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Parentsactive survey report

Survey on Local Authority, Health and Support Services around the pandemic

Conducted by Parentsactive
19th June – 20th July 2020

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Survey on Local Authority, Health and Support Services around the pandemic

66 parent/carers took the survey

Please scroll down for the full list of responses in the appendices section

Full Report

Parentsactive has written this survey in partnership with the Local Authority, the aim of this survey is to help with future planning, address issues and improve standards. The survey went live on 19th June 2020 and closed on 20th July. 66 people have taken the survey. If you would like to see the comprehensive survey results including charts and parent comments please follow go to the appendices section after the main report.

Summary

The survey has been answered mainly by parents of children/young adults 0-25

Age Ranges of children/young people

18 -25	8
13-17	18
5-12	36
0-4	3

Some respondents had 2 or more children and each child was counted within the age range

SEND service

45 people were happy and had issues which were supported and 19 felt that they could do with more support or were not supported

Key Points

- Regular communication and contact from the SEND services seems to be the key message
- Some clarity on what will happen with schools also seems to be another point
- A single point of contact from SEND for parents who have 2 or more children in varied schools with SEN

Educational settings

47 people were happy and had issues which were supported and 16 felt that they could do with more support or were not supported

Key Points

- Experience seems varied with schools with some maintaining regular contact and very supportive while some schools have barely contacted the parents

- Some parents have children in multiple schools with each child receiving varied level of service
- Homework is varied with some schools not checking if parents can cope with teaching their children while others have been very supportive
- Experience with the college setting has been well meaning but chaotic

Health

Health has fared well with 47 parents saying that they were supported or had issues but felt supported, 16 said they could do with more supported or were not supported.

Key Points

- Appointments being cancelled is the main issue
- Lack of consistent therapies with special mention of OT and physiotherapy
- Mental health support and behavioural support was also mentioned
- Regular testing of care workers was mentioned and stressed upon at various points in the survey

Social services

33 people were happy and had issues which were supported and 22 felt that they could do with more support or were not supported

Key Points

- More clarity on what direct payments can be used for
- Avoidance of just saying use your direct payments all the time
- Many have said they don't use social services
- Varied responses with some mentioning housing issues and therapies, health issues in this response

Support Organisations

28 people were happy and had issues which were supported and 28 felt that they could do with more support or were not supported

- Many have said they don't know what these organisations do or what support they offer
- Many have said they use SENDIASS
- One person has said they found AODs virtual play scheme very useful and another person praised the Play Association
- One person has said they get good support outside educational settings and few others have said that they receive support from their keyworkers

Local Offer

18 are aware of the local offer, 24 are aware of it but do not use it, 22 are not aware of the local offer

Key Points

- Many did not know what the Local offer was
- One person said links don't work
- One person said it appears to offer activities for very young children
- One person said they could not find what they wanted

Parentsactive

Timings for sessions

- 11 am and 2 pm seemed to be the popular timings
- 45 wanted weekly updates and 25 wanted webinars
- Parents seemed to be happy with Parentsactive in general and one wished the webinars were recorded

General comments

- Loneliness and isolation
- Disabled children/young people anxious with resulting pressure on siblings and families
- Money worries
- Overcrowding and claustrophobic with the whole family managing in tight housing situations
- Lack of school routine impacting on behaviour, lack of contact from certain schools

A more comprehensive list of comments is in the appendix

Parentsactive Conclusions and Recommendations

- Most services have done reasonably well during the pandemic
- Communication and regular contact appear to be key whether it is health education or social care
- Plans need to be made to reduce isolation and get families together
- Housing seems to be an urgent need for many parents especially after the pandemic
- Efforts should be made to publicise voluntary sector organisations and utilise them better

- Mental health and behaviour support will become key services when the recovery phase resumes
- Local offer needs urgent consideration and overhaul
- Recovery curriculum with schools needs to be planned with sensitivity

