

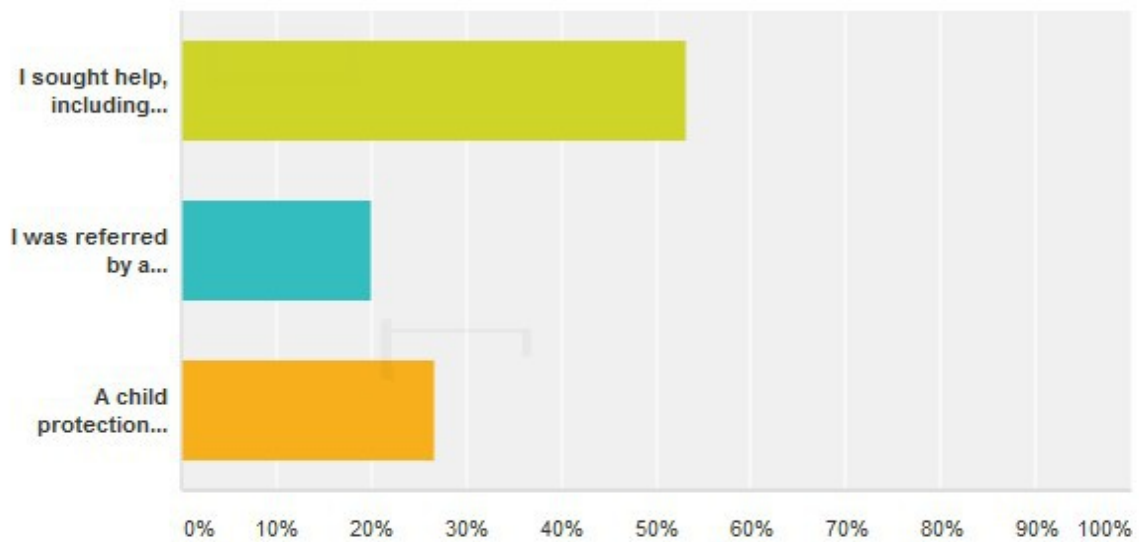
Planet Autism - Interim Results of "Autism Parents Survey on Social Care Experiences"

<https://www.surveymonkey.co.uk/r/B7239W3> Survey is ongoing, these results are compiled from a current total of 16 respondents.

Question 1

How did you first come to have contact with social care?

Answered: 15 Skipped: 1



Answer Choices	Responses
I sought help, including respite care and support for my child/ren	53.33% 8
I was referred by a professional such as teacher or healthcare worker	20.00% 3
A child protection referral was made	26.67% 4
Total	15

Analysis:

Out of only 15 respondents almost 27% were involved with social services through child protection referral. This is unacceptable, if it was on the basis of suspected abuse or neglect due to autistic traits being misunderstood. There are a significant number of families where a parent is also autistic and may be undiagnosed and completely misjudged or [discriminated against](#) by social services.

Significant Respondent Comments

"Referral for [allegation of FII](#)."

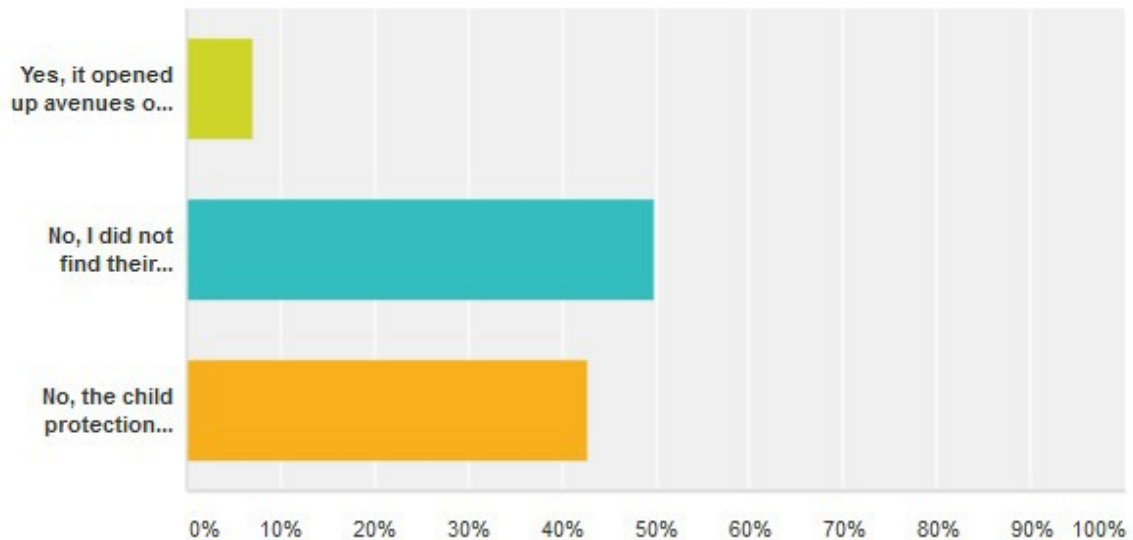
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Question 2

