

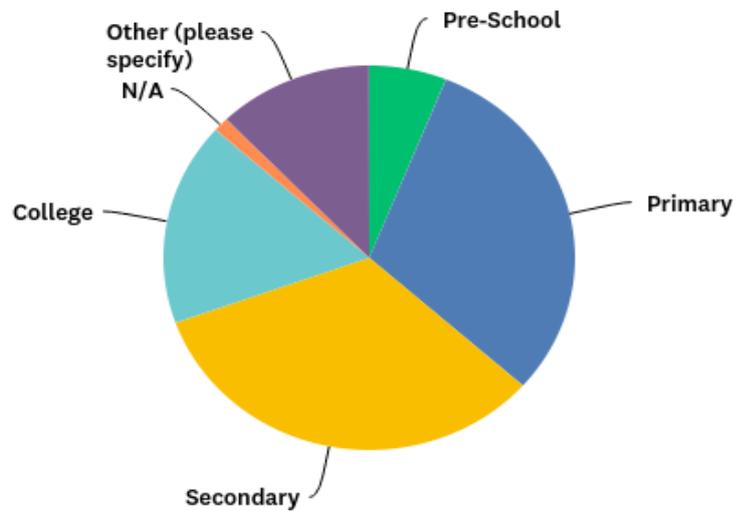


Results from the PCC Education, Health and Care Survey 2019

Thank you to everyone who responded to the survey.

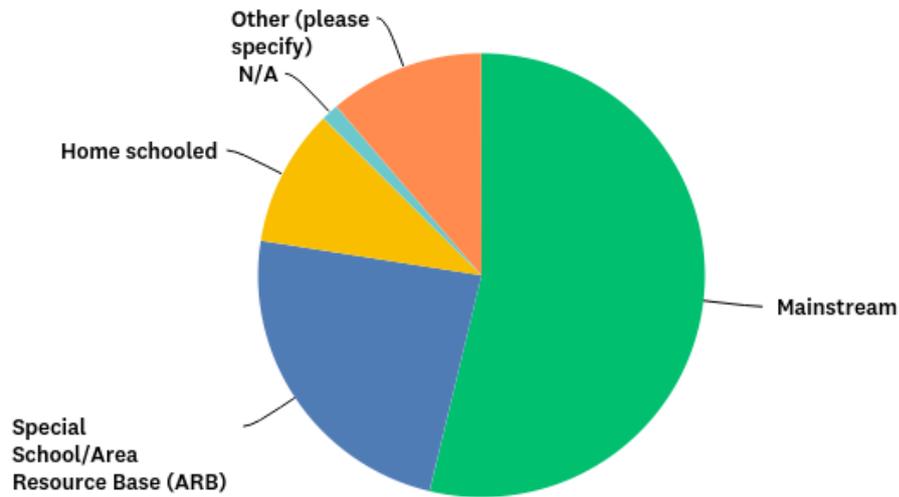
The feedback and breakdown of the questions is below

Q1 Which educational establishment does your child/ren with SEND attend



Out of the 82 parent carers who responded to this question, 5 attended a preschool, 25 attended a Primary, 27 attend a secondary school, 14 go to college, one termed the question as not applicable to them and 10 answered other, these included home study with EHCP, college age but refusing to attend, electively home educated, special school lower sixth form, EOTAS, special school year 10, university and SEN school.

Q2 Please indicate if your child/ren attends

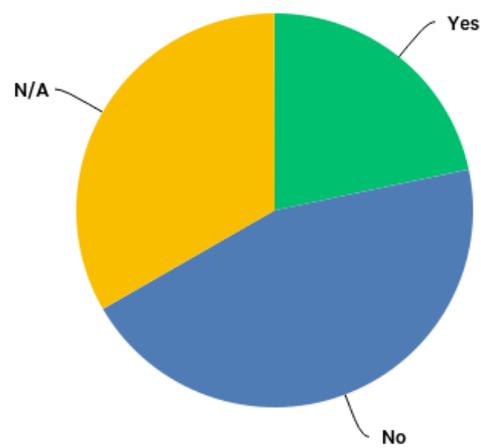


Mainstream	43
Special School/Area Resource Base (ARB)	19
Home schooled	8
N/A	1
Other (please specify)	9

- 1 Specialist FE provision at a mainstream college
- 2 Mainstream but only in the health & wellbeing centre.
- 3 Specialist SEND college
- 4 AIL AT TRURO
- 5 SEND section of college, Independent Living course.
- 6 Cornwall college
- 7 See 1.
- 8 Special needs department in mainstream college
- 9 AIL course

Q3

Q3 If your young person is of college age, Is your son/daughter in Education, Employment or Training



