



# Brighton and Hove Parent Carers' Experiences of COVID-19

## Executive Summary

### A. Context

Amaze is a charity providing information, advice and support to children and young people with special educational needs and disabilities (SEND) and the Parent Carers' Council (PaCC) is the local parent carer forum, representing the views of these families.

Together we have been working hard to respond to the COVID19 crisis: including putting our SEND-specific (parent carer and young person-friendly) information and also providing families with letters to more easily access supermarkets and the outdoors. We have quickly adapted our services and support so we continue to be in touch with large numbers of families: via our SENDIASS Helpline, through our Amaze/PaCC social media, via our online coffee mornings and befriending calls etc.

Through this contact and experience, we know that families with disabled children are especially vulnerable during this time of crisis but decided to run a survey to, more methodically, identify their experience thus far and inform how [Amaze/PaCC](#), Brighton and Hove City Council, local schools, the NHS and other agencies, can best support parent carers and CYPs in these difficult times. The survey focused particularly on how lockdown is affecting CYPs' learning and the support families need around home schooling and in staying healthy and well.

The survey ran on line, over a limited 7 days (17<sup>th</sup> - 24<sup>th</sup> April 2020) and whilst we received a response from 103 parent carers, we recognise there are both families who are digitally excluded, and some who are too stretched/stressed to be able to complete a survey at this time, so please read the findings below with that in mind.

### B. Summary findings



**High levels of stress and anxiety:** COVID19 is clearly causing a high degree of anxiety and worry to both children and young people with SEND and their parent carers. Almost all of our survey respondents said they were experiencing higher levels of anxiety about a wide range of issues such as: contracting the virus, keeping their family safe, not being able to support their child with learning, coping without PAs/respice, child's worsening mental health or behaviour, worrying about loss of income/employment, impact on siblings/other children, worrying about the future.



**Children with SEND not attending school/college:** While CYPs with an Education, Health and Care Plan (EHCP) are entitled to be individually considered for a place in school, only 27% parent carers who responded to the survey have taken up the offer of a school place. 56% said they had been offered a place, in line with government guidance, but most are choosing not to send their CYP to school to reduce the risks of COVID-19 infection. Some also reflected the school place offered to them did not meet theirs or their CYPs’ needs, so they felt they had little choice but to keep their CYP at home. Some added it was too soon to know if they’d made the right decision to not take up the school place offered, as they were still adjusting to home-schooling requirements.

Parents had mixed experiences of communication with schools at the point of lockdown. Some felt there was good discussion and mutual agreement between them and staff about what was best for their CYP/family and parents were understanding of the challenges facing schools. Others said they were told their school was closed and/or the usual staff, and therefore support, for their CYP would not be available. In total 44% said their child with an EHCP had not been offered a place to continue in school.







**Parents need more help to support home learning:** The survey did not highlight a current demand for EHCP CYPs places at school. When asked whether they feel they are getting the support they need at home, experiences are mixed:

Are you getting the support needed	Yes	Partially	No
EHCP CYP	37%	48%	15%
SEN Support CYP	42%	26%	32%
CYP at home	36%	28%	36%

While there are many examples of good support and situations where parents are adjusting to home-learning by developing their own flexible routines and tailored learning, there were as many examples where parents said they are not getting the support they need. Specific issues include:

- i. The work and resources which are being sent home are not differentiated or appropriate to CYPs’ needs
- ii. Many schools are not offering online interaction and lots of EHCP families (34%) want this. They are seeking both opportunities for learning and for their CYP to have social contact with other CYPs
- iii. Parents are struggling to engage CYP in home learning, lacking capacity / skills / resources to do this, eg 15% for SEN Support CYPs and 29% for EHCP CYPs would welcome printed materials being provided to the home; 21% EHCP CYPs want a more structured timetable
- iv. Families need and want access to (online) therapies, which appears to be very limited
- v. For a minority of parents there has been no personal contact from school at all

	<p>vi. Concern about the impact on siblings when parent carers' capacity is stretched and they're required to focus on the SEND CYP</p>
	<p><b>Worsening of child and family mental health and wellbeing for most:</b> Families are affected by not being able to access a range of other services or activities as they would usually, which is impacting negatively on their CYP and their families' wellbeing. These include exercise/leisure activities, open space/outdoor facilities, therapies, young people activities/clubs, PA/respite, seeing friends, learning support and art therapy/music lessons</p> <p>All families (EHCPs, SEN Support and CYP Out of School prior to COVID-19) unsurprisingly reflected that having their CYPs at home 24/7 is challenging and shared a wide range of issues they are experiencing. A handful of families said they are coping fine.</p> <ol style="list-style-type: none"> <li>i. Most worryingly this report demonstrates high levels of anxiety, isolation, stress and depression within the community, about COVID-19 generally, it's impact on their SEND CYP and their capacity to cope at home.</li> <li>ii. Accessing food/shopping is an ongoing concern, although primarily in relation to frustrations around booking online shopping food delivery slots.</li> <li>iii. Juggling working and caring and not being able to go out at all, eg because the CYP is self-isolating or because the CYP is too afraid to leave the house, is also difficult.</li> </ol> <p>It is important to note that very many parent carers reflected their CYPs were benefitting from a more relaxed routine, reduced anxiety in not needing to attend school and having a more informal approach to learning at home. This is backed up by similar experience at the YMCA who are reporting 30% of their 12-15 year olds say their mental health has improved since they stopped going to school for lockdown. This is coupled with worry as to how CYPs will re-integrate in school after lockdown.</p>
	<p><b>Concerns about their child's progress or plans for the future:</b> Several families said they are lacking access to (Speech and Language, Physiotherapy, CAMHS and Occupational) therapies or contact with other health services. There are concerns about the impact of delays to their child's diagnosis or assessments and therefore referrals into services. Some families are concerned that their child(ren) with SEND will be falling (even further) behind in school which may make re-integration back into class harder. Parents are also concerned about preparations for their child's transition to a new setting in September 2020</p>
	<p>Parent carers shared tips on how they are approaching home learning and the coping strategies which are working for their families, including: focusing on informal learning (games/arts/cooking/gardening/reading), being kind to yourself (setting realistic goals/look for the positives), going for walks/getting physical activity/enjoying nature, connecting with others (neighbours or online with family/friends), having routine (familiarity/visual</p>

	timetables etc), having fun/quality time with family, ensuring they make time for themselves and watching films.
	15 parent carers requested a call back from Amaze to provide further support. 37 were unaware of the Amaze FAQs.

### **c. Our Recommendations**

We know there is a huge amount of good work going on across the city to respond to the COVID-19 crisis and we appreciate some services/providers are doing the below things already, and some things might be in train. But we thought it might be helpful to make a short list of recommendations, responding to the data and parent comments, for services to consider as we look set to continue in lockdown:

#### **Schools/Colleges:**

- i. Where a family chooses for their child to remain at home, in consultation with parents and carers, schools to offer adapted/differentiated learning resources to meet the needs of children with SEND in a more person-centred way. E.g. particular resources that might help a child with ASC for instance and/or offering timetable online interaction and video content. Where possible, teachers could contact families to find out what works best for the child.
- ii. Support families who are not online, by providing school laptops/tablets and access to WIFI. Can BHCC give out a clear comms message about how children on Pupil Premium, who don't have IT access, can access equipment?
- iii. Provide the option of printed packs of learning resources where requested and items of stationery if families cannot afford this
- iv. Heads and senior leadership teams to be sending out strong message to pupils and parents that their mental health and wellbeing is the most important thing at this time, but they need to engage with some learning if they can, but to ask for help if they need it. NB A well differentiated and agreed educational offer (as described above) should help CYP to access education in a way which supports their MH and wellbeing.
- v. Begin to plan how to reduce anxiety for children who have been out of school for long periods of time e.g. whether possible to minimize changes to teaching staff i.e. keep staff with current year groups. Consider visits for children to go to school/college for shorter/half days to reacquaint themselves initially.
- vi. Develop videos to (re)acquaint pupils with a school setting, in particular for those at key stage transition points. It is also important to consider the need for CYPs who are leaving to attend a new setting, to have a proper opportunity to attend their old school and say goodbye.
- vii. Where a school has enough teaching capacity and a child's health would not be put more at risk, schools to more clearly state that they welcome children with EHCPs to return to school, and what their offer to them will be.
- viii. Consider the inequality of learning experiences that children with SEND (and their siblings) in the school population will have had during lockdown and how some of this could be tackled. E.g. could a greater proportion of staff time be spent

supporting the more vulnerable, including CYP with SEND, and could SEND children be prioritised to return first if they would like this?

