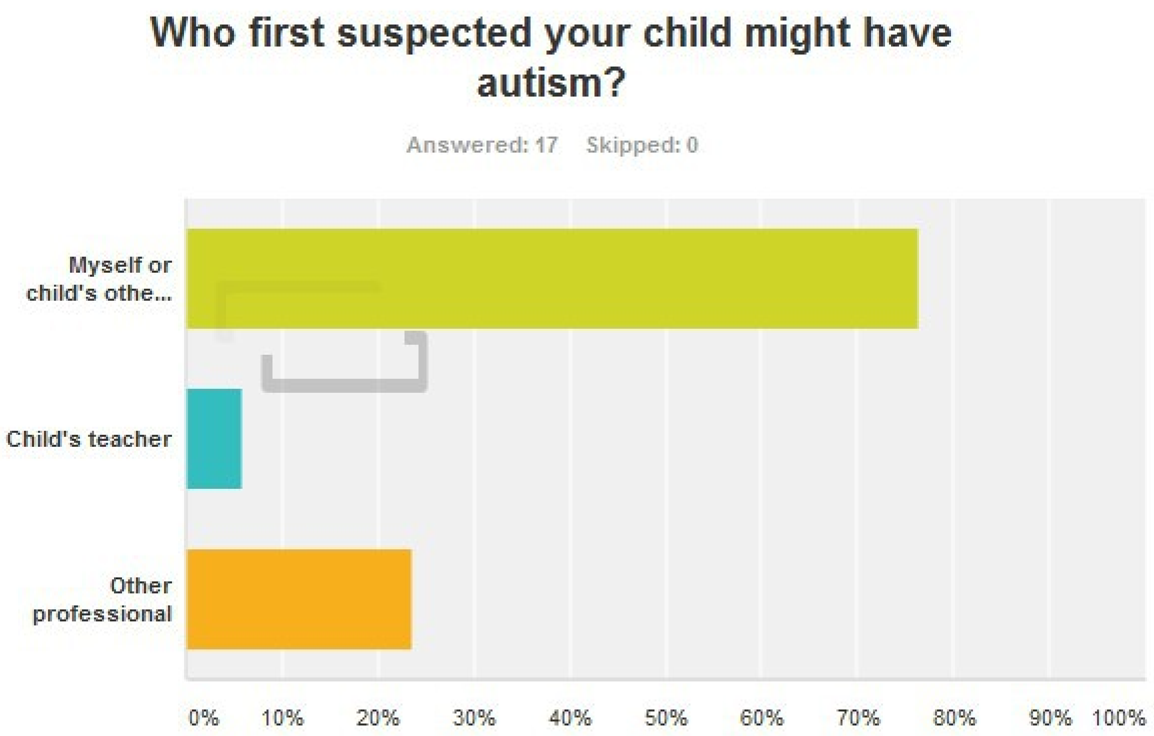
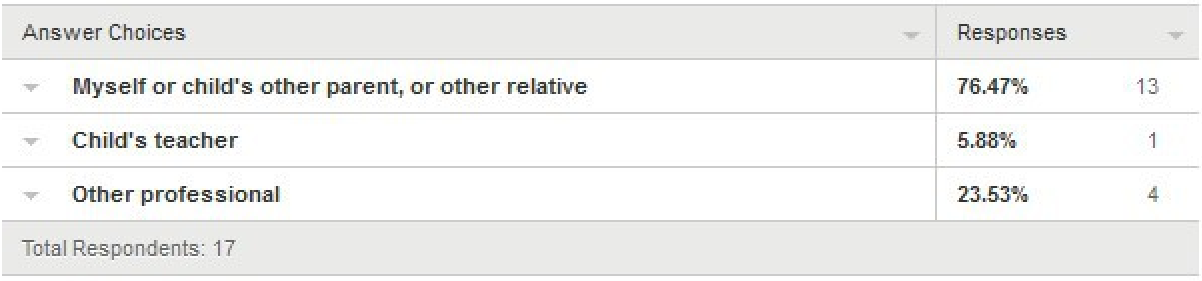
# Planet Autism - Interim Results of "*Autism Parents Survey on Health & Education Experiences*"

https://www.surveymonkey.co.uk/r/G6CHB6W Survey is ongoing, these results are compiled from a current total of 17 respondents.

Question 1





| Answer Choices | Responses | |
|---|---|---|
| Myself or child's other parent, or other relative | 76.47% | 13 |
| Child's teacher | 5.88% | 1 |
| Other professional | 23.53% | 4 |
| Total Respondents: 17 | | |

Analysis:

The vast majority are parents, who first suspected autism in the child. Notably, less than 6% of teachers were the ones to raise concerns. Considering the overall percentage diagnosed is 60%, this is *(dependent on whether the child was at school age or not)* potentially concerning. It confirms that teachers are in need of adequate mandatory autism training.

***Significant Respondent Comments***

*"Was indicated by social responsiveness scale questionnaire that was reluctantly handed out by a psychologist from CAMHS."*

When a parent experiences that a professional is reluctant, this means the parent had to ask in the first place. It's very concerning that CAMHS professionals are not proactively identifying potential autism in children and parents are having to do the detective work on their behalf!

