with issues such as Child to Parent Violence, not intrusive fear provoking scrutiny and unhelpful blame. We urge positive action to be taken to prevent future tragic loss of young life, and young lives ruined – because we could not expedite the help for them that is needed, or worse, we were blamed for causing the difficulties we flag up.

Our suggestions are described under five headings.

### Parity with Adopters for Special Guardians

Special Guardians should have parity with Adopters in terms of being able to access support from dedicated professionals and teams with specialist knowledge. They must have the same allowances to care for their children as adopters and these allowances must be agreed and put in place when the child is placed, and approved through panels. They must have parity of representation in terms of having a voice. It is arguably not appropriate for them to be represented through Adopter's Voice groups<sup>20</sup> facilitated through the charity Adoption UK, which promotes adoption, given that many will have taken on the care of their children with the threat that if they don't do this they will be taken away, never to be seen again, and put up for adoption.

#### **We suggest**

1. Consideration is given to how parity can be achieved for Special Guardians with Adopters.

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<sup>20</sup>The only way that adopters can feed into boards under 'Vision for Change' is via an Adopters Voice group. These groups are not always accessible to parents and there have been issues with their inclusivity, which have been raised with the Charities Commission after they were not able to be resolved with Adoption UK, but not investigated by the Commission.

2. Consideration is given to how the views of Special Guardians may be heard by the Regionalisation Boards and by the Departments of Education and Health

Crisis prevention and minimisation of damage following crisis, instead of viewing us through the 'prism of risk'<sup>21</sup>

Families where children are at the edge of care such as ours need a fundamentally different model and working approach to the risk minimisation approaches used for parents who present a risk of harm to their child through abuse and negligence. Our children also need different and more supportive legal frameworks. A less adversarial approach is needed.

**We suggest:**

1. A review of legislation and legal frameworks for when our children cannot live with the family for reasons of safety – we need legislation developed to meet the needs of our families. A review of the age when the Special Guardian Order ceases – this Order could also be permanent. This could help our children in their transitions to adult life and would serve to give Special Guardians a better sense of security. It is wrong that there is a fear of seeking help from a GP for the mental/emotional duress that arises from the parenting/caring role – and this fear is greater in Special Guardians than adopters in our survey.
2. The Independent Guardian role (see below), should be based on crisis prevention and offer a 'whole family' perspective where the protective benefits of adoption and Special Guardianship can be appreciated instead of the focus on risk to the child in isolation from family. The Independent Guardian might be extended to work with children with mental health problems and disabilities.
3. Models for support and reunification should be developed for when our children cannot live safely with their families. Support should be funded by the Adoption Support Fund.

Training for professionals and services

**We suggest:**

1. A comprehensive training programme to be developed and implemented to cover the impact of emotional dysregulation issues and trauma on a child, and on family life and education. This programme should be rolled out to all services and agencies involved with children and young adults, especially those responsible for supporting where there are emotional/behavioural problems related to early life adversity, or mental health conditions where challenging behaviour is a feature of a child's presentation.
2. That there should be a new role in children's care of an Independent Guardian (not Cafcass), for every adopted or Special Guardian child, and for children not able to be cared for by their birth parents but living in a permanent family or under a permanent order. This individual would be allocated to the child at the time of placement and would support the child, and support the whole family, whether or not the child lived with the family. The Independent Guardian would be independent of Local Authorities and consideration needs to be given to professional standards and code of ethics etc. – how the role could work in practice and who would oversee these highly trained specialist professionals who would interface between therapeutic care, social care and education.

Suggestions/Recommendations for improving the Adoption Support Fund

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<sup>21</sup>See BASW enquiry on the role of the social worker in adoptions where this term was used and came out of the thematic analysis (Featherstone and Gupta, 2017)

**We suggest:**

1. That the Adoption Support Fund is renamed the Special Guardianship and Adoption Support Fund immediately and the fund is actively promoted to Special Guardians.
2. Consideration is given to adopters and Special Guardians being able to access the fund directly without the need for local authority assessment. If the Independent Guardian Role were to be put in place assessment and access could be through these professionals.
3. A formal policy evaluation of the Fund to consider if it is addressing need, which should include a health economics study to investigate potential resource savings through increasing the fund.
4. That a 'practice-based evidence' approach to evaluation is developed for the fund. We would like to help develop this. Service user's concerns must be centre stage.
5. That the Fund is accessible to all adopted and special guardian children until the age of 25, regardless of whether they are living with their families. Our children take longer to mature because of the impact of early life adversity.
6. We recommend respite is available through the Fund. This should be creatively thought about and might include funding self-organised respite and mentoring for adolescents who can become socially isolated because of trauma and anxiety issues. Breaks where children can safely spend time with siblings from whom they are separated by the care system should be part of this respite provision.
7. That there is better transparency about Local Authority expenditure on adopted and special guardian children – match funding by local authorities should be published and in the public domain. Funding for adopted and special guardian children should be protected.
8. The Fund commissions research into the development of models of whole family support and well supported reunifications following care separations, where a child can safely live with their family again.