#### **Social care:**

- i. Clarify what support is available for managing increasing challenging behavior at home. Some clear comms is needed about what a parent should do if their child is violent towards them and they can't safely leave the house.
- ii. Provide additional educational and mental health support to siblings, asking them what would be helpful.
- iii. Look into funding more virtual respite options (like Extratime@home) or virtual social activity/groups where young people can meet up safely with other young people on line e.g. Amaze Amazing Futures groups.

#### **Community teams and the Police:**

- i. Roll out a pilot to open up access to safe outside spaces for CYP with SEND and adults with LD and siblings, non-car drivers, single parents as priority cohort.

#### **Amaze:**

- i. Share parent-to-parent tips about what helps/what's working well for others
- ii. Provide parent carers and young people with Face to Face befriender or Amazing Futures peer supporter (if funding allows)
- iii. Continue to provide the BHCC Parent Carer letter to Compass Card holders, to help them access slots for vulnerable people at supermarkets. Help identify which families continue to struggle with food shopping and try to fix them up with community hub volunteer
- iv. Continue to provide the partnership letter to Compass Card holders, to support families with CYP with SEND to access the outdoors
- v. Develop the FAQ information into bite size chunks to be dripped through social media channels and presented more accessibly on their website
- vi. Continue to offer Looking Forward 1:1 support to YP who need help thinking about their future (college, training, employment) [only funded to August]

#### **Health teams:**

- i. Provide more therapy interventions online – either as 1:1 sessions, small groups, Q&A sessions with therapists or learning webinars for parents to use
- ii. Consider what more mental health/CAMHS interventions/support could be provided virtually and communicate the offer (including what family should do if child is self-harming)
- iii. Consider what provision could be made for parent carers reporting high levels of anxiety. Clarify what the offer for counselling is.
- iv. To ensure there is a way for health teams to be continuing to assess children and provide evidence for EHCP needs assessments

#### **Calling families:**

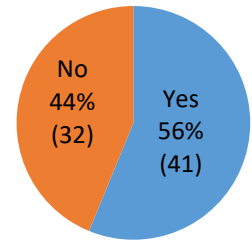
Finally we know that many services, including our own, are making proactive phone calls to families they consider might be at risk, or vulnerable. We have heard that some families have 'phone call fatigue' and are not always finding these calls useful. We have discussed this with PaCC Reps and have identified the following suggestions:

- i. Many parents have their phones switched off or are struggling to answer their phone when they are with their child(ren), so if a professional is going to ring them to see how they are – please text or email beforehand so they know to expect the call
- ii. It is important that risk assessments being undertaken by BHCC are dynamic and are refreshed as families’ circumstances change. This needs to be balanced with not overloading families with contact and ensuring they are involved in this process
- iii. Be clear the purpose of the call and whether it is a supportive check-in, or if practical help is being offered
- iv. Ideally for the caller to be able to resolve, or agree actions/support to respond to the parent’s concerns, rather than just providing a list of places for the parent to be signposted to.

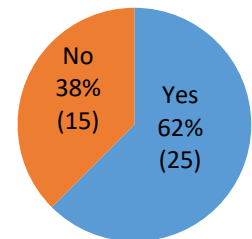
## D. Survey Results

### Section 1) CYPs with EHCPs eligible for school place (n.73)

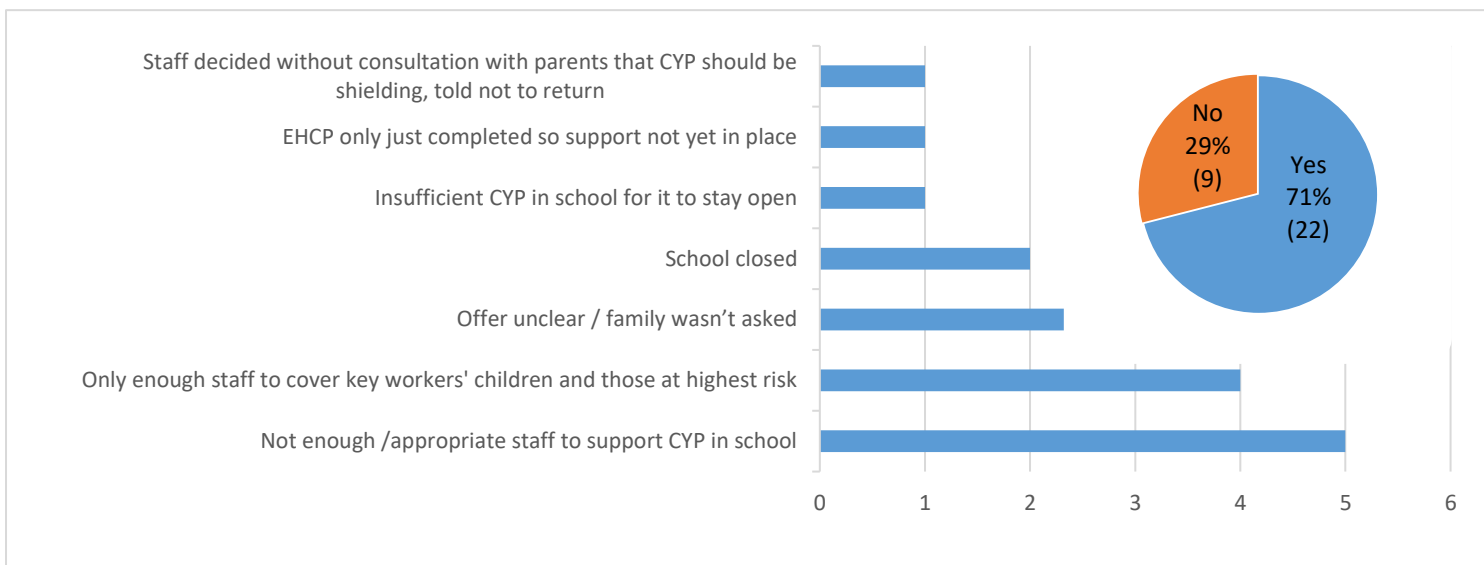
**1.1 Has your CYP with an EHCP been offered a place in their school or another setting during the coronavirus crisis?**



**1.2 Do you think the place school is offering is suitable for your CYP?**

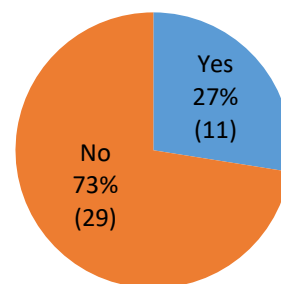


**1.3 Do you know why your CYP's school didn't offer a place?**

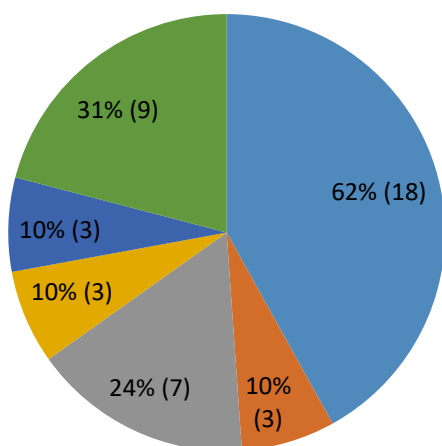


- “The school explained that they could not meet my child's mental health needs. They explained how they were setting things up - computer work, no talking and social distance. I felt it was set up this way to put me off.”
- “At the start of isolation the school SENCo rang to ask what support we might need, we said we could be interested in a part time school based offer. The SENCOs promised to call us back after they had worked out an offer, but this phone call never happened. We feel left in the dark re the school offer.”
- “We were told that she could attend college but wouldn't be able to provide one-to-one support. We are however using the remote learning tasks that have been provided.”