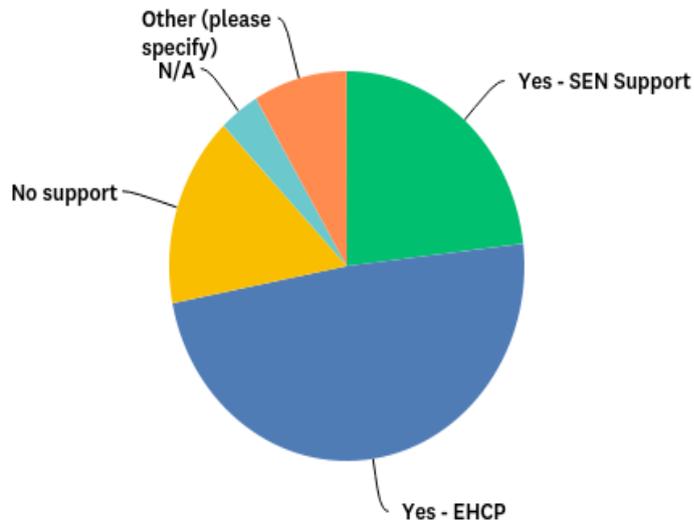
60 respondents answered this question with

13 responding yes

27 responding no

20 stating that it was not applicable.

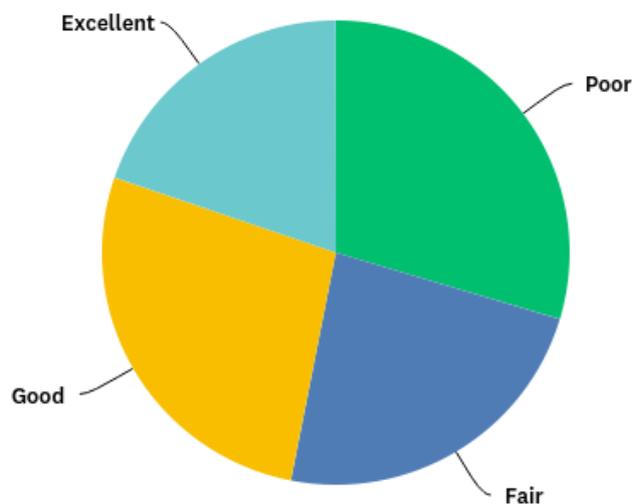
Q4 Do your child receive any support in school



Showing 7 responses

- Some support awaiting EHCP assessment
- EHCP - college
- My son did not qualify for support
- One to one TA. SEN only involved when problems. EHCP applied for
- Speech and language physio
- As EHE we receive no support, resources, input, reports.
- Some support waiting to hear about EHCP

Q5 How do you rate the support that you receive in schools



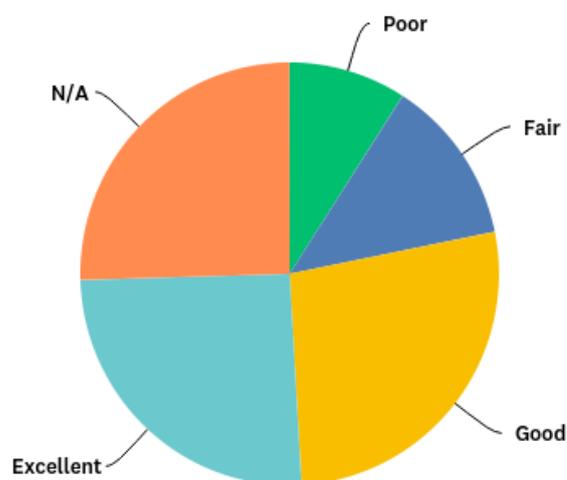
Poor	24
Fair	17
Good	21
Excellent	16

- The school provides good care for our child, staff are caring and kind
- Minimum communication home from school.
- Truro college ACE course has been fabulous for my young person.
- Everything was a battle due to poor and inadequate support. The schools themselves , bar one awful disgraceful one, tried their best but simply didn't have the trained staff to manage complex needs. I felt I was constantly having to drag things out and argue the point and only when something serious happened would I be listened to rather the. Observing and noticing difficulties and plan for them in advance
- My son at Oaktree, which is very different to other schools in Cornwall. They use a LOT of TA's. Most are great but many have little or no experience of SEN & are so young, they often cause problems with thoughtless behaviour or lack of understanding
- when my daughter was at school the SEN help was ok when she was in the SEN department but it didn't filter out and the teachers did not do what they were supposed to to help my daughter be able to stay in school.
- In primary he had good support most of the time. In Y7 he couldn't cope with just help from learning support. The school did try hard to make things work though.