Conclusion

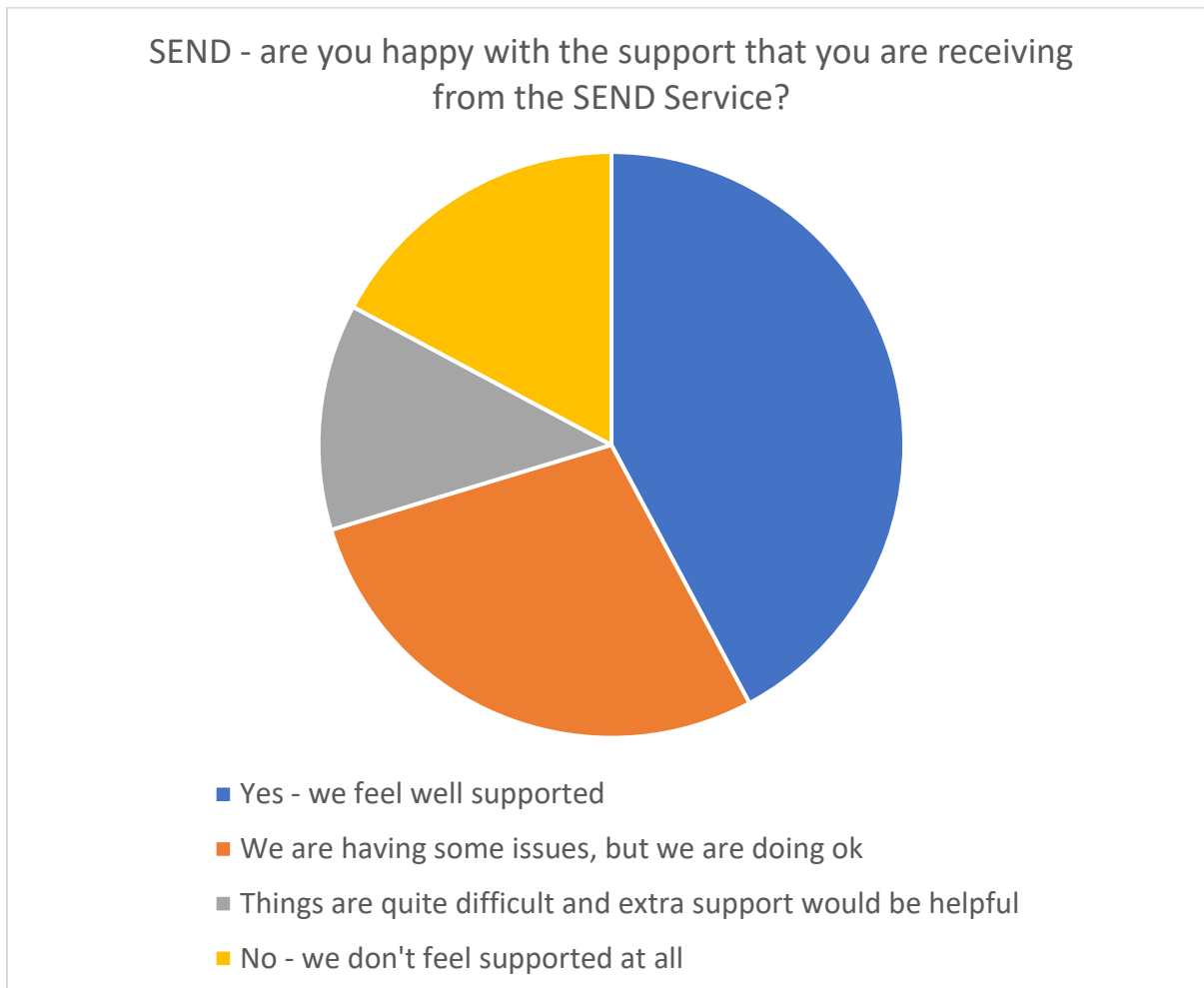
In the light of the pandemic and the extraordinary times we have been through, some sensitivity and patience to the plight of parents/carers is highly recommended. Every effort should be made to reduce frustration and ensure parents get timely responses and reassurances. With SENDIASS coming up for retendering, it will be valued if all support services are investigated. The recovery phase is crucial, and we hope this survey has helped to plan the phase, so life is a little easier for parents and children alike.

The report above are key points analysed by Parentsactive and is for general circulation, the report from Microsoft forms will be shared to professionals in a secure way in case further support is needed for individual comments and casework

Actual anonymised responses in the Appendices below, please scroll down to the next page

Appendix A – SEND service

Q.4 SEND - are you happy with the support that you are receiving from the SEND Service?