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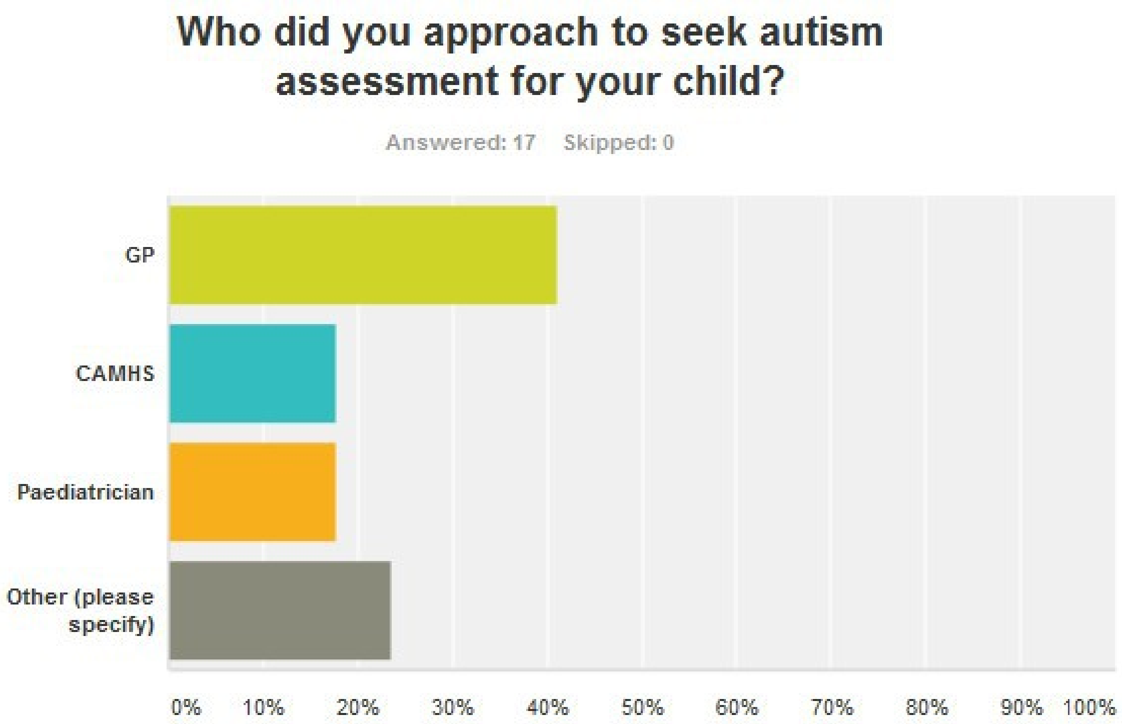
Question 2



| Answer Choices | | Responses | |
|---|---|---|---|
| GP | | 41.18% | 7 |
| CAMHS | | 17.65% | 3 |
| Paediatrician | | 17.65% | 3 |
| Other (please specify) | Responses | 23.53% | 4 |
| Total | | | 17 |

Analysis:
Approaching the GP seems to be a common pathway to first seeking assessment, so it's vital that GPs are trained and aware of their duties to refer. Some children are already involved with CAMHS at the point autism is suspected. Community paediatricians are equally as likely as CAMHS to be the initial route for requesting assessment.

***Significant Respondent Comments***

*"NAS after GP failed to help"*

GPs have for some time had access to free online RCGP autism training modules. Autism was stated by the RCGP to be a priority, but many parents have experienced ignorance and resistance from GPs. Considering that the Government states that parents are the experts in their own children and there is evidence available that doctors must listen to parents as they are the first to recognise autism signs in their child, this is wholly unacceptable for any parent to experience. Fortunately, all GPs are now receiving autism packs.

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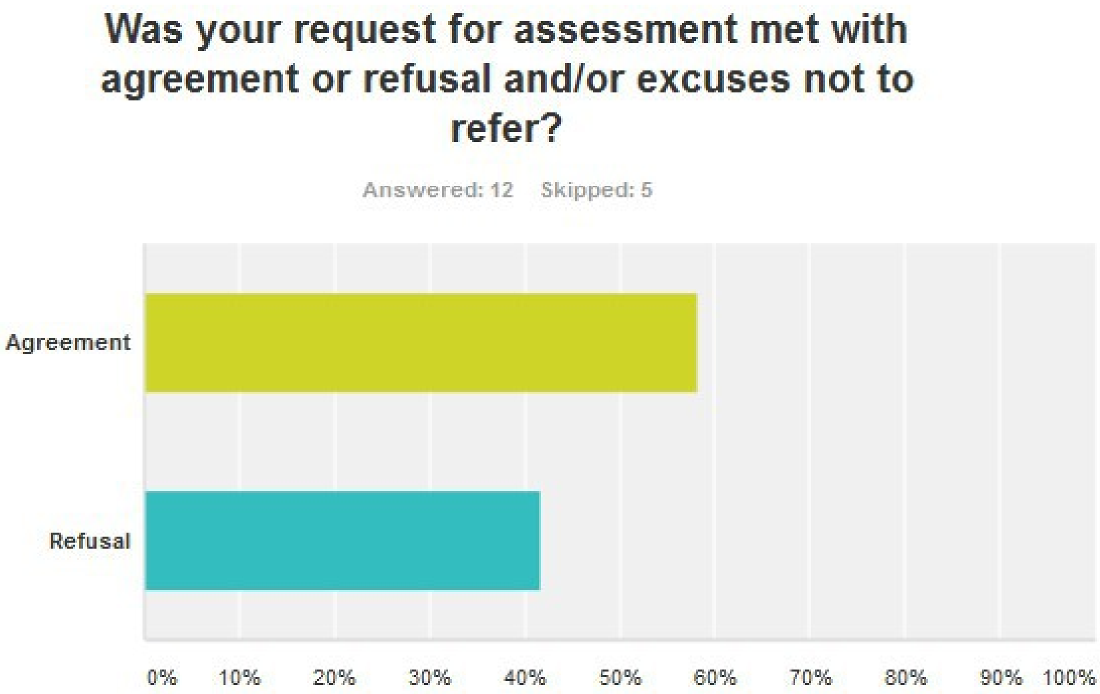
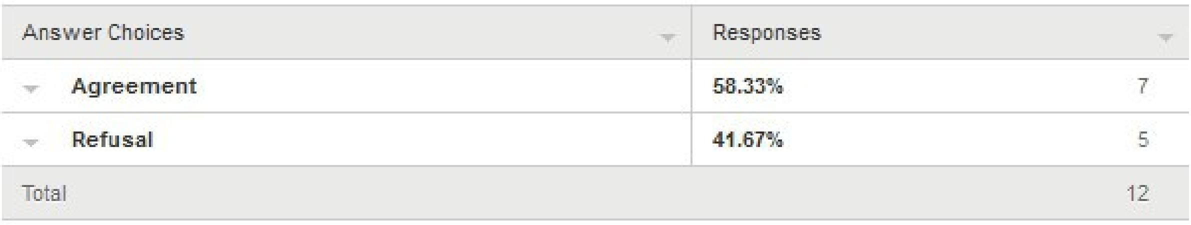
Question 3



Was your request for assessment met with agreement or refusal and/or excuses not to refer?