#### 1.4 Have you taken up the offer of a school place?



#### 1.5 What were your reasons for not taking the offer?



- Thought CYP more at risk of CV19 at school
- CYP's health condition requires shielding
- Sibling(s) at home so didn't make sense to send CYP with EHCP to school
- Didn't think school offer was suitable
- CYP refused to attend the placement offered
- Other

#### 'Positive perspectives' on accessing school places during lockdown

- A significant number of parents chose not to send their CYP to school to minimise risk of infection. Several said their CYP was too vulnerable and in the shielding category. Many felt (it was important) that school places are prioritised for those keyworkers most in need
- Some reflected they are very grateful for the placement offered, even though part time/reduced hours
- Easter provision was welcomed
- 1:1 support is still available at school for CYP
- Consultation and discussion with school around whether CYP would attend was positive
- Some parents didn't want to put pressure on the school by taking up a place and felt they didn't need to send their CYP as they were at home
- One CYP is receiving more 1:1 time because of smaller class sizes

#### Negative experiences of accessing school places during lockdown

- Several families were told that usual support staff would not be available at school. Staff would therefore not be familiar with their CYP's needs, routine and/or communication
- Hours offered were not enough, for CYP who needs routine/structure, for parents' work commitments or for adequate respite
- Parents were concerned for CYP's anxiety in change and whether they would cope well
- Two CYP refused to engage in the placements offered
- Some parents felt it was only childcare on offer, not learning
- Some reported their schools were closed
- Some didn't take up a placement as CYP's friends aren't at school

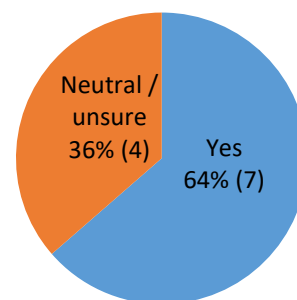


## 1.6 Parent experiences around their school place offer

- “They stressed that home is the safest place and that due to staff shortages they obviously can't take everyone, so it's fair that our son should stay home. It's enough to know we were given a choice.”
- “They tried morning sessions but he was one of the few of the SEN group that came and he doesn't do well in class type setting anyway without full routine plus is teenager. So would quickly leave.”
- “A generic email at the start said the placement would need independent learning which wasn't suitable. Nothing has been offered since.”
- “No communication as to why our child wasn't offered a school place through the last few weeks. No help with suggested initiatives to help my daughter's mental health/loneliness. Newsletters from school with nothing about the very large cohort of SEND children, only phone numbers directing them away from the school. Now being told that College is taking over my daughter's education [when she isn't due to start there until Sept], how when they can't even know her yet.”
- “It is only childcare, and part-time, but in a setting known to my daughter with adults known to her. She will find it incredibly hard as it's not her school and not her adults, but it's not all day every day and we will play it by ear.”
- “Initially school place was offered but the school did request that those who could manage to support their children at home should do so keeping provision for those most in need children of key workers. We felt that it would be safer to keep our child at home and help reduce the number of children going into school setting and limit contact as much as possible. We are fortunate that there are 2 parents at home. We appreciate what a difficult job it must be for staff working in schools through this pandemic.”
- “Initially, my child was in their primary school for the first 5 days. Take up was low and only 3 children attended. She loved the routine, attention and practical activities. She is now going for two days at another local primary school. Still with teachers and staff from her primary school. Again, she needs this structure, and we need the respite to support siblings.”
- “CYP1 has to have one to one support and her key worker is only available one a week, for just 2 hours on a Friday. CYP's mental health is suffering due to Covid-19, as is CYP2, who has been informally diagnosed with ASD with their stage two diagnosis postponed until further notice. School are amazing and allowing CYP to attend for two mornings each week.”

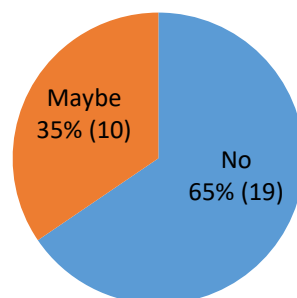
### 1.7 Are you satisfied with what the school is providing?

- “I know they are trying to do their best they can under these circumstances, but I feel they could do more”
- “I'm not sure what activities my CYP is doing but he is coming home happy and settle.”
- “We will take each week as it comes”
- “The staff are known to her. She loves the undivided adult attention and activities. She needs the interaction with other children as she struggles with friendships”
- “Less people, relaxation of rules, they are having fun”
- “Usual workers are there. Good preparation for social distancing. Transport provided.”



### 1.8 Do you now want a place in school?

- “Other than it will give us and him a break, our health is our first priority”
- “We feel desperate that our child is not in school as he has challenging behaviour and does not understand why life has changed and the prospect of ongoing restrictions is frightening. There is huge strain on the family however we would still rather keep him home with the risks of infection”
- “My son would not want to go to school at all but sometimes I feel tempted as he resists doing anything at all at home and is very demanding”
- “I'm finding it impossible to work and give one to one attention she needs. However, I know she would refuse school”
- “I would certainly consider her returning to school in the next few weeks if there were good systems put in place”



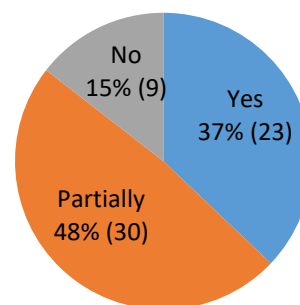
#### Why do parents still not want a school placement?

- The majority of parents are too concerned of the risk of infection to take up a school place and would prefer to keep their families safe at home
- Some say they are able to support their CYP better at home because of inadequate staffing in schools
- Some say there is no need for CYP to go to school while they are at home because of lockdown

#### However....

- Many parents saying they're struggling with having their CYP at home
- They worry that isolation and not attending school is **significantly impacting upon their CYP's education, mental health and wellbeing and behaviour**
- Many are feeling stressed and overwhelmed by the responsibilities of home-schooling

## 1.9 ECHP CYPs: are you getting the support needed?



### Where support is working well for families

- Many are receiving and welcome regular check-ins from school (some daily, mostly weekly)
- Some are accessing some online interactive learning, through a wide variety of platforms (Zoom, MS Teams, Google Docs, FaceTime etc)
- Many are receiving telephone or virtual support from teachers/TAs/INAs, or employing for TAs as PAs
- Several commented on how responsive schools had been when they has asked for help
- Some said they are receiving materials at home, eg printed resources/ sensory pack
- Several reflected their CYP was enjoying a more relaxed timetable/reduced pressure
- A small number of parents reflected they have the skills, knowledge and capacity to support learning – however more said they struggle to engage their CYP
- A few commented on positive access to OT/SALT and resources being sent home to use
- Two parents reflected on receiving support with learning from other SEN parent carers