Were you pleased about having social care involvement?

Answered: 14 Skipped: 2



Answer Choices	Responses
Yes, it opened up avenues of support and respite	7.14% 1
No, I did not find their involvement helpful and they did not understand autism	50.00% 7
No, the child protection referral was unwarranted and based on false accusations/lack of autism awareness	42.86% 6
Total	14

Analysis:

A staggering **92.86%** were not happy with social services involvement. This was either because in almost half of the cases it was due to [unwarranted child protection investigations](#) and in the other half, it was worthless as families did not receive appropriate support or understanding of their child's disability. With social workers [not taking up autism training](#) and no mandatory requirement that they do so, families are being incredibly failed.

Significant Respondent Comments

"But help was short-lived and only involved about 3 meetings and we have now dropped out of the system as the social worker left.", "I was pleased but the child with disability team just passed it to child in need team who made no provision.", "Support refused in England but we got in Scotland, pathetic amount but least we got some.", "Mixed really. Initially very relieved, but as time went on I became more and more concerned at the lack of awareness/modification of processes to take account of my son's autism."

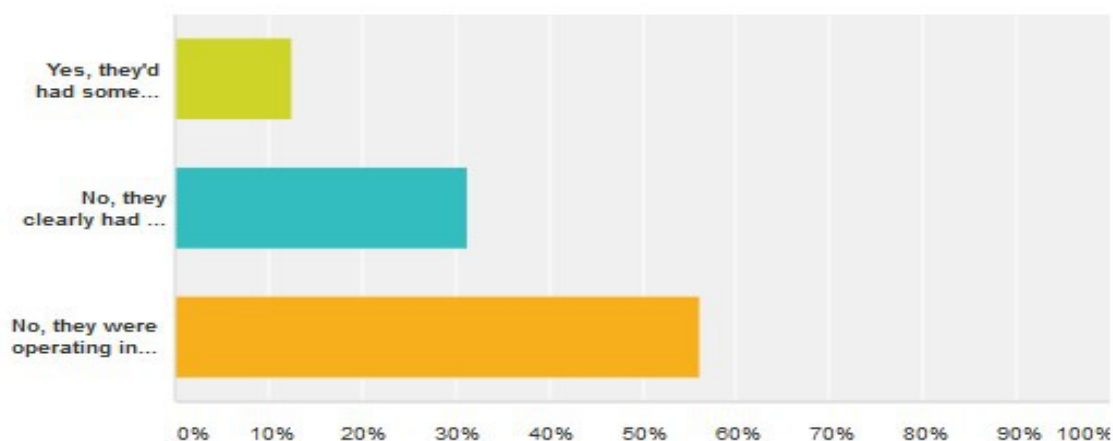
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Question 3

Did you feel the social worker(s) you had contact with were understanding about autism?

Answered: 16 Skipped: 0



Answer Choices	Responses
Yes, they'd had some training and were sympathetic to the difficulties of parenting an autistic child	12.50% 2
No, they clearly had no training and their input was counterproductive and stressful	31.25% 5
No, they were operating in a blame culture and fault-finding my parenting, saying the autism traits were attachment problems/falsefully accusing me of child abuse or neglect	56.25% 9
Total	16

Analysis:

In only 12.5% families experienced autism-aware social work involvement. This is appalling. Social care is supposed to be there to meet the needs of people and provide appropriate support for them – how can this be done if they don't understand the neurology of the children (and families are at high risk of misrepresentation if their children are undiagnosed due to NHS and other service failures) and are wasting public resources on blaming and [wrongfully investigating](#) parents? Parents stressed by this culture are even less able to cope with their children's difficulties.