Answered: 12 Skipped: 5



| Answer Choices | Responses | |
|---|---|---|
| Agreement | 58.33% | 7 |
| Refusal | 41.67% | 5 |
| Total | | 12 |

Analysis:

It's extremely concerning that over 40% of parents were refused an assessment for their child. Even more so when you consider that upon assessment, 60% received an autism diagnosis, meaning that number, or **more** if there were missed diagnoses, were autistic and therefore potentially at least 20% were failed.

***Significant Respondent Comments***

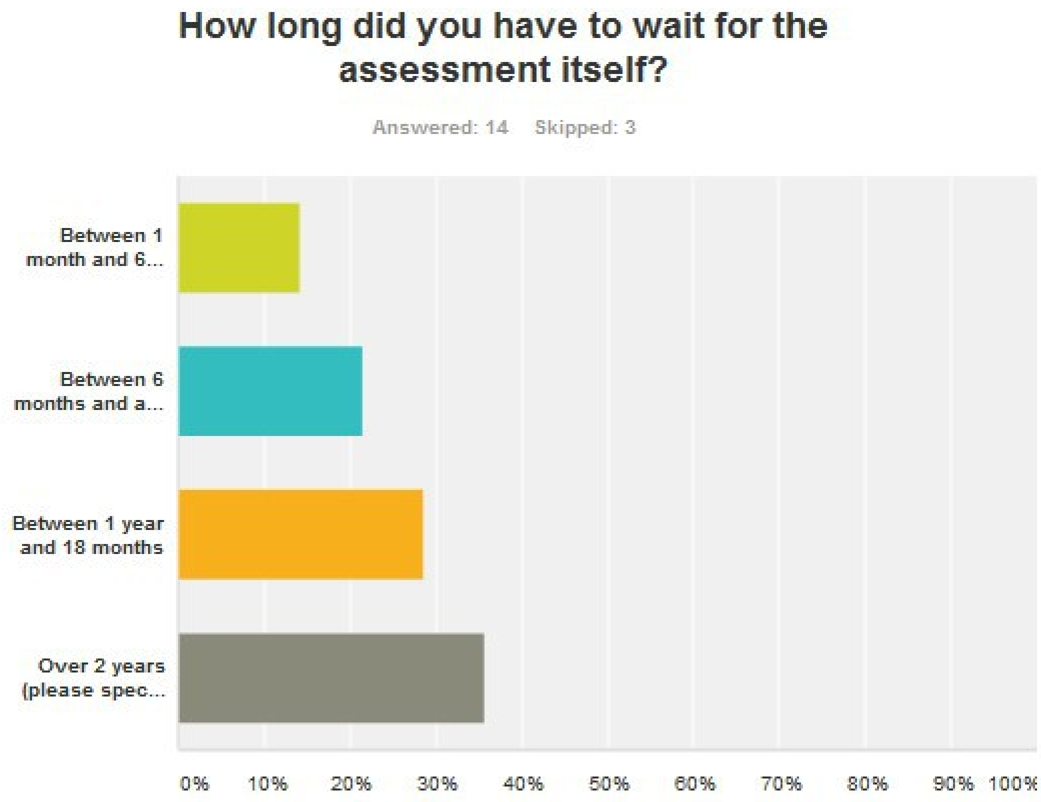
*"Excuses. Was told son was too young to be DX and that I should attend a parenting course before further steps could be taken."*

Yet more of the parent blame culture and failing to assess a potentially autistic child whilst doing so. What happened to early intevention?

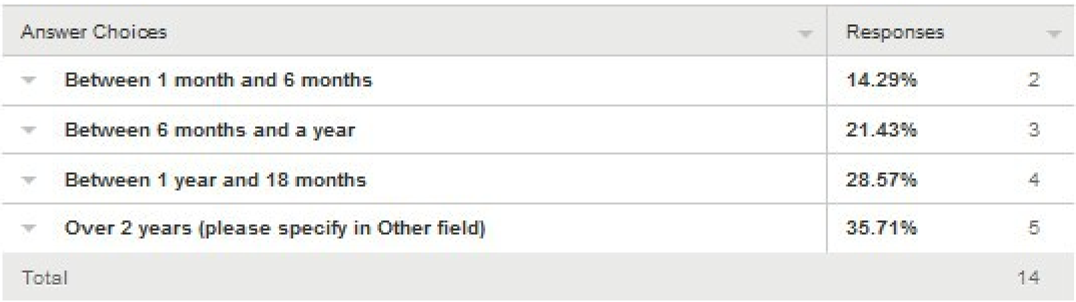
*"1st went through fine but other 2 were refused due to interventions by social services"*

Social services again, often blame parents and are by default, looking for faults in parenting. So if social services state that a parent is doing something they deem wrong, other services will listen and use it as an excuse not to assess. It's called professional bias and is rife! A sibling with autism is stated by NHS NICE Guidance CG128 to be a risk factor for a child to have autism and indication for assessment!

Question 4


How long did you have to wait for the assessment itself?

Answered: 14 Skipped: 3



| Answer Choices | Responses | |
|---|---|---|
| Between 1 month and 6 months | 14.29% | 2 |
| Between 6 months and a year | 21.43% | 3 |
| Between 1 year and 18 months | 28.57% | 4 |
| Over 2 years (please specify in Other field) | 35.71% | 5 |
| Total | | 14 |

Analysis:

The shocking finding here is that over 35% of parents had to wait **over 2 years** for diagnosis. Only 14% waited 1-6 months. Considering NHS NICE Guidance CG128 states children should be assessed within 3 months of referral, this is highly unacceptable and echoes findings in other surveys.