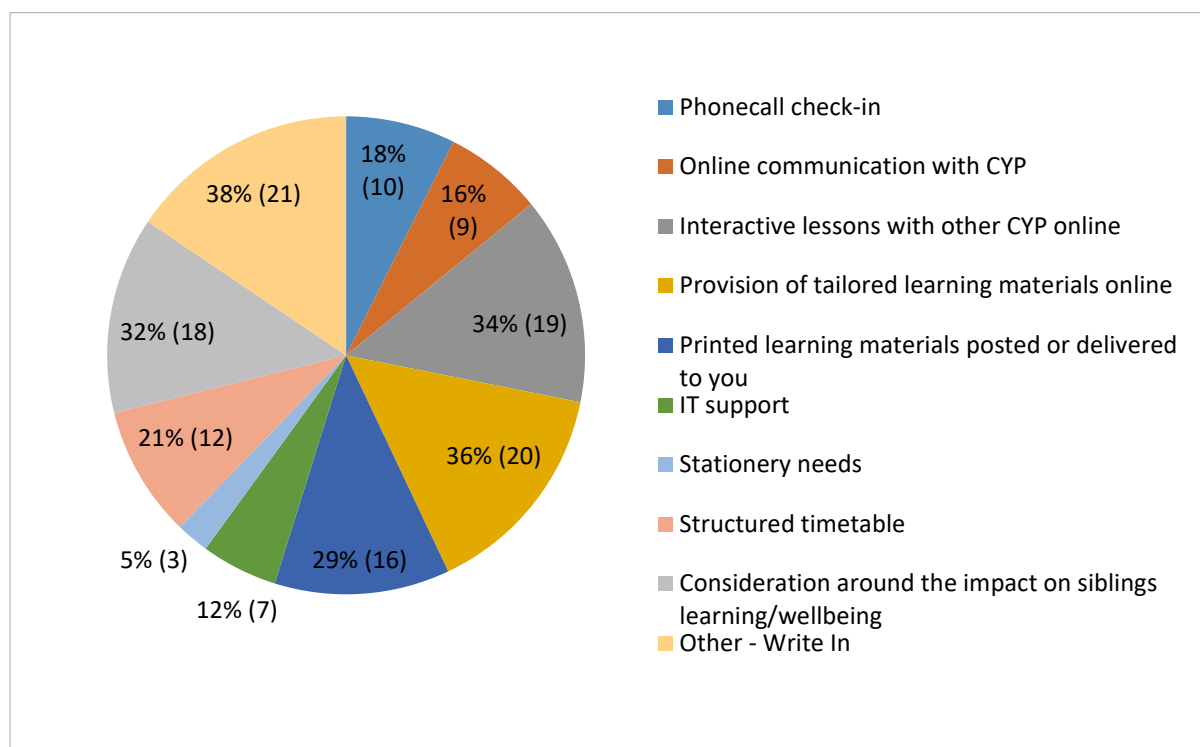
- “We get 2-3 hrs of online school, but I have to do that with him, he gets very frustrated”
- “Video clips created by his science teacher with her voice - more immediate than email”
- “The educational stuff is great - we have Clicker7 at home and have employed his INA two days a week to help”
- “PE lessons on YouTube”
- “School are sending links for physical activities to do before learning, helps regulate CYP”
- “Daily contact with his class teacher has been invaluable. Not putting too much pressure on myself to educate my son but to help him to stay calm and occupied”
- “Structure/routine based around the timings of typical school day, but fewer demands”
- “School contact has been amazing. I do feel very supported”
- “Easy to email teachers if any issues with the work set and they reply promptly. Great support from SENCO. Keeping learning in short chunks so not overwhelmed”
- “I asked if some sort of check-in could be offered so CYP could see a familiar face as she was feeling disconnected. A few hours later, the Head teacher arranged a Zoom session”
- “He looks forward to the weekly teacher call and even gets out of bed to speak to her”
- “School have been very supportive but CYP not engaging”
- “We never had such a full picture of his capability”
- “SALT (through personal budget) is continuing using Zoom”
- “CAMHS Urgent Help have offered us emotional support with managing my child's MH needs as well as delivering risk management and therapy over the phone”
- “We created a parent carer WhatsApp group to support each other and a separate group for the children to communicate what they have been doing”
- “Support from PACC and other families”

### Where families do not feel supported

- Work and resources being sent home are not differentiated or appropriate for CYP; they need to be more varied
- Many schools aren't offering online interaction and families want this
- Where there is no online offer, parents feel unsupported and CYPs lack social interaction, the opportunity for affirmation from teachers and are unmotivated
- Some parents say it is impossible to replicate (1:1) support their CYP would usually get at home (they lack capacity, skills, knowledge, resources etc)
- Some parents are struggling to engage CYP in home learning
- Several families are lacking access to (online) therapies
- A minority of parents appear to have had no contact / support from school

- "Some teachers are good, but most send undifferentiated work for the whole class. I am expected to contact teachers to ask for differentiation. It is hard to decide what are priorities and I don't like to make a fuss. I'd be much happier if teachers contacted me"
- "We have been given a work pack for our CYP, most of which is not applicable and CYP is not wanting to do this in home environment. The teachers have been calling on a daily basis through the working week to check in but that just causes more stress"
- "My son desperately needs some routine online group learning activities to see and join in with his friends and different teachers"
- "One dimensional way of learning isn't engaging my CYP who needs a lot of interaction. I have asked for zoom lessons and posted activities, both have been denied"
- "Work has been sent home with little instruction. The onus is on parental preparation and us having access to resources and a printer"
- "Some work is helpful as provided in the past eg SLT activities. Very short bursts of learning have been working but it is made difficult without the right resources"
- "Fortunately, the school has passed some on and we had some in reserve but we are having to piece things together from diverse and not joined up advice"
- "We cannot replicate the team who usually supports our CYP in school"
- "We have a PA in five days a week. We asked for more direct payment hours from our key worker. They first tried getting school to take our son back but school said no. They then agreed to pay the extra money for our PA with a review every three weeks"
- "Feedback from teachers and interaction with peers and teachers. It all needs my attention though and they can't help with that"
- "Can support with work but child not interested, or motivated"
- "No weekly therapies of OT/Physio/SLT which is worrying the longer lockdown lasts"
- "I'm not sure I can keep up with the standard of the curriculum or if the time off school will be detrimental to mental health"
- "We struggle explaining the reasons for the lockdown and why we have changed our behaviours"
- "My daughter has a child in need plan due to severe mental illness. CAMHS, Social Worker and Urgent Help Service are involved via telephone and talk with my daughter. My child is classed as a vulnerable young person due to her mental health and school have not made any contact about her welfare other than generic whole school emails"

## 1.10 EHCP CYPs: what further support do you need?



### More / tailored learning support

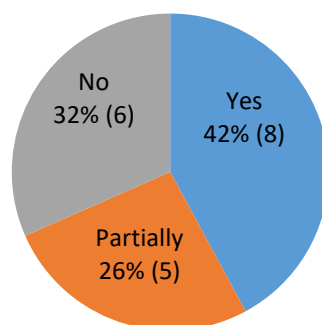
- “A teacher led video interactive lesson to keep him connected to school and ensure learning”
- “It is difficult/ impossible to support with learning when my husband and I are both working as CYP needs 1:1 support / is unable to do any self-directed learning. Online tuition from a TA/ teacher would be welcome”
- “Video calling as his language difficulties mean talking on the phone is impossible for him”
- “Clear guidance about which subjects to prioritise. More focus on basic numeracy and literacy”
- “Life skill activities to do with my CYP at home”
- “Some online school learning is too complicated. I need bespoke worksheets and games set by teachers who REALLY know CYP. It was helpful for school to provide stationery. Remote teaching would help CYP understand need for regular learning at home”
- “Contact with key staff for my daughter. My daughter has SpLD which she is not receiving interventions for from BHISS. The longer lockdown goes on for, the longer it will be without them and she will fall further behind”
- “Info about managing siblings always welcomed, and printed learning resources helpful as we don't have a printer and CYP is very hard to motivate”
- “Some online face to face with support staff, his favourite faces from school. And ESPECIALLY some SALT sessions.”