- General ta's trying to follow a joke of an EHCP. School aren't seeing the big picture, and just keep mentioning us looking elsewhere. He needs a proper set learning plan with things to help him access that learning!
- School been very supportive of his needs. Also have regular meetings.
- Fought & they got very little, nothing or taaught in group
- Excellent at specialist provision school in the main - and can say the same now transferred to college
- Put in a taxi without pa present, driver was not epileptic trained.
- Daughter has asd, left to cope on her own , because she can mask her problems at school..
- The school has gone above and beyond by providing full time 1 to 1 support without applying for an EHCP. They may have stabbed themselves in the foot by doing this though, as his support would be seriously threatened by any funding cuts, and he is not eligible for any extra Grant's that he would get through an EHCP.
- When there are signs of improvement support is stopped
- I took my children out of mainstream education as their needs were not being met
- for 5 years the support and knowledge about treating my child differently BECAUSE he IS different fell on deaf ears. The SENCO was a full time teacher who delegated to 2 TA's with some SEND training (I never have found out what this training is!) and my child was just meant to do the same as everyone else. He was being set up to fail every single day. Then we had a new head teacher, the SENCO went off sick, and I have to say things have started to improve. School still greet me with the same old thing every day " he didn't manage to do..." or "he refused to ..." and yet they haven't sought any further training to learn how to deal with his "challenging behaviour!" I believe he has a dual diagnosis (but we have to wait 3 years to be assessed) and until then he has a far from helpful EHCP, which fails to mention he is a danger to himself and others, so looks like his "needs" are being met. Far from it. And nothing has ever been mention in his social needs, so it looks like he has none. I am not impressed with the way EHCPs are in categories, most "needs" overlap, and only those that affect school seem to be included. I had hoped (being a nurse) that a combined Plan would be all encompassing, it doesn't look like it to me, or maybe Cornwall is just rubbish at it.
- Assessed for EHCP and denied and then school said he would have no support even though he would really struggle without.
- You can only access help if you have an EHCP what about the children that haven't got one bit still need help with school, they are always overlooked
- Previous school would not help and wouldn't even listen to my daughters doctor
- Only his first week but so far is much better than primary
- EHCP is not fit for purpose. school have been shocking and now my child is too traumatised to attend.
- Mainstream school previously not great but current SEN school very good.
- Not enough speech and language and waiting for school specialist is ridiculous therapy's have diminished
- No communication from school. School SENCO is very hard to get hold of.
- Primary school was appalling. Then 5 very happy years at Pencalenick - excellent plus!
- It tends to be reactive to problems and only after it's asked for rather than proactive to prevent a problem. Also when measures are in place and help my child access education and so they are attending the school then try to remove them as they think they are no longer needed. When in fact the reason things are working is because the support required is in place.

- Had to fight too much to get a life support she has
- I worked hard , fighting Cornwall County to get an EHCP for my child . Penwith College are amazing at working with it and helping my child achieve as her peers
- My son receives excellent support at Camborne Science & Int. Academy, they really go the extra mile in providing core and additional curriculum support (e.g. trips and DofE, after school clubs, homework club)
- ARB learnt more in 1 week that 5 years
- In the meetings the school is good, but outside of the meetings it tends to be forgotten, also meetings cancelled with no notice etc
- Our experience with school was awful. Lack of support and understanding.
- Teachers do not support my son at all despite me providing equipment to use and sensory items

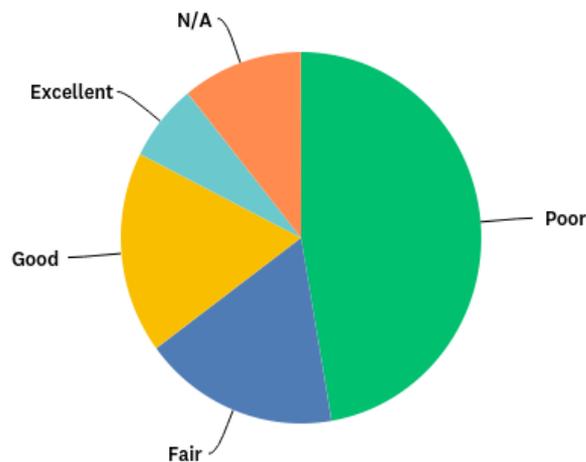
Q6 Looking at Special School and ARBs , how would you rate the support here?



Fair	7
Good	15
Excellent	14
N/A	11

- Not enough trained support staff for more complex needs children
- Insufficient places. Also not always using appropriately trained or qualified staff - Young & cheap seems to be the criteria rather than trained & experienced
- Any issue we have had, we've felt supported and has been addressed.
- Excellent support from the ARB enables him to attend most mainstream lessons. There should be more of these places available. It took us almost a year to get him in.
- Not enough to serve the county. No special school in North Cornwall. Added long journeys for disabled and sick children is not appropriate.
- Not explored yet!
- I found that when my child was at school it varies staff member / year group but good communication cleared up any issues - it's a team effort around my child
- There is no individual centred approach. They are all shoved in one box
- Our experience of Pencalenick. Can't comment on the others.
- My son is in a special school and he is completely supported over and above
- Fab he smiles every day learning more than ever has
- Goes to mainstream
- From what we saw when considering our child attending an ARB, very friendly and relaxed but staffing levels a bit on the low side.