Yes - we feel well supported	27
We are having some issues, but we're doing OK	18
Things are quite difficult and extra support would be helpful	8
No - we don't feel supported at all	11

Q.5 SEND - what do you feel will help? - Comments received:

1	Communication. Communicate things that going on regarding the child whether it is positive or negative issues.
2	More information on what is available during this time
3	More parental support
4	It would nice to be contacted. We have not had any and feel very isolated
5	Unsupported - no help or communication
6	No contact at all from SEND
7	Note: We haven't used any SEND resources but haven't felt like we have really needed them
8	FIND OUT WHAT IS GOING ON IN SCHOOLS WITH VULNERABLE CHILDREN... HIRE SPECIALISTS AND TEACHERS WITH EXPERIENCE.
9	A mental health support worker or a befriender as she is very isolated.
10	More online activities or groups for my child to participate in, over and above those offered via their school setting. As an isolated child, now cut off from contact with peers, he is stressed and anxious. There have been more incidents of feeling overwhelmed by uncontrollable anger and incidents of self-harm during these episodes. I don't know where to turn for support for either of us.
11	We have had no contact at all with the SEND services
12	The main issue we are having is lack of response from SEND - having to chase them up regarding an appeal for my son's SALT reduction in his EHCP. It would be great if they could contact us to see if we are ok.
13	It has not always been easy to contact my keyworker, I have left emails and contacted the Stephen Wiltshire centre, it is now the 26th June and I sent an email on the 8th June. I am not expecting an email the same day but at least within 7 days I think is reasonable. I understand there is a lot of pressure on the service, but parents do need clarification on what is available to them and they can not get that if they are unable to get hold of anyone.
14	Clearer communication now we have been granted the ECHP. There has been no mention when the extra help will start or what the procedure is after an ECHP is granted. Is there a delay with sending the money to the school because of covid-19?

15	We have little interaction with SEND services as school is being very supportive. That said, like all parents I'm very concerned regarding the duty of care changes to EHCP and do feel my son is not receiving all the elements of his EHCP. This relates specifically to OT and Physiotherapy input/support. Physiotherapy input was also due to be delivered by Health, but our therapist was then re-deployed due to Covid. She is now back in clinic but still not allowed to conduct face to face therapy input which is difficult as she has not met my son in person yet and therefore a zoom call is not sufficient as she would need to do an in person assessment first. On a positive note, Transport has been amazing and has enabled my son to return to school for a few hours every morning - with same staff as before so really smooth operation.
16	We haven't had any contact from the SEND service at all - a check on our situation and wellbeing would have been appreciated.
17	some support with child's behaviour, advice.
18	Returning to school
19	Police, H&S executive, medical and social care
20	He with forms to fill out for my son's i have my 4-year-old that has no school for sept due to moving and lockdown. I really don't know what to do.
21	Communication
22	I've got 3 children with additional needs and it's very hard meeting all their needs. It feels like there's not a lot of outside support available.
23	Nothing as I feel Everyone doing a great job
24	We need respite
25	Being more open with parents to how long timings may be. I'd rather know how long I have to wait than looking forward to a date that isn't possible for the send team.
26	Getting the right support for our so. At School. Liaising with the school
27	Under 5 stay and plays sessions to be reintroduced so normal routines can resume. More support with areas outside of the 'educational settings'.
28	Before all the playground were closed my child was terrible upset , he can't ride a bike he doesn't know how to play football and the only thing that we could do was to walk in the park(my child couldn't not understand that he can't go to the playground, he did not understand the whole situation. I think that council left people like us completely without any chances and help of doing any outdoor activities with kids with special needs. They told me that during, in the middle the pandemic I can go to Steven Wiltshire Centre. The Centre was packed with kids, they put all this kids in danger. If was safe to send kids there, why on earth the schools were closed. Council should have open at least playground in