### Less pressure/expectation

- “Better understanding of the stress/additional demands that school are placing on whole family by insisting child follows interactive school day via internet, where parents must act as 1-1/ teacher and expectation to complete, or school calls to ask why work is not completed”
- “No pressure, happy for work to be sent but no timescales or issues if not completed”
- “I cannot engage her in learning activities at home so just hitting pause for now”
- “We get check in phone plus some online work and encourage him to do it - which he will do to limited extent then he goes. I don't expect more.”

## Section 2 SEN Support CYP (n.19)

### 2.1 Are you getting the support needed?



#### Where support is working well for families

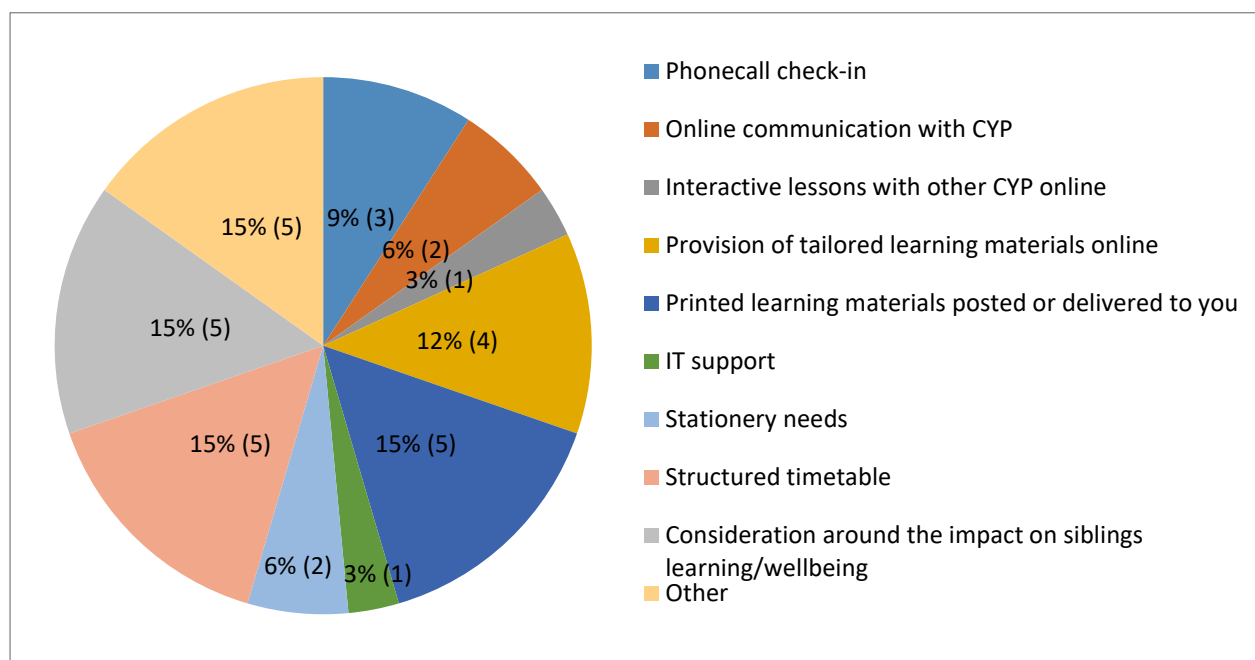
- Many parents said that schools are in touch providing clear, specific tasks, suggested timetables and support around learning. Some are offering online interaction
  - Many parents commented on CYPs' reduced anxiety without the pressure of attending school and increased flexibility around learning
- 
- "CYP has a school laptop and staff have emailed us several times, which is much more than previously. She loves lockdown and attainment has shot up but I have to remind to keep in touch with the one or two of friends she has. Social issues and bullying all gone but **concern is the utter shock of going back.**"
  - "Not having to attend school! She is much happier not having to go."
  - "She's less anxious in some ways as the pressure of school has gone. She's enjoying learning life skills. such as online shopping and doing the washing etc! Also liking being able to set our own routine with no external demands. It's helpful having school set work that is a manageable amount and not overloading her."
  - "She gets on with schoolwork much more readily – no bullies, no transitions, no misunderstandings with teachers, no rigmarole with one way systems in corridors or queues for lunch. I've never had as much attention from school. who have refused to refer for EHCP for past 2 years despite repeated issues."
  - "Contact by phone from Deputy Head to check how my child is coping, from SENCO, 3 emails from my child's teachers and TA. Also Face to Face have been in touch."
  - "BHISS sent through links with activities and things to do. Doing many varied activities as a 2 year olds attention span isn't always great!"
  - "We have kept a good routine daily and have fantastic support from school year head and teaching assistant. We talk every evening about worries and openly about everything."

### Where families do not feel supported

- Similar to EHCP CYPs, several parents say work set by school is not tailored to their CYP's needs
- Some have not received any personal contact from school/SENCO etc
- Several parents commented CYPs are struggling to focus on learning at home
- Some were concerned about the impact of delays to their CYP's diagnosis/assessments
- One parent reflected that the Covid crisis provides an excuse for provision being poor

- "All contact is generic. No check in or acknowledgement that either doing the work or organising themselves or dealing with the wider context might be harder than neuro-typical children. No check to see if parents are available to support child. Schools are under enormous pressure, completely appreciate that. Tbh, school is pretty poor in normal circumstances so not really expecting better now. Am concerned that gap will widen as a result of this though. Neuro-typical sibling able to learn ok as a self-starter. Neuro-developmental child less so"
- "The school have simply told us to log on to a portal - that's it. No personal contact with the SENCO or any more detail than that. My child is being treated exactly like every other child in this situation"
- "Printed material - ideas about how he can be motivated. Some tailored/personal messages from his teacher/SENCO to motivate him to do work. If he goes onto my laptop to do any sort of work, we end up with an immense battle as he simply wants to play games"
- "I thought someone would check in by phone at home but that hasn't happened. But he hasn't an EHCP so that might be in keeping with procedure"
- "No contact from SENCO for 4 weeks, then it was a brief email. Asked about how they will support my child upon returning to school and got a generic response about how they will support all families, not my child individually"
- "Need diagnosis of autism"
- "Because of the non-diagnosis at the moment the school won't apply for a EHCP"
- "We've given up on any demands, no school work getting done really. Mainly doing what we can to avoid red zone"
- "A learning mentor appointed by a 3rd party is offering 2 x 1hr weekly slots but apart from that nothing from the College. There has not been a named Additional Needs coordinator for nearly 16 months, staff 'pick and choose' what they 'feel able' to do from the Provision Plan, which is very little. Overall made to feel like a burden and actually quite useful that Covid has now overridden everything even tho issues predate Covid"