Significant Respondent Comments

"Medicalising my son and if he went in foster care he would be back in education within 2 days. They were not involved for the first 11 months."

"I feel I've had to train everyone who have contact with my PDA child in Scotland, some resort to typical ASD type training which does no good whatsoever. It's been 3 years of hell up here!"

"Sympathetic as individuals but they were pretty powerless to change a whole culture that ignored autism as an issue."

False accusations are a handy weapon for social services who don't want to provide resources!

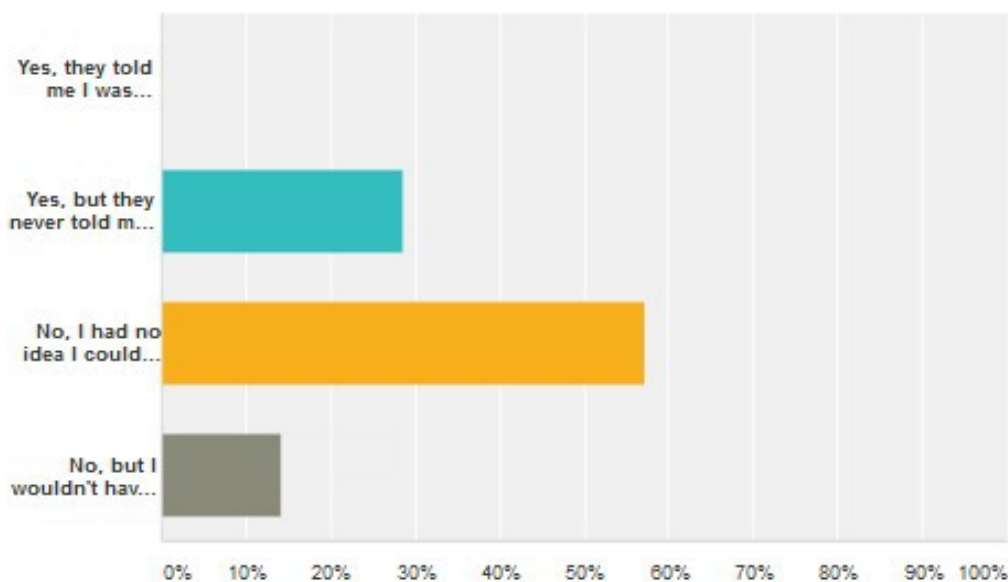
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Question 4

Did you have an assessment of need as a parent carer of your autistic child/ren?

Answered: 14 Skipped: 2



Answer Choices	Responses
Yes, they told me I was entitled to one and it generated respite and additional supports	0.00% 0
Yes, but they never told me I was entitled to one and even though I was in need they said there was no funding for supports	28.57% 4
No, I had no idea I could have one	57.14% 8
No, but I wouldn't have wanted or needed one	14.29% 2
Total	14

Analysis:

Clearly authorities are playing the same old game of hiding (not making the information available unless someone finds out to ask for it – a well-worn ploy among services) what they are entitled to, so that they can by design restrict numbers of applicants and withhold resources from families. This means vulnerable [children in need](#) are not receiving support and parents are struggling along without respite.

Significant Respondent Comments

"They told me my daughter was not disabled and I was not a carer. Repeatedly."

"No, none was offered as my child was classed as and adult at diagnosis." (this breaches the Autism Act 2009)

"Now statutory in Scotland but they don't tell you and took over a year to get 1, then got sod all carer component, both me and child have care needs so respite is paramount!"

"We had previous bad experience with SS when we did request help ending in one SS worker being struck off."