Q7 Looking in more detail at just mainstream schools, do you rate the level of support for your child as

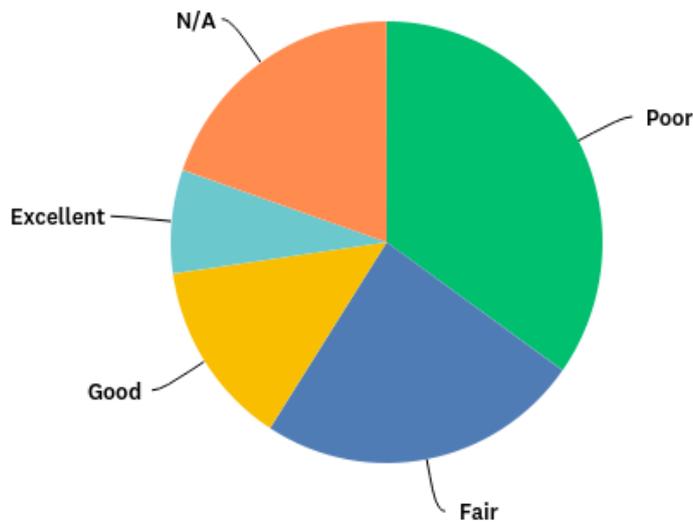


Poor	34
Fair	13
Good	11
Excellent	5
N/A	8

- We are waiting for a diagnosis for our child and hoping to get more support as it is really needed
 - Mainstream couldn't meet her needs.
 - Awful experience that led to my son getting PTSD from the whole mainstream experience. Poorly trained and educated staff and nowhere near enough monitoring of academies when failing those children
 - My child is in an ARB in a main stream, i feel they could be integrated more. Not just to support those with SEN but for those who do not experience SEN on a day to day basis but to help them understand a person with SEN.
 - The support my daughter got was not great - she was in a private school and I'm guessing you aren't including that in this survey - even though you should as they are ofsted assessed
 - Not sure how this is different to Q5
 - No support. Ot isn't bothered, SALT come in but school.dobt follow all the plan. Now have camhs but how do I know what they are doing??? No special ta or teacher
 - My son receives 1:1 teaching & support for 2 hours a day. He also has a differentiated timetable, which is bespoke to his interests & learning needs.
 - because we have no diagnosis other than spd and dyspraxia hard to get support, cahms lack interest waiting for autism assessments
-
- Could not accommodate his needs in mainstream education.
 - It's all to do with funding and how much they want to help your child.
 - It's great he gets 1 to 1 in school hours but I feel he will soon need further support to access after school clubs. School has said they cannot offer him this as things stand.
 - Support was so poor we had to move schools - hopefully thing will be better, but lack of choice of special schools means she has to try another mainstream
 - I have 2 children with SEN and one is treated with less respect than the other because of lower communication skills. They are seen as non compliant instead of what they really are, which is frustrated and depressed
 - As soon as a professional has an increase in their amount of children on their books they are trying to discharge my child, despite him still needing intervention. "but just keep following the plan" and "you can always ask to be put back on our books" (yeah, after a nine month wait) are what I'm told. No, just keep under review, no point having a SLT plan if no-one is checking it's working or needs adapting. It's hard work just trying to get professional in in the first place. Other support from 1-2-1 TA is excellent, even if they don't know HOW to deal with the challenging behaviour, 7 years in!
 - As already said without EHCP you cannot access the help that the children really need!
 - my child has been physically hurt in school. bullied, suffered unlawful exclusions. school do what they like and do not keep records. my child is still on role but not able to go to school.
 - Complete lack of understanding and unwilling to take responsibility of their duties.

- Our experience of Veryan Primary and visit to Roseland Secondary. Again can't comment on the others. (Gerrans Primary where our son did year 6 was very good).
- as a child with adhd and dyspraxia he hasn't got an EHCP and therefore no help in class and is frequently reprimanded for not concentrating and fidgeting !!
- Terrible time at mainstream , no care at all , left to fail
- for previous year the teacher wasn't very supportive new teacher is better
- It was always my child who had to make adaptations. Every reasonable request I made was met with NO before I even finished the sentence.
- As before son not supported teachers not interested

Q8 If you have SEN Support in mainstream schools, how would you rate it



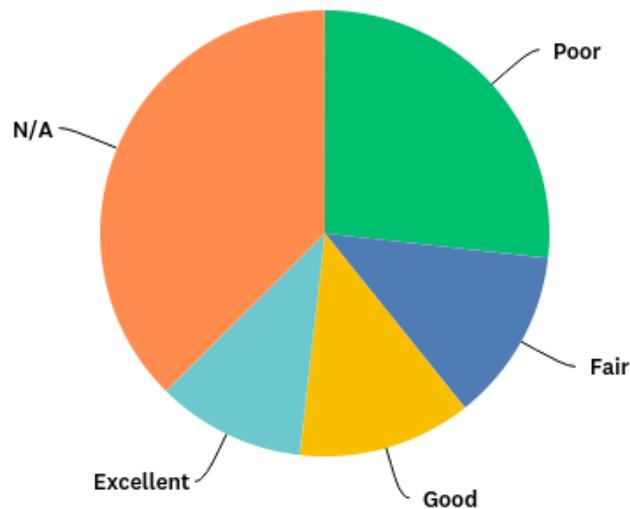
Poor	23
Fair	14
Good	8
Excellent	5
N/A	13