	special schools for children in special needs that wanted to play. My son has written in his EHCP plan to do as much as possible climbing, swinging and outdoor activities.
29	Yes
30	OT Music therapy Art therapy Support with education regarding specialist interests creative writing
31	We weren't offered any support from the SEND service.
32	A Single point of contact to co-ordinate comms & actions to/from the individual schools and SEND service. A family such as mine has 3 children with EHCPs. Each of them has completely different needs, which jars with the widely varying practices from each of their educational institutions, oblivious to the wider family impact since they only are concerned with one of the three. The burden of managing that disconnect and comms avalanche from three separate institutions falls on the family, who are already struggling to manage the rest of the kid's daily needs.
33	Clarity about return to school plans in the new school year.
34	Continuous follow up
35	Our Borough SEND is very active and try their hardest to see and engage with everyone. It would help a lot if H&F would listen to what they need in order to help out more families like us.
36	To update us with what help or support we can get from the government (agency/group) that will help him to grow and develop.
37	Life back to normal!
38	We feel supported.
39	My daughter has a health placement
40	Support with finding carers but they already assist.
41	I honestly don't know: the uncertainty surrounding the pandemic and all the changes that have resulted from it have sent our ASD son into a tailspin. Perhaps direct access to OT-type therapy

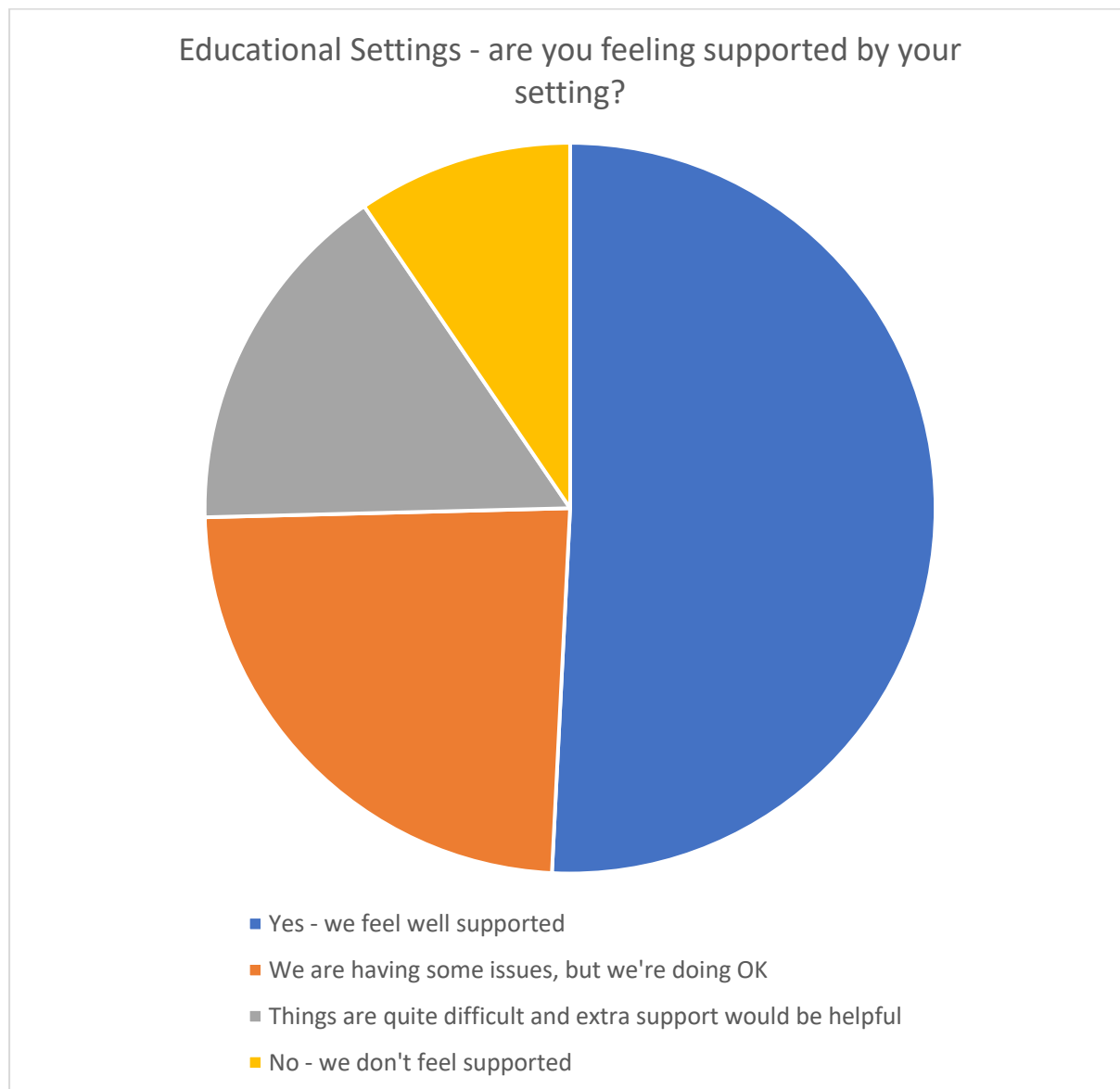
Appendix B – Educational Settings

List of Educational settings and figures for responses

Addison Primary	3
Ark Burlington Danes Academy	1
Ark Swift	2
At home	1
Brackenbury Primary	2
City of Westminster College	1
Fulham College Boys School (Queensmill Unit)	1
Greenside Primary	1
Hammersmith College	1
Hurlingham Academy	5
Jack Tizard	2
Lady Margaret School	2
Larmenier & Sacred Heart Catholic Primary School	3
Linden Lodge Southfields	1
Marlborough PS, transitioning to Woodlane High School	1
None	1
Oratory	1
Priory Lodge School	1
Q6	1
Queens Manor Primary school	1
Queensmill	1
Queensmill college	1

Queensmill Unit at Fulham Primary School	1
St Augustine's RC Primary	1
St John CofE Primary School, Walham Green	4
St Marylebone CE Bridge School	1
St Marys Catholic Primary School - Brook Green	1
St Paul's School	1
St Stephens	1
The Children's Trust Tadworth	1
The West London free school	1
Thomas' Academy	3
Woodlane	1

Q.6 Educational Settings - are you feeling supported by your setting?



Yes - we feel well supported	32
We are having some issues, but we're doing OK	15
Things are quite difficult and extra support would be helpful	10
No - we don't feel supported at all	6

Q.7 Educational Settings - what do you feel will help? – Comments received:

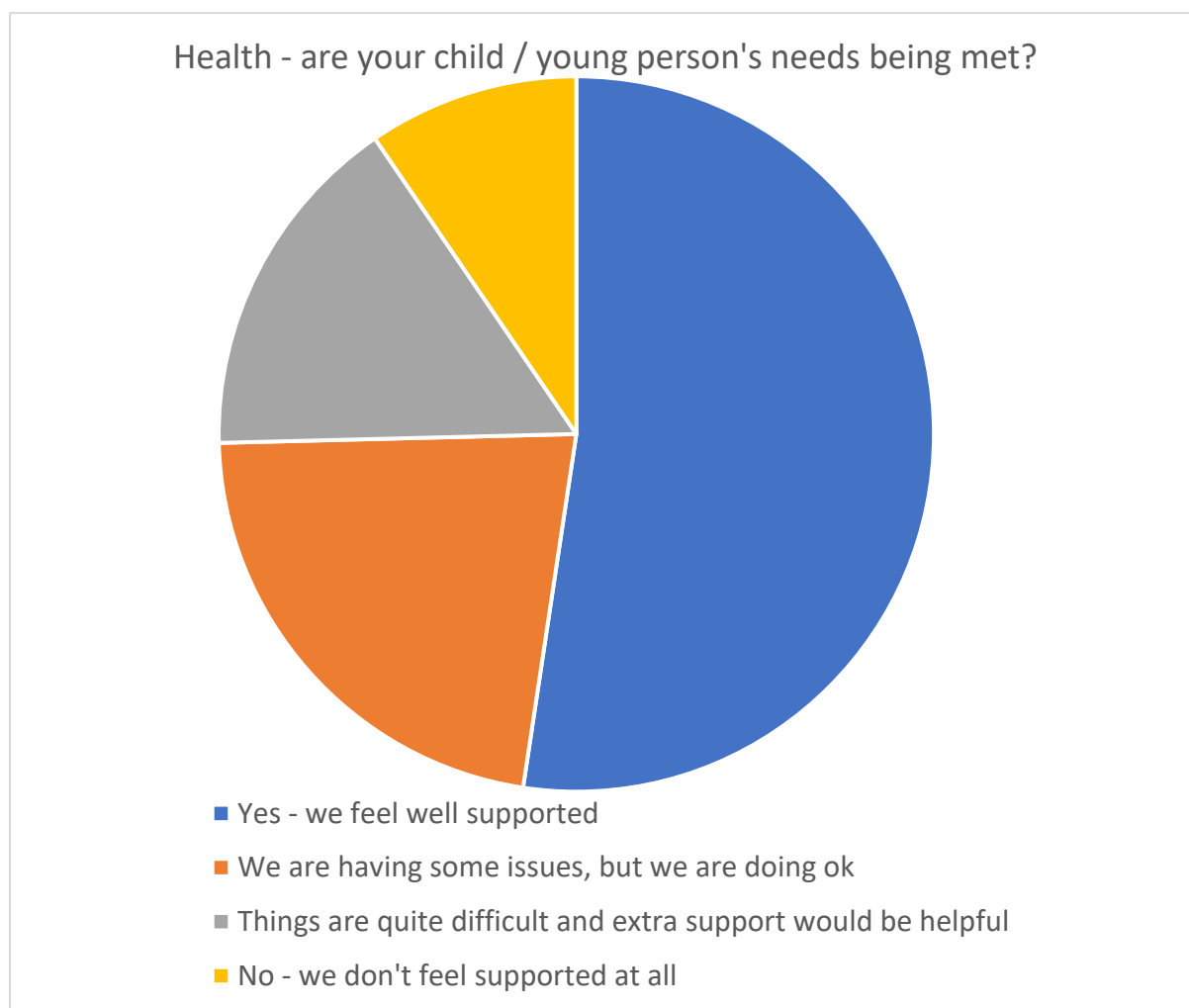
1	Understanding and patience
2	College have been really good about keeping in touch, sending work and now setting up online lessons
3	Meeting other parents going through similar situations
4	A phone call, direct email, any direct contact. No body from the school has been in touch with us directly which is very bad.
5	Since 20 March we have had no contact with the school apart from work being set. Not one single telephone call or direct email to ask us how we are and if we are coping.
6	It has been really nice as my daughter gets daily emails from her LSAs to see if she is all right. The SENCO, Miss Sparrow is always helpful if there is a problem and my daughter feels confident to get the help she needs if she asks. The girls also get a daily email from the Headteacher praising different girls every day for their work which is very motivational and makes them feel that they have not been forgotten. The school have been very good at communication despite the fact that the girls are not at all.
7	APPALLING LACK OF SUPPORT FOR AUTISM CHILDREN
8	A creative writing support worker
9	They are out of the borough, but they have been amazing. They were totally up and running with an online classroom within a couple of weeks which is rich, has loads of activities and provides a wonderful resource for my child.
10	Good
11	This is difficult, as I have had two very different experiences - my Daughter's school Lady Margaret have been excellent - regular contact, direct emails, calls, zoom meeting with SENCO etc. My daughter also has daily contact with her LSAs which is brilliant. My son's school, St John's, have not been in contact with us at all. Communication is non-existent. No check in to see if we are ok, alive, need help. Anything.
12	Dedicated keyboard device (e.g tablet)
13	I think the school are will intended in some of their actions but the pressure to try and complete homework that can be complexed for parents who have been out of education awhile in regards to the core subjects like maths and English and no teaching experience it's a great challenge. I have not felt that there is any real interest to find out what education is she receiving, it's like out of sight out of mind and maybe their attention is on those children attending the setting. She's missed a lot of the assigned work from school because I have been doing other things with her like cooking and work set by her new