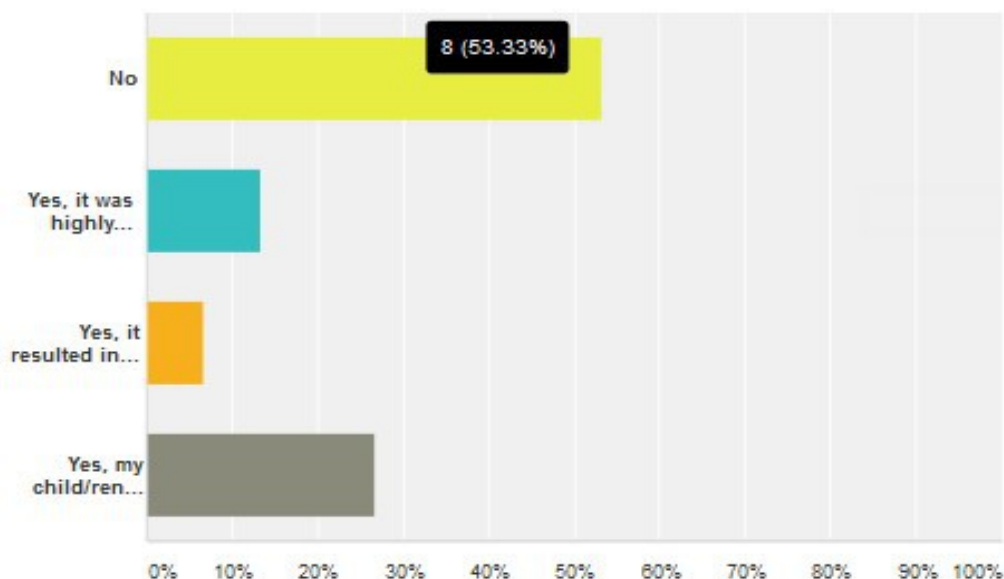
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Question 5

Did you have a Section 47 child protection inquiry raised?

Answered: 15 Skipped: 1



Answer Choices	Responses
No	53.33% 8
Yes, it was highly stressful, there was no cause for it and I was kept out of the loop until it was resolved	13.33% 2
Yes, it resulted in removal or threatened removal of my child/ren	6.67% 1
Yes, my child/ren was/were fostered/adopted/in care due to their misunderstanding/misrepresentation of autism in my child or myself as a parent	26.67% 4
Total	15

Analysis:

So almost half of respondents had a formal Section 47 child protection investigations undertaken against them – this is another shocking statistic. Having autistic children, is leaving parents vulnerable to such far-reaching misrepresentation and misunderstanding. Heartbreakingly, one parent has had their child taken. A judgmental and fault-finding attitude by social services is **not** helping families, it is traumatising them!

Significant Respondent Comments

"Recently referred to Children's Reporter (similar thing). Reporter threw case out."

"CAFCASS SW not LA SW. Abusive ex and CAFCASS abused me in private family defined contact court case."

"We were unaware of it until the police arrived."

Social services referrals are [meant to be transparent](#) UNLESS there is a serious risk of harm to the child/ren or the referrer. This means [parents must be told](#)! Unfortunately, many LAs are abusing this and not telling parents. How can the record be set straight or correct paths followed, without transparency?

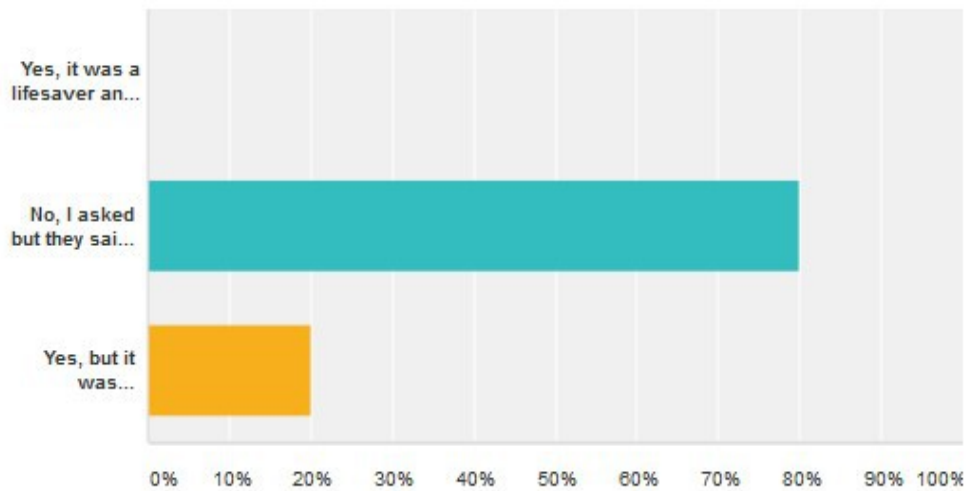
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Question 6

Did you get respite care offered by social care?