**Improved accountability- greater transparency**

Trust and confidence is extremely poor in services. This is acting as a deterrent to help seeking and there are fears of the consequences of help-seeking and reporting, from those that are supposed to safeguard our children, and have a duty of care for permanent families. Serious thought needs to be given as to how trust might be rebuilt and maintained by the government and organisations.

**We suggest:**

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1. Consideration is given as to how the Independent Reviewing Officer could become truly independent of the Local Authority. The fact that no cases are being returned to court<sup>22</sup> suggests something is not working currently with this role. It is the lack of 'independence' from Local Authorities that is the issue rather than the role itself, which is potentially vital as it allows reflection and consideration about children's needs with all involved, and care planning for them. It also allows agencies to come together with those with parental or care responsibility. The LAC review may be the only time that parents and carers can meet with social care and other professionals when they have parental responsibility for a child<sup>23</sup>.
2. Cafcass Children's Guardians and court advisers have a great deal of influence in court cases and if they take up an adversarial position to a parent or Special Guardian this can have a considerable impact on trust and relationship building as well as a significant bearing on the outcome of a case. We recommend specialist Cafcass Guardians are allocated to adoption and Special Guardianship cases with these Guardians having undergone additional training in bereavement issues and

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<sup>22</sup>See Lord Justice McFarlane's lecture in honour of Bridget Lindley page 13

<https://www.judiciary.gov.uk/wp-content/uploads/2017/03/lecture-by-lj-mcfarlane-20160309.pdf>

<sup>23</sup>If disabilities are not acknowledged by the LA, which can be the case in our experience when these disabilities are hidden or less obvious, then the child will not be considered a 'Child in Need'.

dealing with bereaved people. Bereavement training would be beneficial for all Cafcass Guardians as the removal of children, especially when this is against the wishes of the child, is a catastrophic trauma.

3. At the moment the formal complaints process is the only way that parents and Special Guardians can get their cases back on track and our report shows far too many complaints needing to be made. One issue for us is that making a formal complaint can lead to organisational defensiveness and labelling of the complainant as 'difficult' and 'challenging' to work with. Part of the problem is that the opinions of professionals are beyond the remit of the Local Government Ombudsman so negative opinions and attitudes towards parents and carers cannot easily be challenged. We recommend that the impact of being labelled as difficult or challenging on a complainant is given more consideration by those investigating complaints and these perceptions about people under great duress, trying to achieve support for their children, are not taken at face value.
4. That trust in services is used as a measure of performance and that every adoptive parent and special guardian is asked each year by the DfE / LA to rate their experiences of services and agencies involved, and the sense of trust they feel in those with a duty to provide education and care. Tables of results should be published and in the public domain.
5. Data from each LA should be published by the DfE on the legal status of children coming into their care – in this way accurate figures can be obtained about adopted and special guardian children that re-enter care and the numbers of children that return to care under Section 20 or other Orders such as Section 31 – for each Local Authority. This information should be collated by the DfE, and in the public domain – with clear information about which authorities are not providing data for the public.
6. The Regionalisation Boards and the Adoption Leadership Board should find ways to reach out to Adopters and Special Guardians to input and provide feedback in ways that are empowering and build confidence, perhaps using co-production methods and considering us as 'Experts by Experience'. There must also be learning from negative cases so any case of a child re-entering care needs sensitive consideration to reflect on what might have prevented this. Counselling should be provided in such cases for all family members through the Adoption Support Fund.
7. Greater transparency is needed about what goes on in Board meetings (Adoption Leadership Board and Regionalisation Board) and we recommend that the minutes should be publicly available.

## Concluding thoughts

**In conclusion we hope our efforts to better understand the stresses of the adoptive parent and special guardian role will be appreciated. We hope that our suggestions will be given consideration, and funding support might be given to help us take this project to the next stage with research partners.**

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