	secondary school which she will start in September. In my situation they are aware how much she dislikes the school and no effect has been made by the school to change this or interact with her at all, I received one call from the headteacher. Although, I am in contact with the SENCO via email, that has been more to do with her EHCP annual review. A zoom lesson once a week on a piece of work she finds most difficult would have been helpful to her.
14	More clarity about when the extra help will start and in what form.
15	More understanding of disability and sharing information with staff
16	Better communication
17	Due to staff shielding or staying at home as not travelling via public transport to minimise Covid risk I feel that my son's support in school is less vs normal, i.e. his dedicated 121 (LSA) is not in school. Not sure how school can overcome this unless they employ new staff.
18	There has been a real issue with regular contact in how we are getting on; we received one call from his teacher and one call from the SENCO throughout the pandemic. My son receives work daily via email, but I am not able to support him throughout the day because I am working from home. He is occupied to some extent but whether he is learning is another thing. A weekly/ bi-weekly telephone call would have made all the difference. It would also have been good to have some class sessions via Zoom/ Google etc.
19	More support from the Senco. Only had to phone calls from them. Lots of calls from class teacher.
20	Returning to school
21	We want educational support we don't want head teachers playing 'social worker'.
22	One of my son's has support from his school but my younger one's nursery is in Ealing and we can not travel to get him in.
23	Longer school days, more days in school. It feels like they're using 'deep cleaning' as an excuse not to open, or to operate very reduced hours.
24	Covid-19 affecting; thus no help is given. Facilities has stopped but my children disabilities haven't.
25	Adequate support
26	The time it takes to set up additional support in classrooms seems unnecessary. My son could have started long before this September coming but wasn't able to one because of Covid 19 and two because of the time it was going to take to arrange his support worker (which is still ongoing on and he is due to start in September 2020) Also, I was given wrong