Answered: 10 Skipped: 6



Answer Choices	Responses
Yes, it was a lifesaver and enabled my child to have some fun and me to have a break	0.00% 0
No, I asked but they said our needs were not great enough	80.00% 8
Yes, but it was inappropriate respite care and caused more problems than it resolved	20.00% 2
Total	10

Analysis:

So not a single parent was offered suitable respite care! Of the 20% that were offered respite, it was clearly problematic. Those looking after autistic children on behalf of their parents must be autism trained or it causes more problems than it solves!

How are autism parents supposed to cope and have their own wellbeing addressed without any respite? How are their children supposed to have opportunities that they might otherwise not have, without respite?

Without respite and other supports being provided for autism families, they will crack under the strain and then social services will, instead of supporting them, be penalising them and potentially removing children. It should not be that families hit crisis before help is offered!

Significant Respondent Comments

"It was supplied under Sec 20 and ended up being a gateway into care proceedings."

"Inappropriate respite only offered 1 time."

"4hrs is pretty pathetic."

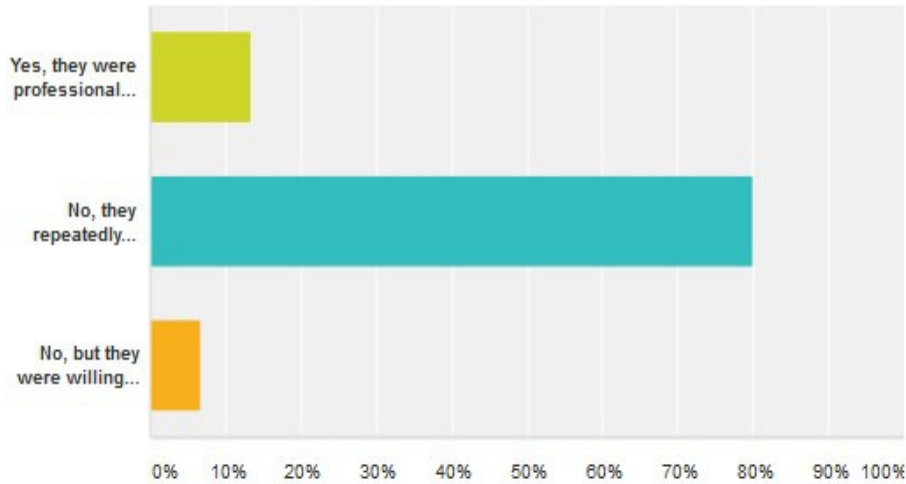
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Question 7

Did social workers know how to engage with and understand your autistic child/ren?

Answered: 15 Skipped: 1



Answer Choices	Responses
Yes, they were professional and kind and bothered to ask me about my child/ren's needs and work with me	13.33% 2
No, they repeatedly expected my child/ren to behave as neurotypical children behave and did not understand their needs or ask me for my parental expertise	80.00% 12
No, but they were willing to learn and read up about autism	6.67% 1
Total	15

Analysis:

So the vast majority – 80% - encountered entirely autism ignorant social workers, who were tasked with understanding and supporting the family's needs! Some very worrying comments below.

Significant Respondent Comments

"At that time we didn't have an autism diagnosis. With hindsight it was obvious and the only positive input they could have had was to spot this. But they didn't."

"No, they banned me from meetings because I 'kept butting in', and denied my daughter had autism."

"No concrete support was offered, no talking therapy for my daughter or ourselves - felt ditched."

"I gave them all the info and links to PDA, told them anything they knew about typical ASD to forget it when with my child."

"They interviewed my children without adult or advocate being present."