***Significant Respondent Comments***

*"It took 3 referrals over 5 years to get an inaccurate diagnosis of ASD"*

*"I fought since age 2-3 till she was eventually diagnosed with PDA age 6, to get professionals to take note, she was echolalic to age 5 and they did nothing till I moved to a new area, different professionals!"*

*"4 years!"*

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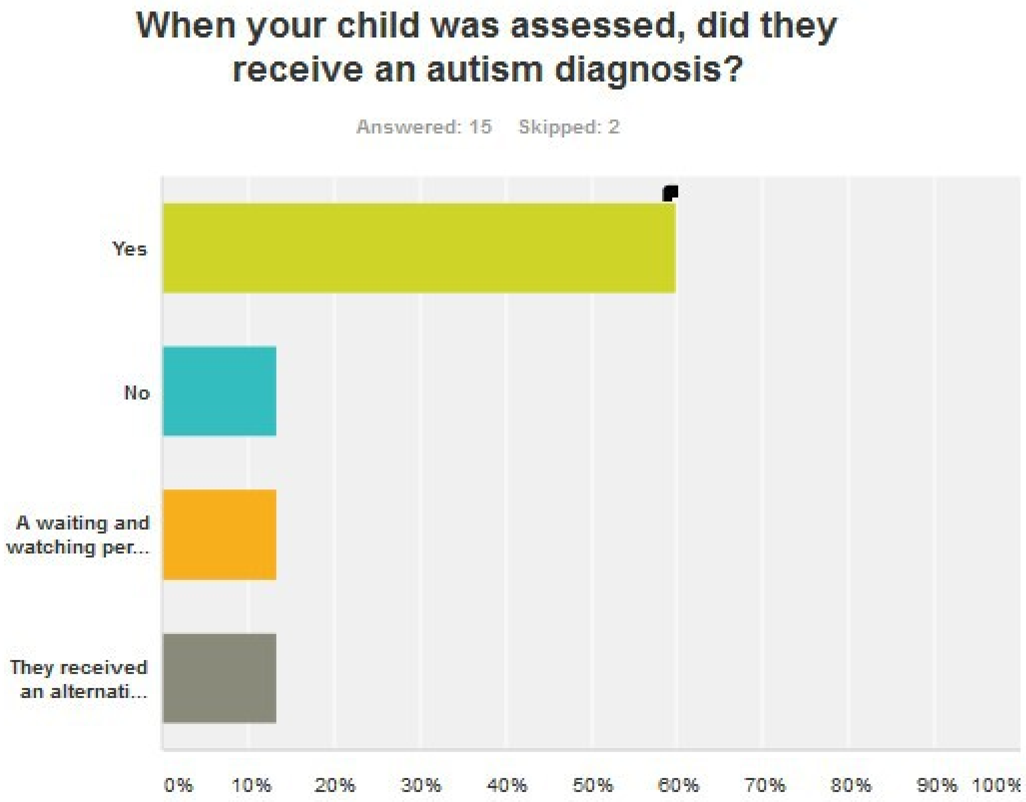
Question 5



| Answer Choices | Responses | |
|---|---|---|
| Yes | 60.00% | 9 |
| No | 13.33% | 2 |
| A waiting and watching period was recommended | 13.33% | 2 |
| They received an alternative diagnosis (specify below) | 13.33% | 2 |
| Total | | 15 |

Analysis:

Significantly, 60% received an autism diagnosis when they were finally assessed. Whilst we cannot 2nd guess whether the almost 13½% who weren't diagnosed should have been, it is a fact that the ADOS-2 is only 77% clinically accurate in "high-functioning" individuals, because it was researched on prototypical autism cases and females present differently to males, upon which the diagnostic criteria are also based. There is also anecdotal evidence that PDA subtype isn't always identified with the ADOS, as there are differences in traits and there is an extreme dearth of clinical expertise in PDA, meaning there are likely to have been a number of families sent away with the old chestnut "*not enough traits for a diagnosis*".

***Significant Respondent Comments***

*"Not on 1st assessment. Diagnosis on 2nd assessment", "No formal assessment, school suspect ASD", "Asperger's, not ADD. Now believe he has PDA. CAMHS clueless.", "1st child did but other 2 were refused", "Received atypical autism, more specifically PDA diagnosis so the dual was covered.", "I sought a second opinion - she got a DX!", "Autism with PDA and ADHD".*

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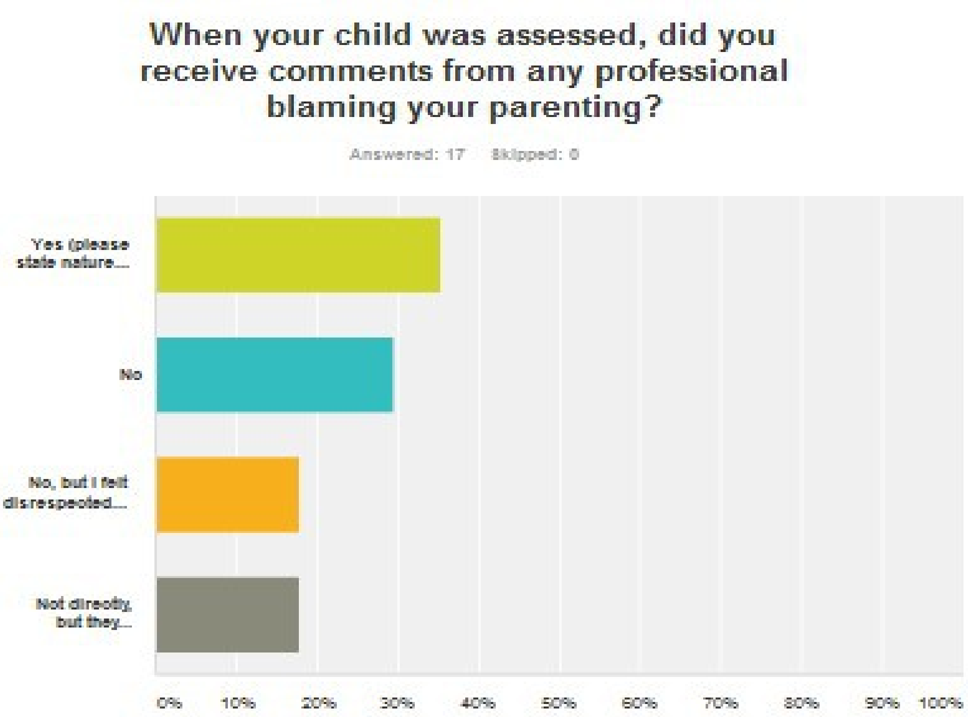
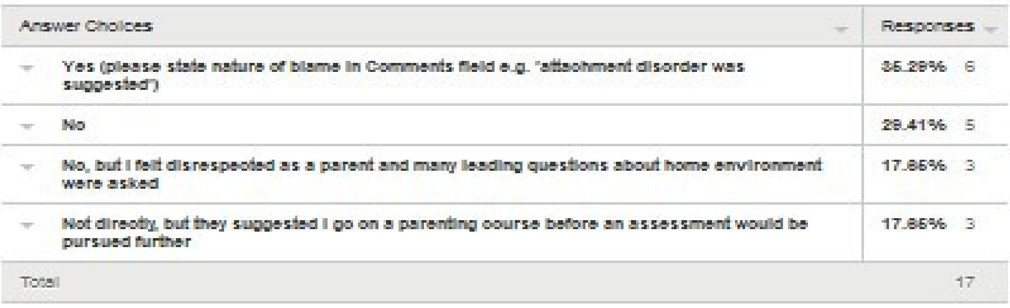
## Question 6