	and discriminative information when I was viewing all the main stream schools on the area - such as the schools wouldn't be able to take my son as he not toilet trained. Had it not been for my key worker and meeting with a lady from the insight team I would have been extremely stuck.
27	Teachers and head need to stop trying to being social workers. Stick to the job you are paid for
28	Yes
29	Online support with therapy and education for specialist interest
30	I'm answering this on behalf of three children, so my answer has three parts. The youngest one's plan is fine. The second child (in mainstream maintained secondary) simply must change school - the placement is entirely and irreparably broken. The oldest one - in West London College - needs much better comms about their plans. Everything they do seems to be well meaning but it is a very chaotic setting and difficult to know how to get the right information and progress enquiries
31	As above
32	Keeping it conducive to learning for special needs pupils
33	It has been difficult for everyone as we all have to adjust to corona virus restrictions. As of now, we do not know what we are face with, so I will answer this question when things gets clearer as to how schools will operate in September and what extra help they can offer my child.
34	To enrol him in swimming lesson because he loves water (to swim) for his safety. Good and dedicated speech and language therapist and LSA.
35	REGULAR TESTING to keep groups SAFE and thereby other vulnerable family members shielding at home
36	More structured Planned work to assist my son at home during homework. It would have been helpful if I had a planned homework for each week to follow on.
37	We feel supported.
38	More therapy support
39	All services stopped by my child's education setting. There was no communication and what was stated in his EHCP was not delivered.
40	Increased budget: our son has 24hrs 1:1 a week as part of EHCP but the TA who delivers it is also the class TA so her time with him is compromised. She is also expected to deliver the majority of his SLT and OT interventions after only minimal training.

Appendix C – Health

Q.8 Health - are your child / young person's needs being met?