Showing 17 responses

- Keeps changing carer

- We have a senco 1 day a week, she's also a teacher in a partner school. EHCP guidelines aren't followed, paperwork late, not given ahead of meetings.
- My daughter was failed time and time again in trying to get a dyslexia assessment - despite me being an OT and asking for it at primary and secondary school on many occasions - just told she was ok and as could read and write well not dyslexic. Fail to assess and then when apparently was done found out only a screening tool was used and teacher knowledge was inadequate - took Truro college tutor to ask for a screen and only just manage to get reasonable adjustments in place just before IB exams - only once got to Ballet School at University and dyslexic tutor agree and help make possible a full assessment. The results were shocking but not unexpected by as said with helped she'd have achieved much better at school and got better grades...itsxtaken 2 years to build confidence and now just starting university 'academic' course as believes she can do it with right supports in place. As an OT mum was judged to be overly anxious and seeing things not there and then frankly just dismissed.... the school system let my daughter believe she wasn't as smart as others... My frustration is as an OT I was helpless to act - even more so as judged to be just seeing more there than there was - parhologising her when I didn't need to! It's a story i hear over and over again with the children i treat for dyspraxia, ASD and sensory difficulties... and the brighter or more well behaved they the harder to get a diagnosis. Judging of parents as anxious is endemic and systemic... a culture if us and they instead of team around child 'we' !
- Not enough of sen
- No support
- It all looks good on paper but the strategy for meeting goals are poor to non existent and mainly placed upon the parent as they responsibility without the support or training or the choice to refuse the responsibility especially when they have enough on their plate as well as struggling with depression themselves
- My daughter only gets it when there is a TA in the same classroom for another child
- Senco has no idea about the childs' diagnoses. does not make reasonable adjustments
- Didn't know there was a sen coordinator until exclusion.
- We get no support
- Teachers never take notice of SEN file. New or supply teachers never know of her needs. Always having to chase school about not doing what they are supposed to as it states in her sen file
- Based on experience over 6 years ago now some was poor and some good.
- It was terrible at Hayle School , no support , left to fail
- Again during meetings is good outside not so good
- Wouldn't listen, didn't want to know, didn't want my child to 'be different'.
- needs much more support than she gets

Q9 If you have EHCP support in mainstream school, how would rate it

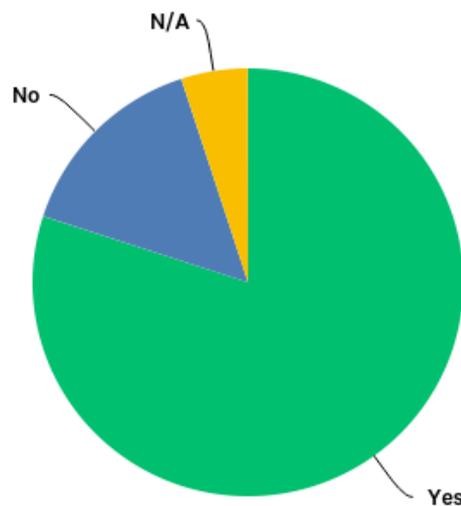


Poor	15
Fair	7
Good	6
Excellent	6
N/A	19

- Got denied
- It gives you more of a say but often it's not adhered to and you spend countless hours chasing up the correct support
- EHCP department are rubbish. Review may 2018 was in the end never printed. Received a letter Jan 2019 stating they'd made an error and reviewed it against his first EHCP not current. Decided not to redo it but wait until next review of 2019. Had that in June, got draft and it's got bit from 2018 and added 2019 so two reviews running into each other it's a mess. Not mentioned cahms report!!!
- Still fighting to get one for both my sen children
- My son has an in-depth plan & at present very happy with it. We are still in the early stages, as only received final plan in August.
- I've been trying to get EHCP for daughter for 4 years , school will not help
- She has EHCP but her needs were not being met

- I've had a meeting for one, but still not seen the final document. It's been a year and my child has gone up a class. Which means another report is due
- See previous comments. Disjointed, not all encompassing, only school orientated (cos obviously his disability disappears the minute we leave the playground!!!!)
- EHCP is incorrect and not fit for purpose. it does not meet legal criteria. it is all about cost saving not support
- Don't have EHCP and school won't apply for one.
- We don't have one
- Would be a start to help my daughter but the school didnt and wouldnt start a EHCP process
- n/a got EHCP properly for college
- Awaiting draft
- School refused to follow most of the advice in EHCP.