| Answer Choices | Responses | |
|---|---|---|
| Yes (please state nature of blame in Comments field e.g. "attachment disorder was suggested") | 35.29% | 6 |
| No | 29.41% | 5 |
| No, but I felt disrespected as a parent and many leading questions about home environment were asked | 17.65% | 3 |
| Not directly, but they suggested I go on a parenting course before an assessment would be pursued further | 17.65% | 3 |
| Total | | 17 |

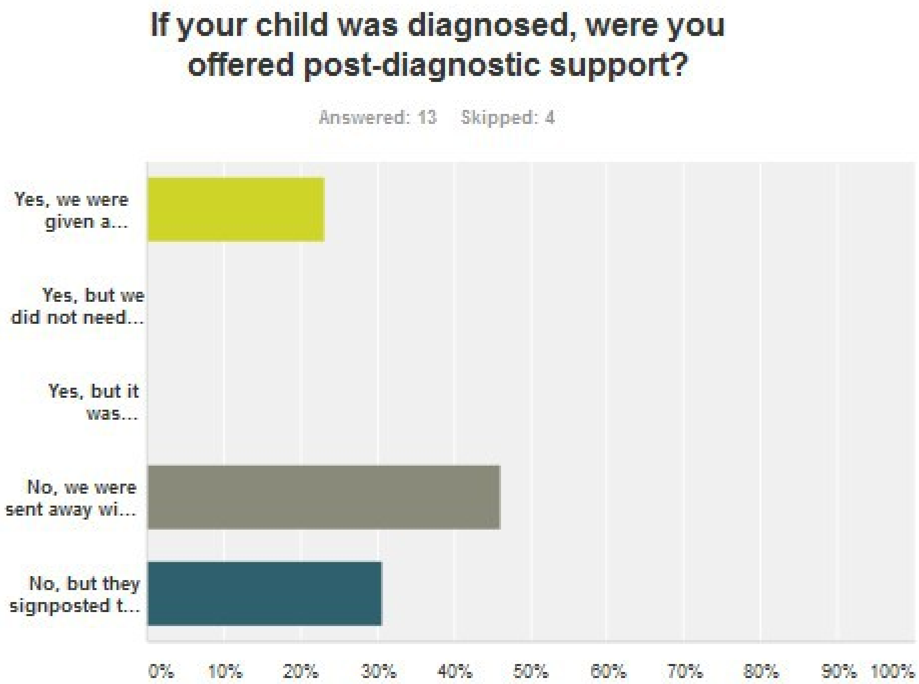
Analysis:

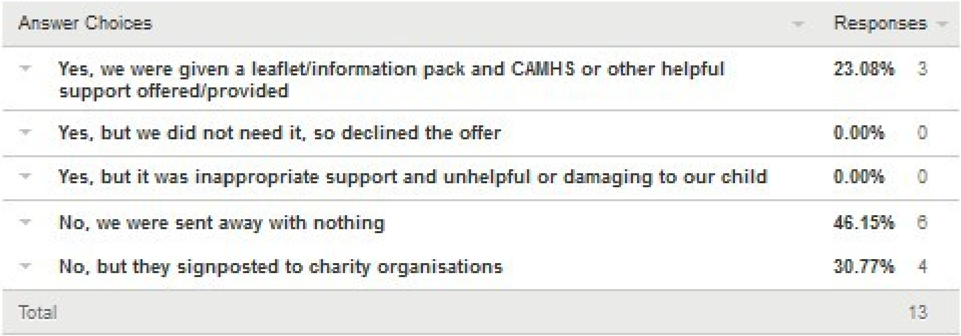
There is a worrying trend of over 70% of parents either being directly blamed or blame was implied. This culture among professionals, particularly in CAMHS has to stop. Children are being failed in breach of all legislation, guidance and ethics, that state children must have their needs met, their rights respected, early intervention to give them the best chance in life and professional duties to do their job appropriately and adequately, ignored. If parents were at fault in some way, it is ridiculous to assume they would bring their child for any sort of scrutiny and unfortunately, attachment disorder is being misused by too many professionals. Shocking how many accused of MSBP/FII and totally unethical when diagnoses are questioned – no parent can 'make' doctors diagnose autism if it's not present!