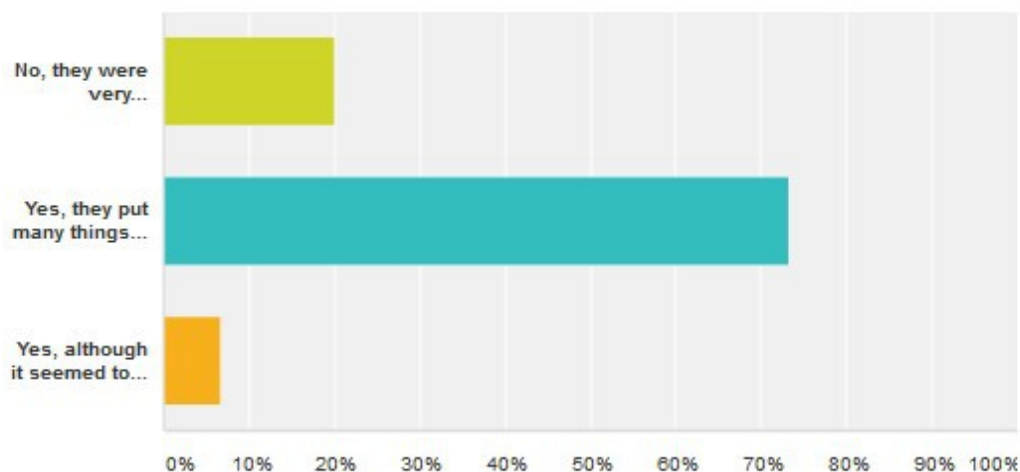
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Question 8

Did you have a bad experience with social workers putting lies in reports or on file about your parenting or your child?

Answered: 15 Skipped: 1



Answer Choices	Responses
No, they were very professional and tried hard to understand our difficulties and record only accurate things	20.00% 3
Yes, they put many things that were not true in reports that misrepresented autism and my parenting and it was very worrying that they had the level of control they did and the power to cause problems because of it, they refused to change anything that was incorrect	73.33% 11
Yes, although it seemed to be genuine misunderstanding and when I pointed it out they were happy to amend it	6.67% 1

Analysis:

Almost 3/4 parents have reported social workers lying on record (which this author has also experienced). This is disgusting and sadly, another endemic problem. Only honest social workers should be in the job, it is very damaging as these lies are taken as gospel truth by every other professional the family encounters and the power social services have to destroy families, means that such lies are not harmless words. These words carry enormous consequences. It is not only the parents that suffer due to this, the children social services are meant to support suffer terribly too.

How can any family have faith and trust in social services let alone families with disabled children?

Significant Respondent Comments

"Although the social worker was a very nice person she was totally clueless about AS, came up with some totally useless ideas, had no understanding of anxiety, sleep deprivation. When she left, said no one else to take on case, could not offer anything else as child could not engage with Autism Initiative."

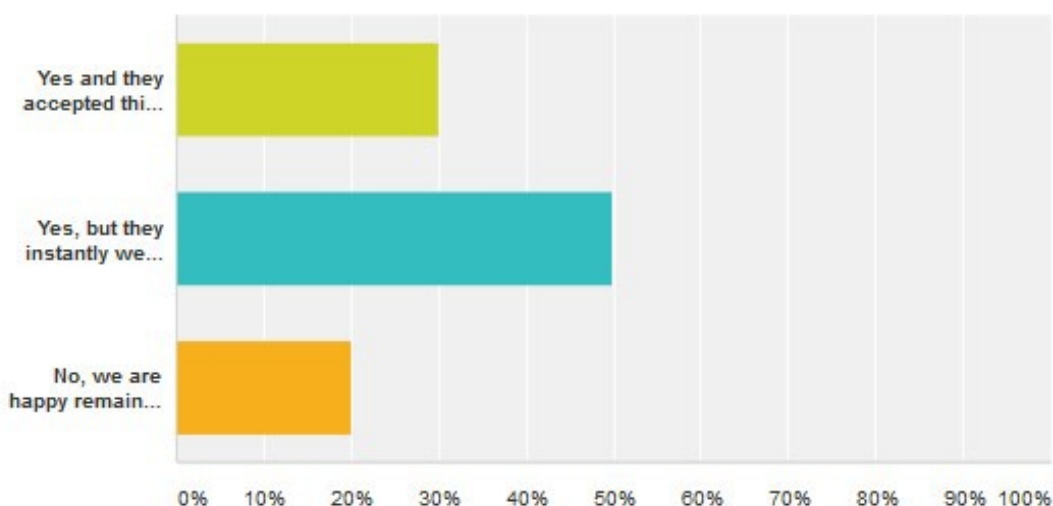
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Question 9

Did you choose to cease your connection with social services?