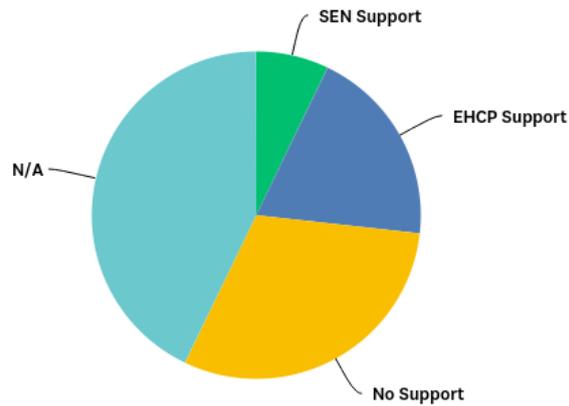
Q10 Does your child attend school regularly



Yes	61
No	12
N/A	4.

- Our child suffers with anxiety and worries about school sometimes so we sometimes have to cajole him to go
- He's now EOTAS on PB as no schools can manage his needs
- May not get there on time due to a melt down
- My son is autistic, has severe social anxiety & is a school refuser. He is timetabled to attend for 2 hours a day. However, we are not always successful in getting him into the school's building.

Q11 If your child does not attend school regularly do they have

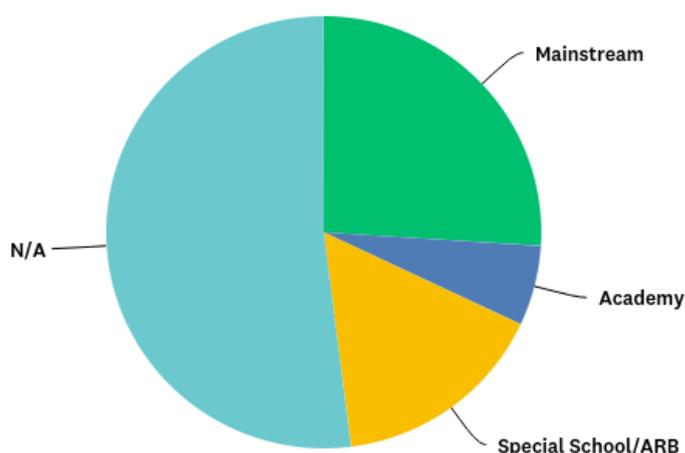


- But lots of days at home with sensory overload and sch changing stuff with out no warning so she couldn't cope
- Apart from appointments at hospital
- often hard to get into school
- As they are EHE they attend every day!

if you home educate your child with SEND, please comment as to why

Answered: 16 Skipped: 66

Q12 if your child does not attend school regularly do they attend



Mainstream	13
Academy	3
Special School/ARB	8
N/A	23

Q13

If you home educate your child, please comment as to why?

Because it works for him and his needs and means I can employ better trained and more suitable staff to meet his needs rather than forcing him into environments where he has to make do with staff that aren't competent

Secondary school got complicated for my daughter - relationships, homework, teachers shouting at classes etc etc which started causing her anxiety and huge meltdowns at home. She reached a point where she wasn't able to be in school for more than an hr a day. The stress on her was showing mentally and the stress on the family was horrendous - we have never been in such a bad place. There was no support from school or CAMHS or anywhere (we were waiting to hear from CAMHS for the 2nd time) we were lost as to what to do - and we reached breaking point and decided there was no other option but to home school her and give her a break from the things that were stressing her. She has since been diagnosed with ASD which explains why school was stressful. We still don't get support, and we've found certain services seem to be related to you having to be in school - so she cannot get mental health support because she's not in school - this doesn't make any sense especially as we are in this situation because we didn't have any support when she was in school.

College can not accommodate his needs. Home education is provided by the LA with online education.

School were not supporting them as they should

Right sided hemiplegic cerebral palsy. Turned down for EHCP and school said no support necessary. He would manage most of the time but would never reach his full potential, and would use his right side unless supported to do so. He also gets very tired quickly and has emotional outbursts which need to be supported for his safety as well as others.

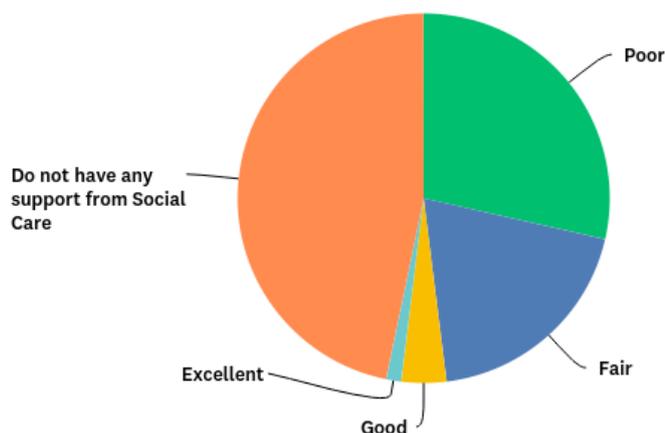
I do not home Ed I have asked for EOTAS so my child gets the support they need. this has been ignored. I may have to choose non elective home ed to keep my child safe

My eldest(Asd) is in secondary and in school my youngest is 11 and home educated due to lack of support for his needs

I don't think it's best for my child so despite it being suggested I have avoided it (so far)

School made my child ill. They didn't allow for any individuality. It was their way or no way. After 6 years of fighting my child was unable to attend due to physical and mental health problems.