### *Significant Respondent Comments*

*"Lack of routine, lack of boundaries, altogether an ineffective parent, competitive and confrontational with child etc.", "Various damaging and libellous statement within school files. Hostility daily from school.", "Was forced on all parenting courses 1 lasting 13 weeks, even after diagnosis, had it insinuated by 2 social workers I was Munchausen's, putting it all on my child and her diagnosis wasn't real, I threw them out my house!", "Attachment, refrigerator mother, need a parenting course. I had an ASC DX and was able to (try) protect myself using Equalities Act and Autism Act. Still ongoing with new profs - very worrying.", "Social care blamed us for socially isolating our son. We are also now being blamed for suspected FII and the children are being subjected to reassessment.", "I was asked if I did everything possible to help my child after scoring 48 on cognitive functioning. Accused of fabrication."*

Question 7





| Answer Choices | Responses | |
|---|---|---|
| Yes, we were given a leaflet/information pack and CAMHS or other helpful support offered/provided | 23.08% | 3 |
| Yes, but we did not need it, so declined the offer | 0.00% | 0 |
| Yes, but it was inappropriate support and unhelpful or damaging to our child | 0.00% | 0 |
| No, we were sent away with nothing | 46.15% | 6 |
| No, but they signposted to charity organisations | 30.77% | 4 |
| Total | | 13 |

Analysis:
What is noticeable here is that only just over 23% were offered helpful support, almost 77% were **not offered** anything or were basically sent elsewhere. The state is too often using the charitable sector for providing support that they should be providing and this is fobbing people off and absolving themselves of their duties.

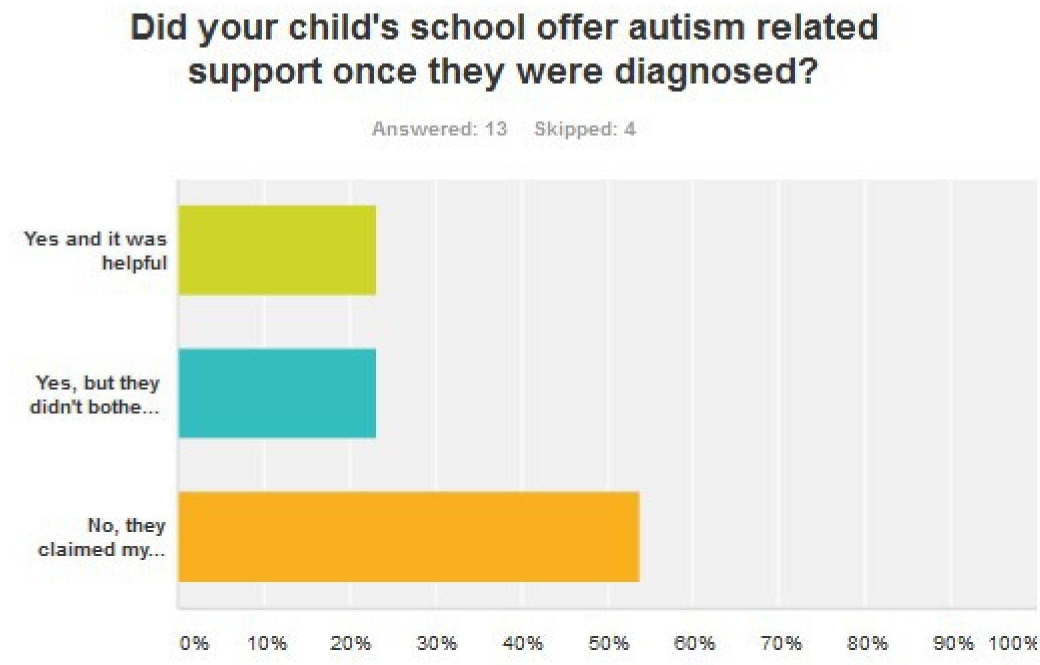
***Significant Respondent Comments***

*"Its a case of get on with it."*

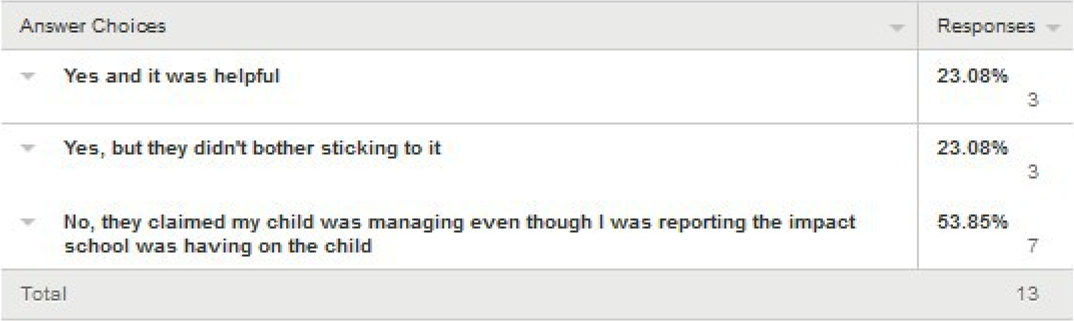
*"It wasn't really explained well."*

*"We fought the LA and won two years later."*

Question 8


Did your child's school offer autism related support once they were diagnosed?

Answered: 13 Skipped: 4



| Answer Choices | Responses | |
|---|---|---|
| Yes and it was helpful | 23.08% | 3 |
| Yes, but they didn't bother sticking to it | 23.08% | 3 |
| No, they claimed my child was managing even though I was reporting the impact school was having on the child | 53.85% | 7 |
| Total | | 13 |

Analysis:
Schools have a legal duty to provide the support a child needs to fully participate in their education and meet potential. Parents should not have to home-educate because schools fail to provide appropriate support.