Answered: 10 Skipped: 6



Answer Choices	Responses
Yes and they accepted this and closed the file	30.00% 3
Yes, but they instantly went into child protection mode and made our lives very difficult, without any cause	50.00% 5
No, we are happy remaining engaged with them for the foreseeable future	20.00% 2
Total	10

Analysis:

So half of all parents found, that when they declined further 'services' from social care, they didn't want to relinquish their hold! This is a case of social services overstepping boundaries and if parents are struggling, it should be that support is offered, not punitive controlling and initiating of child protection measures. Some families are easy targets for social workers, whilst all the Baby P's, Daniel Pelkas and Victoria Climbié are desperately failed, resources are being wasted on critically micro-managing the innocent families who are being denied the right support.

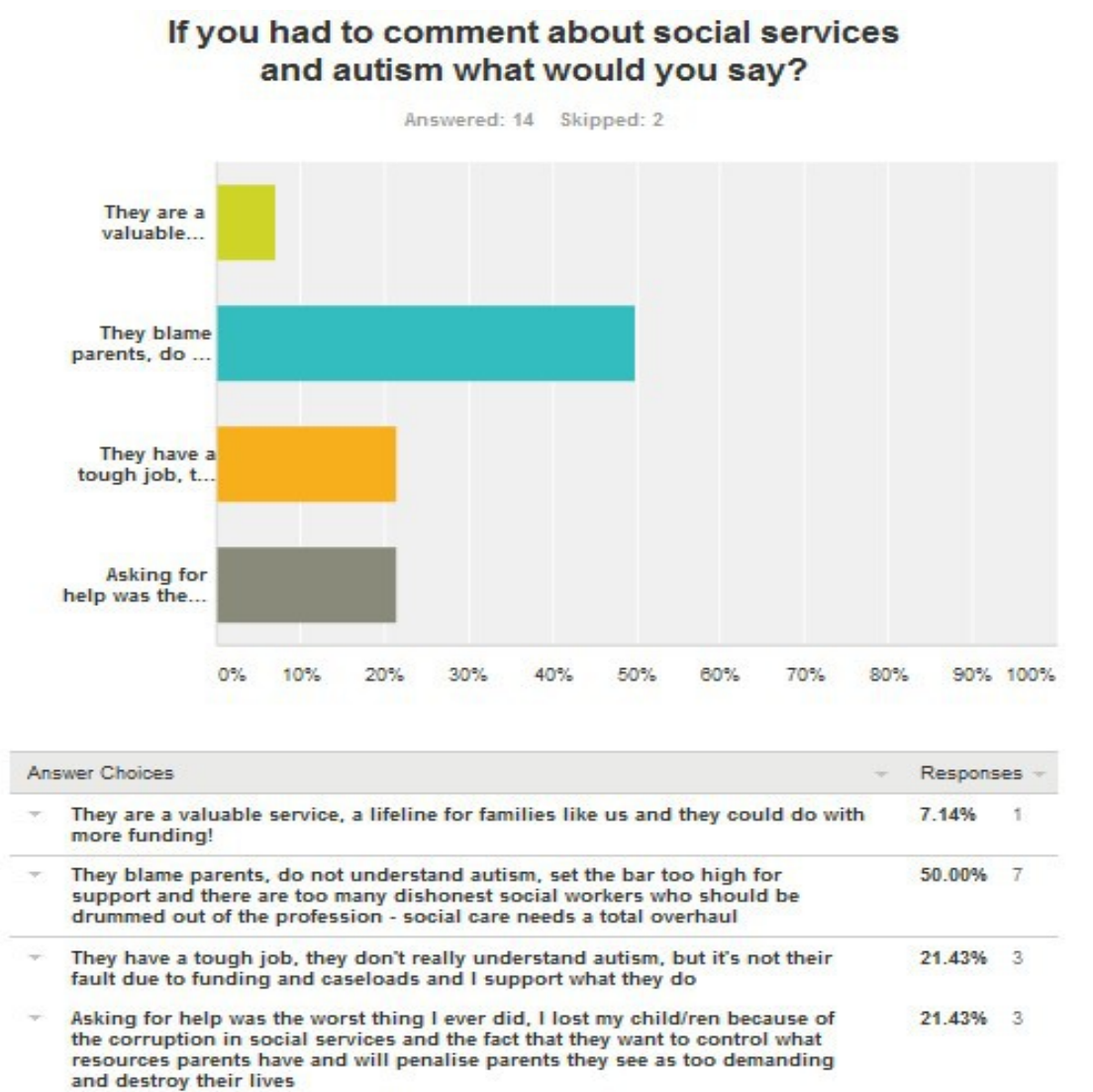
Significant Respondent Comments

"Abandoned once she left. No support given for second child or me, mum.", "Only after we had jumped through useless hoops to appease them.", "I requested different social worker.", "It was a CAFCASS SW LA SW.", "I did not cease services but they went into CP mode anyway.", "But the social worker left and no one filled their shoes so there was no further support and we were told case was closed. Fearful of the future.", "Yes, because the only support was with parenting and no direct support to my son.", "No I had no choice and being autistic myself I was labelled a bad parent because according to my LA autistic people are selfish and void of all emotion, I was labelled too autistic to be a parent but not enough to have any support and it has distorted my life, the social worker constantly triggered my son's meltdowns and blamed me."

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Question 10



Analysis:

Almost 72% of parents believe that social services do not understand autism and some have lost their children as a result of their involvement. This is unacceptable on every level. Do autistic children's lives not matter?

Significant Respondent Comments

"I think some are burnt out and dangerous because of it."

"They need training!"

"I am at risk of losing my children because of inadequate investigation and false accusations from GOSH."

A significant number of parents contact support groups regarding great Ormond Street Hospital. They appear to have garnered a reputation for falsely accusing parents of MSBP/FII, abuse or neglect and resulting in the most traumatic interventions for families of autistic children.

Conclusions

Social services is unfit for purpose when it comes to neurodevelopmental conditions. The autism training that is

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out there is not being taken up and families – including the children – are suffering as a result.