Q14 We would like you to have your say about Social Care Services in Cornwall, how would you rate them?



Poor	22
Fair	15
Good	3
Excellent	1
Do not have any support from Social Care	34

Showing 27 responses

What is it?

ASC is complex and difficult to access with no designated specialist social workers. Direct Payments are complex and flexibility is difficult. Parent carers are left on the poverty line with the extra expense of caring for a severely disabled young person on far less benefits and help than we get on children's services. Costs are increasing, but there is no increase in allowances by the government. Some families will have to give up caring because they can't afford social care so will not get a break from caring full time.

Although things are finally improving it has been a constant battle with social care to provide the help they agreed to years ago. It's now got to the stage of JR and often their input has driven me to severe stress and illness. The service needs a major overhaul

We are fortunate to have an outstanding disability social worker at the moment. But we have been through hell with 6 different social workers of varying standards in 6 years. In December, during a time of family crisis for us, just before we were made homeless, our social worker was removed & replaced with family support worker (not appropriate) without warning or even advising us, leaving us totally unsupported at a crucial time. The constant upheavals in the department & constant re-organisations have created a very fragmented department with no one apparently knowing what

they're supposed to be doing to actively support our children & parents unable to access the system efficiently. The direct payment tool is terrifying in its inability to recognise need, it's inflexible & has seen us lose hours & money, which is desperately needed. Our carers carry out a lot of hours for free, as we no longer receive enough hours to cover - we receive 9 hours per week but have 24 hour breaks once a fortnight. Social care is well below even a basic standard required & largely unfit for purpose

No support. Our child has a rare genetic condition rarer than downs syndrome but of similar disabilities.

Everyone has pulled away no help at all now

Bad experiences all around with social care. Will not give me the help I need with my severely disabled child with complex health needs. Social care have failed our family and is only interested in how they can save money. No consideration for families at all

Currently we don't receive any support. However, we have previously had a family support worker.

Excellent support in Children's . Poor in Adults - other than one stand out Social Worker and Manager .Very frustrating but I do understand there are capacity issues and budget issues

Not enough respite for 18 to 25 it is very poor.

It seems that social workers are schooled to try & push short breaks away from home which in our case is completely unsuitable for our family.

Failed to give the right support

We had a social care assessment but no support was offered at this stage, despite our family clearly stating he needs an inclusion so he can access holiday clubs and after school clubs. We also clearly stated our family is under a lot of strain from managing challenging behaviour. A carers assessment was offered but we were told that there was basically no point having one as no services can be accessed through it for parent carers.

What social care?

Need more funds From referral to support can take months. Often that is too late for the individual child. Their mental health has already suffered and they have damage

We have a need for respite, it was once agreed we could have direct payments for a PA, we couldn't use it (child was too ill) so when we got round to it (6 months later) were told we had to re-apply as the criteria had changed, and even though MY circumstances had worsened, we then were NOT eligible for any assistance. \$ years later we are trying again (at the request of his Lead professional, who believes we need help) and have been offered an overnight stay once a week at a centre locally for children with SEND. NOT what we had asked for, and are still waiting for, a couple of months later (they are currently full) so no help for us, even though it is agreed we need it, so no costs incurred by SS, hooray for them, boo hoo for us. MY needs have not even been discussed, even though it was meant to be a carers assessment too. No, SS not helpful in my life. Now they will change TACs to ChIN meetings, then just disappear out of our lives for another x amount of years, until child reaches 16 when we will no doubt be encouraged to switch to lesser benefits and still not be offered any REAL help. Rubbish.

The support came far too late. Promises of support were made but not kept. Their understanding of the send process was poor they stated facts that were wrong ie parents can't apply for an EHCP the school has to. They often created more barriers rather than helping.

no support from social care despite requesting an assessment this is still written up incorrectly in the EHCP

Child has been waiting for overnight respite for over 6 months, 10 months since first referral. Rules about DP ridiculous compared to rest of UK. System biased in favour of certain families who shout the loudest. No help given even though Carer's Assessment recognised the need for a break, no assistance given.

Takes too long and plans takes forever and nothing in stone I've broken due to lack of support, school holidays finished me

Transition from children to adult services is still a concern for many families

We think we probably need some support from social care!