***Significant Respondent Comments***

*"Referred to autism outreach with denial of son's needs and hints of child abuse at home."*

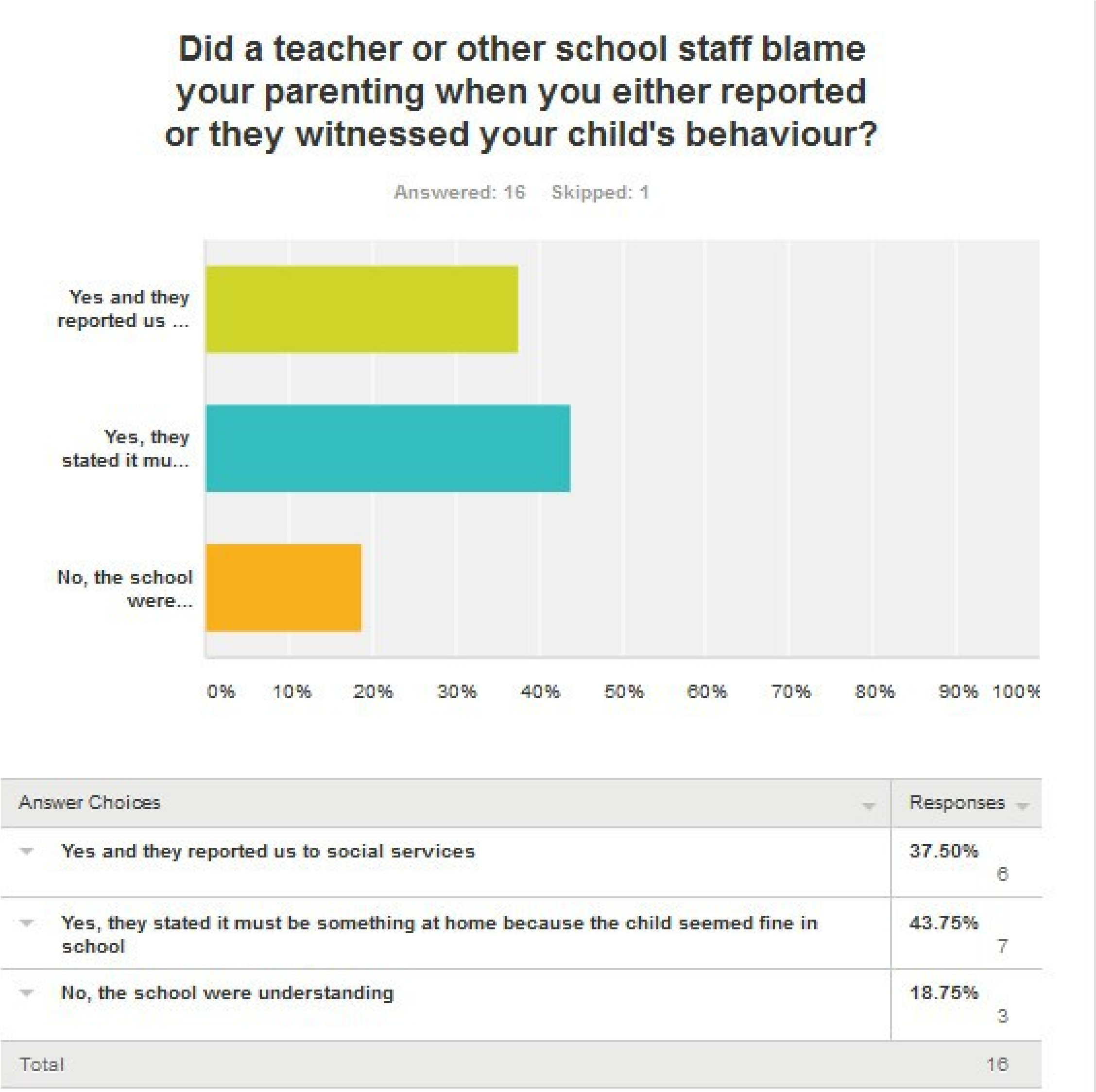
*"1st child was removed from school as school were not supportive and other 2 were pulled out and homeschooled for 2 years until appropriate school was found."*

*"Her new school North of the border are crap to say the least, total nightmare last 3 years, staff assault and abuse towards my child etc."*

*"We took our son out of school due to inadequate provision."*

*"Had no school for 12 months."*

Question 9



Did a teacher or other school staff blame your parenting when you either reported or they witnessed your child's behaviour?

Answered: 16 Skipped: 1

| Answer Choices | Responses | |
|---|---|---|
| Yes and they reported us to social services | 37.50% | 6 |
| Yes, they stated it must be something at home because the child seemed fine in school | 43.75% | 7 |
| No, the school were understanding | 18.75% | 3 |
| Total | | 16 |

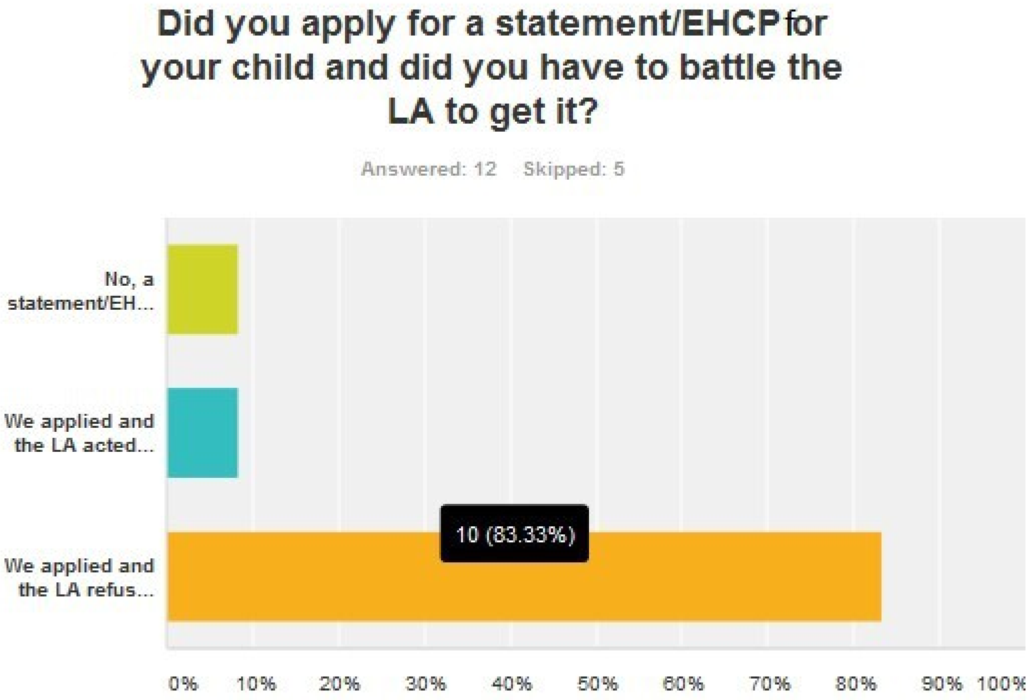
Analysis:
Only 18.75% didn't get blamed by their child's school! This is frankly appalling. It's more of the professional blame culture and most concerning is that almost 38% were reported to social services as a result of autism ignorance. If those children had not yet been diagnosed *(which is most likely to be the case, or surely schools would be understanding of the behaviour being special-needs related)* this means families will have been thrust under the social services spotlight, and faced with yet more judgment and criticism. Social services are usually not autism aware and the repercussions of their inappropriate involvement can be devastating!