Social services should be a welcome addition into an autism family's life, a source of relief and support, not a traumatic and stressful, overbearing dread. Support should be honestly assessed and given where needed. Even if not enough is there in the pot to give all families, shared out a little bit each could make some difference for people. Why aren't LAs petitioning the Government for more funding so they can perform their duties adequately? Why is the status quo accepted? How much financial mismanagement is going on within councils? Agency social care staff cost a fortune (£70m extra p.a.) and this is money that could be spent on autism families!

Autism parents are entitled to an automatic assessment of needs being offered. Why is this not happening? All autistic children are considered in law, as Children in Need defined in Section 17 (10) of the Children Act 1989 and this makes them eligible for support.

The blame culture that exists has to be stamped out. These autistic children are tomorrow's adults and must be supported now and their families respected and valued for the amazingly hard job they do.

How is it helping, to destroy and traumatise families with false blame? Someone has to pay for the care of autistic children who are taken and it should first and foremost be their families who care for them, as it's by far best for them and it's far cheaper for the state! The state should be supporting those families with respite, understanding, signposting to other professionals that can support and help.

It is established that autism parents have stress levels equivalent to combat soldiers – without social services doing their job and providing support for these parents, they will be responsible for their health breakdown and in the longer term that costs far more to the state.

The Government must make autism training mandatory for social workers. Until it is mandatory they will not bother to do it and they will continue to fail these families. There must be accountability for social workers breaking the Data Protection Act 1998 by making false entries into files and reports. Social workers should be monitored by some form of feedback from parents being included in their appraisal system. The arrogance and misuse of power has to go. Parents should not live in fear of social services.

Until autism is understood, hysterical (*and sometimes vengeful*) child protection investigations will continue. This will continue to divert valuable resources from those who really do need child protection interventions. Sometimes at the cost of lives of others who really are being neglected or abused.

Autism parents are undervalued, unpaid carers to vulnerable children, many with very challenging behaviour and significant mental health needs. Instead of appreciating them and supporting them to continue in this role with the best health and wellbeing they deserve, social care is largely kicking them in the teeth.

Sister survey on health & education experiences here <https://www.surveymonkey.co.uk/r/G6CHB6W>