## 2.2 SEN Support CYPs: what further support do you need?

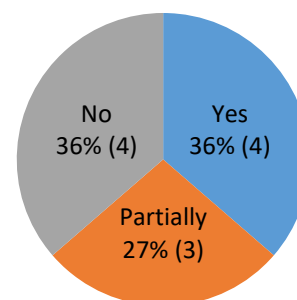


- “Help doing EHCP application. CYP "scores" currently are higher but this just highlights what being at school is inhibiting her from attaining”
- “I find it difficult to deliver speech and language support for CYP, however S&L has been in touch and promised to send some games and exercises”
- “Just someone to check in and care what is happening with my autistic child at home”
- “Suspension of the behaviour points system for not handing in work, when everyone is trying their best. Especially as the work was handed in. Very demoralising and unhelpful!”
- “Really feeling the lack of organised sport, and physical energy used while getting to/from/at school. Being inside house for so long is difficult for everyone”
- “No friends in person mean less opportunity to sound off when dealing with feelings - especially important for teens. We were lucky to have CAMHS appt just before lockdown as needed meds review. Not sure what would have happened otherwise”
- “Mascot groups. They are holding online ones, but we really miss the physical groups which obviously can't go ahead at the moment”
- “Everything that CYP had worked so hard to achieve involved gaining scraps of independence beyond the home, e.g. volunteering. Was just about to get support with public transport training - having waited 4 years for this, when everything shut down. Also had just been in touch with a befriender, with whom had hoped to e.g. go on walks/ to the cafe. These were all lifelines and the positive effect on mental health was noticeable. They cannot be replicated and so the isolation is even more intense”



## Section 3 CYP Out of School (11)

### 3.1 Are you/they getting the support needed?



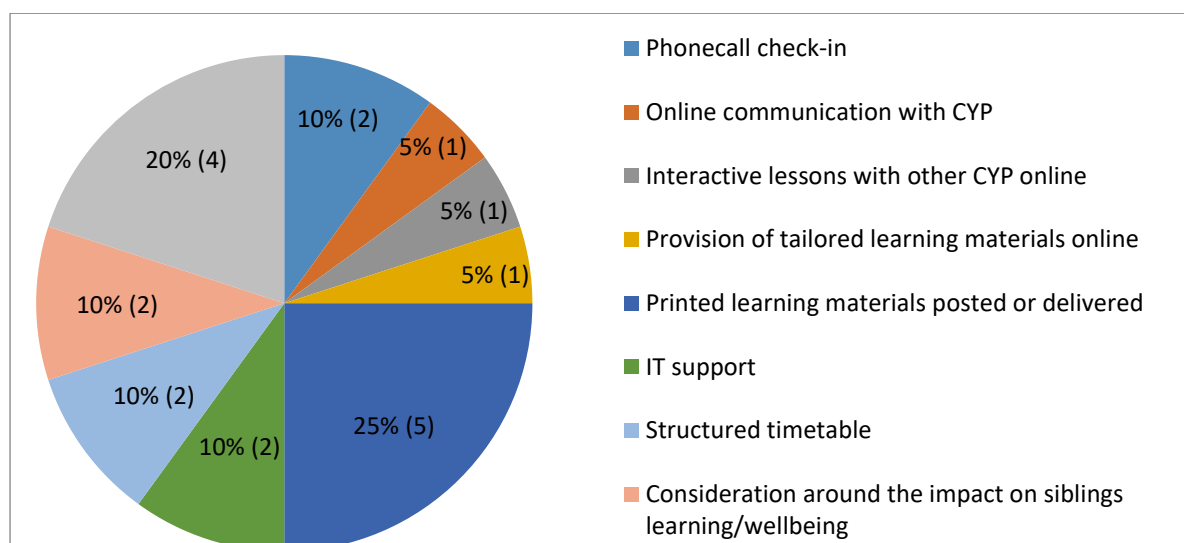
Families in this cohort tended not to answer this question in the same way as EHCP/SEN support families. They reflected more on the longer-term challenges around not attending school, rather than how the COVID lockdown is affecting them, perhaps indicating that little has changed for them.

- “My CYP is 22yrs old. When in school CYP had a statement but after serious illness during Yr 11, I felt the school just abandoned us and left us to it. I've tried all different ways to get my CYP help but to no avail. I feel their life is just passing by with no future”
- “CYP has not attended school for 2 years. They have been given home tutoring, however sleep disturbances cause meltdowns, and neighbours then complain about noise, so this is preventing lessons from happening”
- “CYP has epilepsy, refuses to wake up and this causes fits. Refuses to go to college now”
- “Receiving support from Function First Team but on waiting list for autism assessment”
- “Medical appointment cancelled since Jan due to illness, waiting for reschedule”

Some reflected:

- “Reduced pressure, eg for school work/allowing time to be, with low demand nurturing and more flexible routines which suited their CYP's needs”
- “A quiet and supportive environment with plenty of room to bounce”
- “Need for constant reassurance to CYP that all is okay”
- “CYP is disinterested in all things at moment”

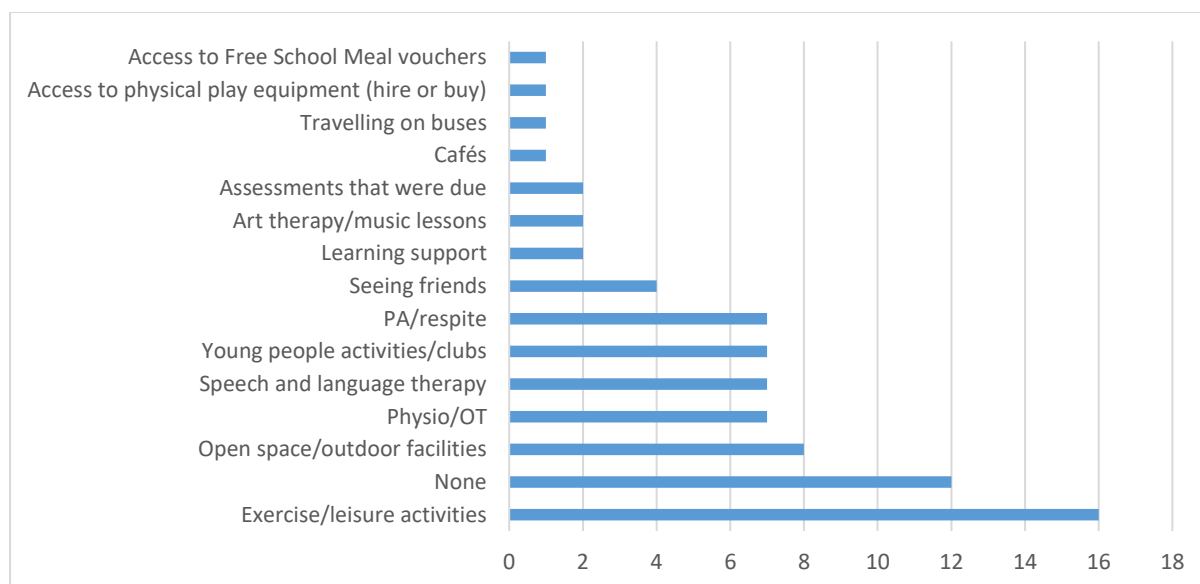
### 3.2 More support needed



- “Support needed with transition to adulthood”
- “School can't expect me to get to collect printed materials/we don't have tech at home”