***Significant Respondent Comments***

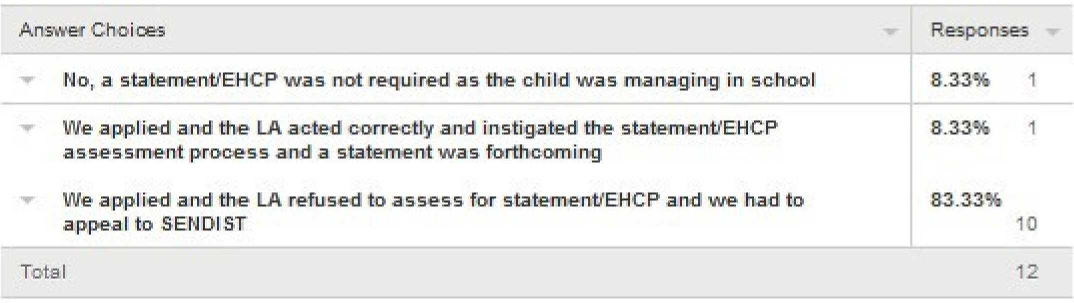
*"And also that it must be something at home."*

*"School totally clueless then lied and covered up laws being broken."*

Question 10


Did you apply for a statement/EHCP for your child and did you have to battle the LA to get it?

Answered: 12 Skipped: 5



| Answer Choices | Responses | |
|---|---|---|
| No, a statement/EHCP was not required as the child was managing in school | 8.33% | 1 |
| We applied and the LA acted correctly and instigated the statement/EHCP assessment process and a statement was forthcoming | 8.33% | 1 |
| We applied and the LA refused to assess for statement/EHCP and we had to appeal to SENDIST | 83.33% | 10 |
| Total | | 12 |

Analysis:
Another shocking statistic. The vast majority of parents had to go to tribunal to obtain a statement/EHCP for their child. This researcher has experienced and read much anecdotal evidence, that LA's refuse to assess by default. They are testing the mettle of parents to see which ones will pursue an appeal. This is shirking their duty towards children in need. EHCPs are for children regardless of diagnosis, they are supposed to be needs-based. But bearing in mind that 60% of respondent's children received an autism diagnosis, over 83% being refused for assessment for statement/EHCP, means that many autistic children’s needs are being ignored and denied.

***Significant Respondent Comments***
*"Have already lodged 3 references to ASN tribunal and currently have 4 reference loged over inadequate contents of CSP (co-ordinated support plan) as it only has 1 sentence on it 'child will attend school regularly.'", "Only IEP till 6th form. Too late for anything. Scottish Borders shocking. SNP covered up laws being broken, Council also covered up. Scotland hides behind strategies and policies. 30 years behind the times.", My daughter was too old at 18 and no help was forthcoming.", “With 1st child they said he was too old for statement and too old to place into special school (16 when diagnosis finally came through) and he's too young for adult services, so we had to find alternative educational support.”, "Was refused, school were fantastic and appealed we won. North of border not even entitled to co-ordinated support plan coming from intensive statement in England with over 22hrs 1:1 support SEN support etc. Scotland is pathetic!", “The EHCP was weak*

*and we are using a solicitor to appeal to SENDIST on parts B and F. They only acted correctly because I pointed out the Code of Practice and Children and Families Act. The school said she didn't need one.", "In our son's case we got a statement, for our daughter we had to go to SENDIST but lost because the LEA lied.", "I had to withdraw application until R was officially diagnosed as the school had actively hid evidence."*

## ***Conclusions***

It is apparent that GPs and teachers urgently need to receive autism training and this needs to be **mandatory**. Nothing else will do. Some parents may not know what autism is and not recognise it in their child, with the clearly apparent blame culture by professionals, a parent might blame themselves for their child's challenging behaviour instead of seeking assessment for autism. So teachers are a vital part of recognising potential autism in children and assisting in the pathway to assessment - and this includes, the type of autistic child who is masking in school. GPs cannot refuse to refer for assessment when a parent raises concerns – "Mother is always right" has a basis in truth!

The blame culture among a variety of professionals, is sadly endemic, these things don't change overnight, but the Government should be making stronger statutory guidance for professionals on their duties and spelling out how and why, they are failing children and their families by persisting in this culture. There should be accountability and repercussions for professionals who do this! No professional should be in their job if they fail to perform their expected role and may be responsible for emotional abuse of children struggling to cope without support in school and life.

It is clear that the state is shirking it's duties and putting parents through wholly unnecessary battles to obtain much-needed support for their children. It's no good assuming a school will provide needs-based support without an EHCP, because there is no legally binding document to say they must otherwise. LAs forcing parents to start appeals wastes public funds which could be spent on supporting those very children!

Parental evidence and information based on expertise in their own children is not being respected, to the detriment of these vulnerable children. This cannot be allowed to continue.

It's high time the Autism Act 2009 was revised to include children and accountability brought in.

Sister survey on social care experiences here https://www.surveymonkey.co.uk/r/B7239W3