Service is hit & miss. My sons both had poor to non existent transitions to adult services & it has been a battle but probably not as bad as the fight for adequate education support

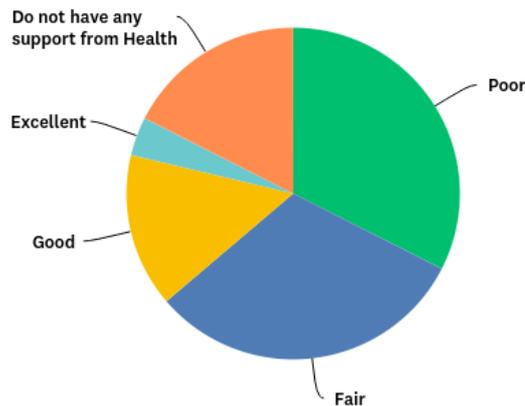
Hard to access social care, I am trying currently for my child !!

Social care and early help teams pretty efficient; OTs have too big a backlog and it can take months to be seen

Direct payments stopped and been waiting for assessment for transition to adult services

Not enough support to busy ticking boxes on paperwork and no interest in the actual situation

Q15 We would like you to have your say about Health Services in Cornwall, would you rate them



Poor	26
Fair	25
Good	10
Excellent	3
Do not have any support from Health	13

We have great support from the school nurse and have just been offered help from an OT

Good until she lost her Paediatrician. No explanation about what has happened, no replacement / appointment offered.

Good support from the Specialist Learning Disability Service for my young persons Epilepsy and behaviour that challenges. RCHT need an area where young people with PMLD can be admitted rather than on a general ward, which is very distressing and raises anxiety.

Appointment times way too long and often when complex needs longer than average , especially dental. That is an overall nhs issue tho. Staff are fab and understanding and LD team are ace.. but often not enough specialists so you're waiting upwards of a year to 2 years to be seen for something that impacts quite badly on child and family

Very difficult to get CAHMS support when needed

Need more active hands on therapy input. Physio and occupational therapist if we had that years ago or even now he'd be miles further ahead. We are just being left

Only Drs help now and don't understand child

Health seems to be a bit better than social care but both services need to get priorities right for families with young children with severe complex health needs

We don't receive any support from health. My son does however, have a bladder & bowel problem & been under the bladder & bowel specialist nurse since he was young, but he is not seen regular.

it is service dependant - can't rate neurology investigations and ENT enough - but getting to them via A and E and paediatrics was terrible!

Not enough specialist departments for our needs. No help for autistic adults.

Takes far to long to get the help and support needed

We have requested mental health assessment through his paediatrician but this was refused and we were signposted to CAMHS. We then saw the GP who referred him to CAMHS but they refused to see him even though we described risks to his safety and that of other children who play with him. We were told to access services through the Early Help Hub first. When we did this they told us they could not help us to access mental health assessment for him either.

What health services?

We haven't seen 2 health prof for about 2 years, a clinic got cancelled (ill health) and we've "slipped through the net" since. The paediatric community cons is a stupid service, all too often I'm told "we are here to supervise and signpost" hell no, I want someone to chase the missed appointments, help us with our sleep issues, get me a safer bedroom lock so my child wont escape, and not keep us waiting when it's one of the main things my child struggles with. No appointments take into consideration the environment, if it's too bright, noisy, smelly etc for children (or anyone) with sensory issues, or if there are other noisy children or people with nasty infections near vulnerable, immuno-suppressed kids. Most waiting rooms are boring for kids with SEND to be in, there is no "safety gate" so they can run if you take your eyes off them for 2 seconds, or they have to be "restrained" eg strapped into his wheelchair. The cost to park is mad, when most of the time we are paying for, is the wait due to clinic running over.

We have to travel to Plymouth for some appointments and and Truro for others. Services don't/won't talk between the trusts and we have been told we can't move all healthcare to one place because of our postcode.

If you live up the county and go derriford, and then cornwall don't take over care when needed

Asdat services waits are far too long. There is no support whilst waiting other than parenting courses and the Wheel!!!! After diagnosis parents still just left to get on with it! School nurse service was ok but again didn't understand the process for referral to other services

my child has got to the end of the consultant's expertise so i have had to pay for a private consultation for him now. there is no SEN dental service. there is no joined up communication between depts.

CCN is fabulous as are the team who work with my child.

Lack of care been waiting for a specialist to help with my child's impacted bowel and it's must be going on 2 months as no one reply's

Long waiting times to access services

Community Pead always changing so no continuity

We've been asking CAMHS for help for 18 months now, but our son appears to fall through a gap between CAMHS, which he would not be able to access and CAHMS LD which we are told he does not qualify for. TOTAL CRAP!!!

Again, services are hit & miss & transition to adult services is poor. Because my sons health needs are not straightforward, it's a constant battle. Both sons do not meet the criteria for mental health services despite ongoing depression & anxiety

Most paediatric healthcare services are good but there are a few exceptions. The waiting list for many services such as asd assessment and camhs is far too long

everything just takes so long and soon it will be too late as he is now in year 9

I have been so impressed by individuals dedicated to supporting my son

Never enough appointments, when you get one it's rushed