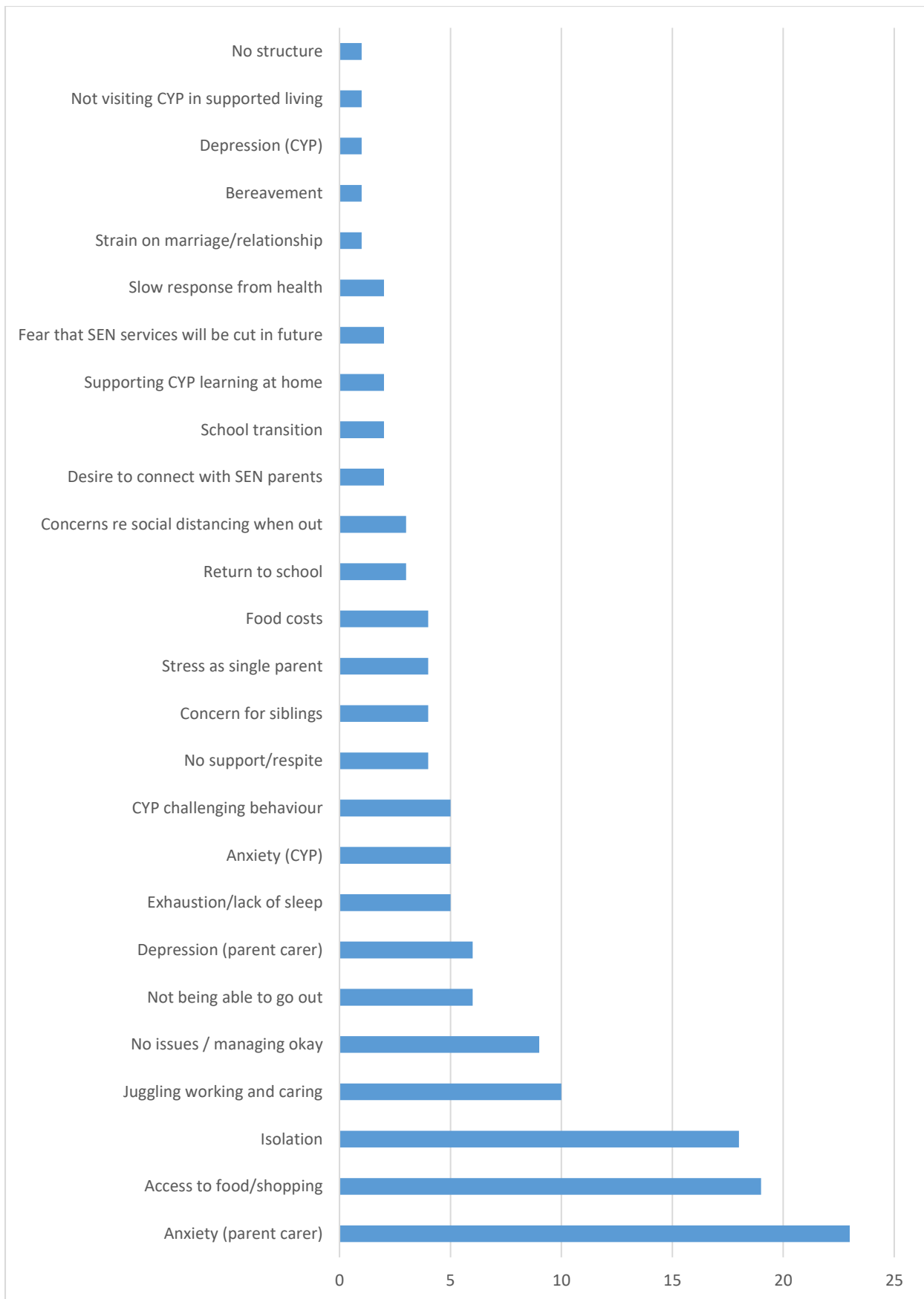
## Section 4: All Families (EHCPs, SEN Support and Out of School)

### 4.1 Are there other services or activities that your child would normally use that you feel they/you need, that are no longer available to you or not in the way you need?



- “He is unable to attend Art Therapy at CAMHS. His therapy is over the phone. It's working reasonably well but isn't the same as face to face contact”
- “Extratime: as a key worker I had to work over Easter, but I was informed that DVLC was not included when looking at which students are key worker children”
- “My daughter was on a waiting list for a full cognitive assessment at Seaside View. Had a phone call to say this was delayed. We were also going to attend an OT sensory workshop, which was cancelled”
- “I'm concerned he won't go back into school he's already said he prefers this learning”
- “Being around mainstream peers - I'm sure they're all checking in with each other right now but for our CYP, this has fallen off a cliff compared to the 'friendships' she experiences at school. Major isolation right now”
- “Used to have weekly OT, Physio and SLT delivered in school. This is not happening now”
- “Individual in-class teaching support. We are both working FT and it is a real challenge to find a balance between a lack of stimulating work and finding time to do this”
- “Access to online resources that are good for the special needs community – a lot of good learning resources but very challenging to sift through what might be a good fit”
- “There has been very little SALT input, just a couple of attachments with 2 words to practice blending, and a garden scavenger hunt! For a child who has severe S&L Disorder and provision of 9-12 hours per term, this is pretty lame”
- “Usually have check ins with physio and audiology”
- “CYP's respite at Tudor House is about to end due to him turning 18 in March. It's been [temporarily] extended as transition planning to adult services came too late. This respite is the only break we have during this crisis and we've now been told our CYP's last visit will be on Monday because they don't want to set a precedent with having over 18yr olds”

## 4.2 All families: are there any other issues you're struggling with?

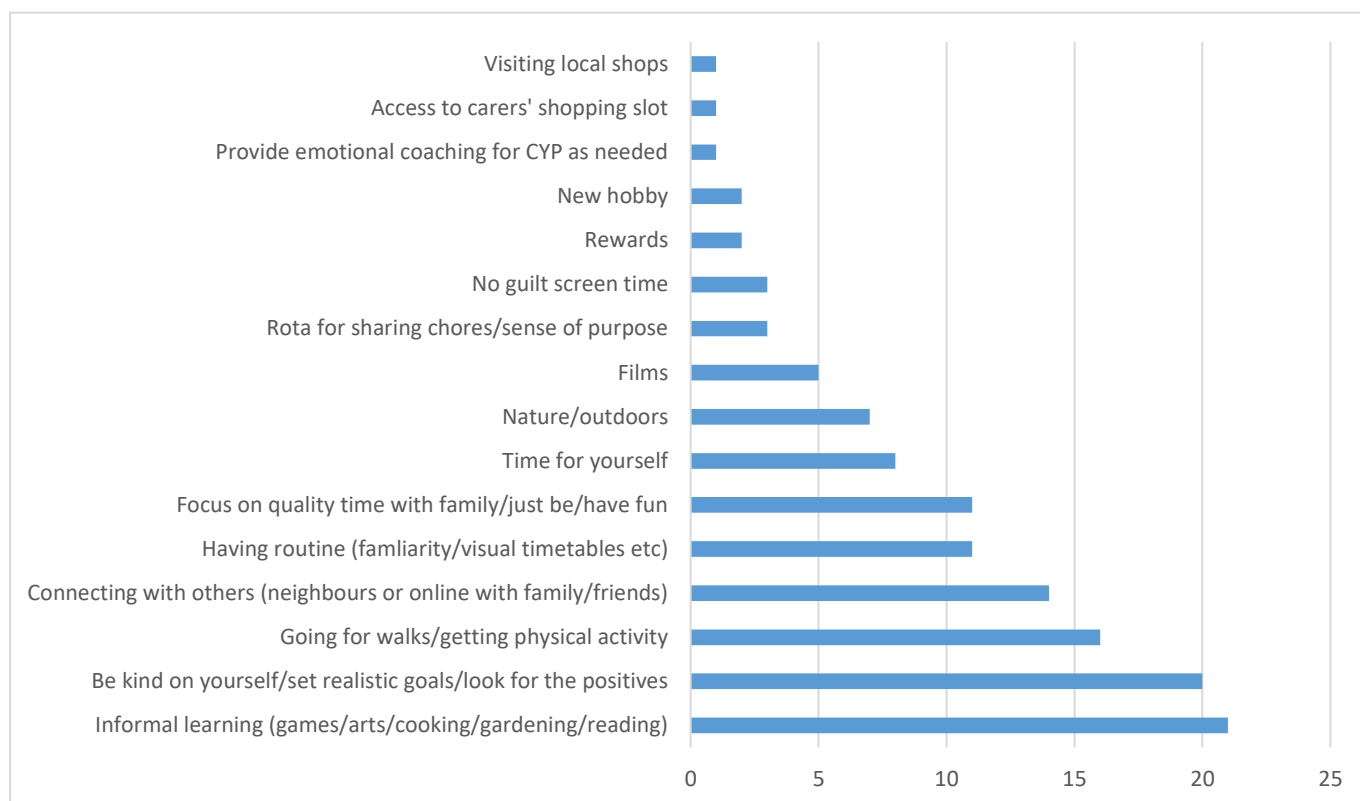


**\*\*Access to food shopping: 12/19 are struggling with food delivery slots, and 3/19 are struggling with food restrictions)**

### 4.3 Examples of issues families are worried about

- “Anxiety about contracting the virus, about how safe I can keep my family even when lockdown ends/children return to school and until such times as a vaccine is developed”
- “Anxious that because we have coped, it will be considered that we no longer need respite. This combined with economic impact of CV may see a reduction in our package”
- “Anxiety as a keyworker hoping not to bring the virus home”
- “We're all anxious living with our son, we don't know when he'll "explode" next”
- “Foodbank are bringing food tomorrow, they said they will call the week after to see if we need food. Eldest daughter is staying as university closed, has no money to contribute so I'm feeding her to. Starting to feel more anxious and isolated than before as I'm finding hard to do the usual routines I had before, missed a first session of counselling for my anxiety that I had waited ages for”
- “We can't get priority click and collect as we are vulnerable but not the highest risk. We don't feel we want to risk physically going to the shop to take advantage of the letter Amaze provided” “It's taken 3+ weeks for health authorities to record CYP as extremely vulnerable”
- “No delivery slots to get our shopping as we'd normally. CYP is frightened to go out”
- “CYP has to keep herself entertained for periods of time during our working days”
- “Sibling gets no attention from me. Supporting 2 SEN CYPs disparate needs is a struggle”
- “We are experiencing more breakages than usual as CYP feels confused, out of routine”
- “CYP has started being able to resist taking his melatonin”
- “My child was due an ed psych reassessment- I am concerned for this delay”
- “It was agreed that transition would start in April due to CYP's SEMH. I worry what will happen if she hasn't had a proper transition and is unable to communicate with staff”
- “Secondary transition scuppered. School had a whole term of transition activities planned and we fought tooth and nail to get CYP placed there”
- “My CYP needs to let off steam. We need support accessing outside space. We live centrally, I'm a non-driver, my CYP is unable to just go for a walk as he needs a focus”
- “CYP doesn't understand he can't go anywhere on a walk and so gets aggressive. We don't take him out as it's too confusing. He has very limited self-occupying skills and is bored senseless”
- “Worried about confusing guidelines about who will get critical care, CYP is an adult”
- “I am not worried about my kids' education but bigger worries re getting ill and work”
- “Helping teens (neuro-typical and neuro-diverse) deal with their emotions about uncertainty, missing friendship, impact on next education stages etc”
- “Regressive/clingy behaviour again now. Shopping and planning meals is a constant pressure since so much else has been stripped away the attachment to the 'right' food has become even more obsessive, so sourcing that is an issue. Also the amount of handwashing for CYP was already high before Covid due to OCD, now it's even more so, and constantly trying to source handwash. Maintaining my mental health is hard whilst trying to boost MH of CYPs who have little or no insight into their feelings”
- “CYP has lost interest in activities we used to do such as arts and crafts”
- “I've not had the head space to do anything about secondary application and I feel like I've missed the chance”
- “I feel trapped from time to time with an abusive child”

## 4.4 All families: is there anything you have found has really helped you cope during the last few weeks that we can share with other families?



- “Writing together a list of 20 activities to do so always something to do”
- “Mixing learning with sensory/physical breaks. Lots of play based learning”
- “We have looked at wildlife in the garden, drawing them, habitats etc”
- “Creating virtual versions of things we were going to do anyway. Clapping is a big event!”
- “Our Pebbles pilates teacher has been doing a morning workout each week day on FB”
- “Be kind to yourself. You can't do everything!”
- “Having one or two 'set' structures or rituals each day”
- “Just taking each day as it comes and trying not to think too far ahead”
- “A sense of humour!”
- “Luckily we live on the edge of the Downs and have an allotment so can avoid people”
- “A FaceTime Barbie play session with a school friend”
- “Fighting for direct payments and being able to have our PA in five days. We would not have coped if she wasn't here”
- “A Zoom session with his LGBT club once a week”
- “Having the letter stating that we can go out on a more regular basis is very helpful. For my own sanity getting out of the house to walk up to the Downs for a walk is a lifesaver”
- “I'm autistic myself and not going out is my norm. Not having to explain myself to other people why I haven't planned any fun activities is actually a great stress reliever”
- “Share jokes/laughter/silly videos - record your own”
- “Giving up on bedtime battles. 'Normal' times to do things doesn't matter so much now”
- “FB mAScot supporting ASC families has been a great reference. And Amaze sending emails with support and BHISS too”
- Online counselling (Better Help), Reading Eggs App, Social Detectives by TLC, online videos by Music Mike, finding author CYP likes & linked resources, online drawing course, Arthub, Phonicsplay, Twinkl, Joe Wicks, David Walliams, Carol Vorderman Maths.

### Top tip 9-3 timetable

9-12 school learning and the afternoons are for art, cooking, gardening, cleaning. School work is aimed at CYP level, little and often is key. Lots of sensory/physical breaks. Try to include some short fun activities before the main learning. Fridays as a fun day so finish early, bake a cake, do crafts and then have a prize assembly. Allow computer games after school has finished every day!

#### 4.5 All families: is there anything else you would like information about/support with?

- "How to keep daughter safe from son"
- "Schools legal responsibility regarding school places for vulnerable at this time"
- "I am diabetic and was told to shield but I may have to go out shopping anyway as I'm not vulnerable enough to get any help. It doesn't make sense"
- "How to access support without being made to feel we have done something wrong or are undeserving of help, which is what has happened frequently previously and has stopped us asking for help"
- "I feel that the impact on siblings is not being discussed at all"
- "As my son is year 11 I am trying to apply for a place at college but have been unable to contact anyone there. I have also emailed but had no reply. I have posted an application but have no idea if it will be received if the college is shut"
- "Keeping healthy and not putting on weight at the moment"
- "Just having helpline there can be very useful so this is great"
- "I would like to explore the value of having a social worker as I feel we are managing too many elements of our son's care without support"
- "Some online exercise class specifically for disabled kids they could do together"
- "I need understanding from employer that to home school a child with additional needs is a FT job and I need to be furloughed. I'm a key worker and haven't asked for this (yet)"
- "I need help to move. Lockdown would have been very different if both my children had their own bedrooms and a garden. It's a nightmare that I wish won't be repeated again"
- "Connection with other parents of children with ASC"
- "Podcasts from those with young adult dependents with ASD"
- "Information on whether or not increased screen time is actually harmful"
- "EHCP self-referral"
- "Forum for CYP with anxiety to get help/tips that is specifically aimed at CYP not adults"
- "A phone call from the appts that were supposed to happen to see if we could be doing more to help during this time"
- "Support applying for DLA"
- "We had to go to A&E last Sunday. He had a head injury after a seizure. We got told off 3 times because there were 2 of us helping him. When one of us managed to leave as they instructed he left the cubicle looking for us. The Nurses and Doctors were good and helpful medically but couldn't understand the severity of his learning difficulty and Autism plus the extra challenging behaviour due to a seizure"

**REPORT ENDS**

**Appendix 1:**