Yes - we feel well supported 33

We are having some issues, but we're doing OK 14

Things are quite difficult and extra support would be helpful 10

No - we don't feel supported at all 6

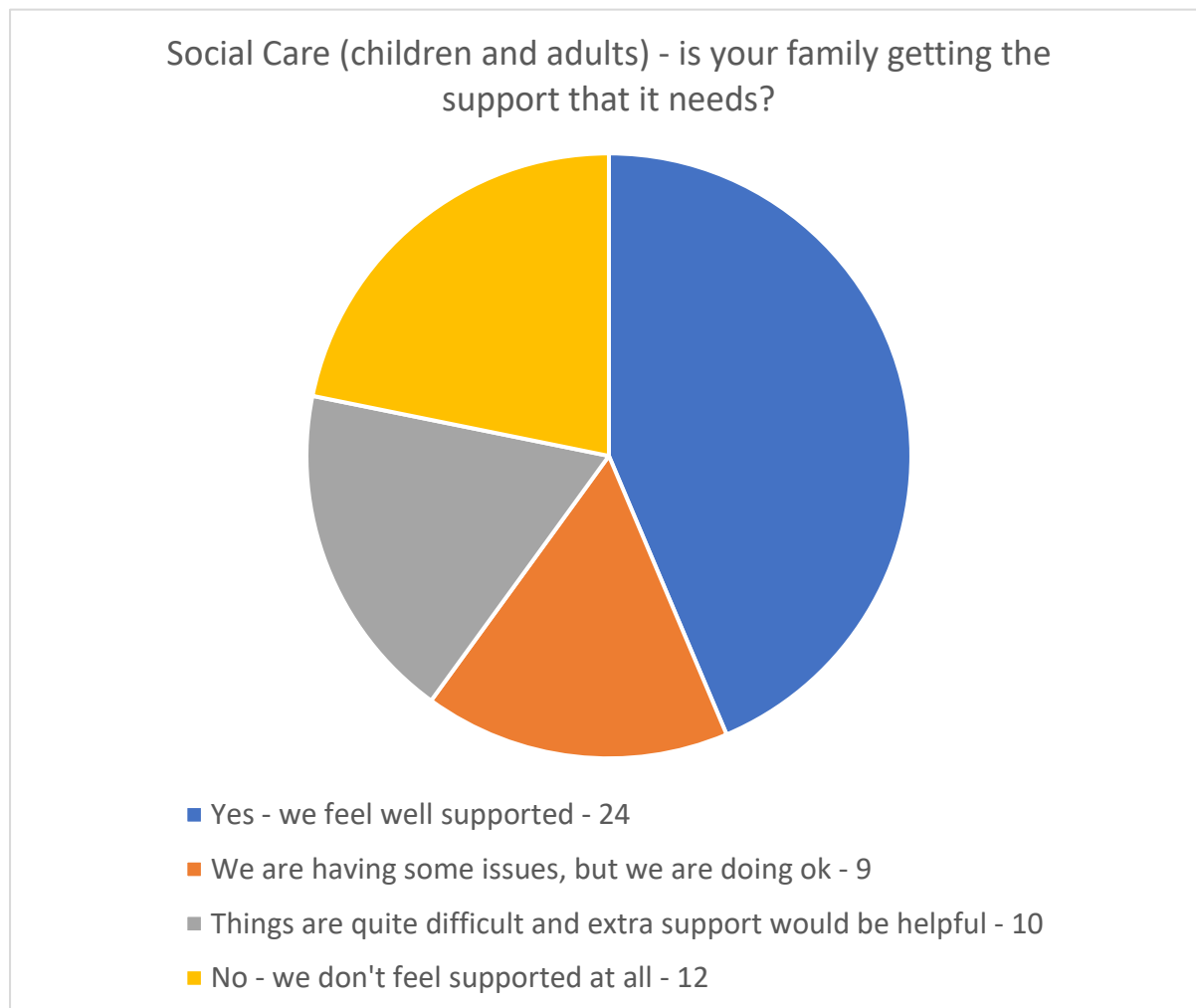
Q.9 Health - what do you feel will help? - Comments received:

1	My son always has issues with his health especially with respiratory infection that cause his absence in school.
2	Luckily my child is healthy as I don't know where we would go for help if not
3	Groups to encourage children to participate in similar interests
4	n/a
5	n/a
6	Appointments have been cancelled and we don't know when they will be reset up.
7	Note: We haven't used any Health resources but haven't felt like we have really needed them
8	SPECIAL SCHOOL AND THERAPY IN SCHOOLS
9	A mental health worker to support due to the isolation. Of the young person.
10	N/a
11	Would like to see all care staff tested regularly not just when they show symptoms
12	He has had no therapies at all
13	Good
14	Quicker fast tracking to see specialists. All appointments are delayed.
15	Staff sharing info
16	Better ASD awareness
17	See above - Health Physio not available currently for clinic or home visit and I would like this as my son needs new splints and walker review.
18	Regular physio therapy sessions
19	Both my boys have weak muscles and need OT, i am a single mum so doing this all alone.

20	One of my children has a few other medical needs along with autism and it feels very difficult to get in top of it all.
21	Easier access to a GP
22	My son has behaviours have changed a lot since his ASD diagnosis nearly 2 years ago. But we've had no further assessment.
23	All my son appointments has been cancelled. yes we have speech and OT online. It is impossible to make special need kid participating in online session.
24	No support available from OT since the beginning of the lockdown, very limited support from SLT
25	Yes
26	Problems with Psychological trauma Alt therapies to shift this as talking therapy retraumatizes
27	Health has been mixed, have been discharged from services because they cancelled the appointment - nightmare!
28	My son needs to see the orthodontist urgently. His teeth (after 7 years of wearing braces) are shifting because he was supposed to have his permanent retaining wire installed in March, which never happened due to lockdown. After having all of his teenage years with fixed braces on, the last thing he or I need is for him to have to have them put back on again.
29	N/A
30	assurance that he will be taking care of specially this coming school year with the current situation because he has poor respiratory system.
31	No input received
32	We feel supported.
33	Would like to see health carers tested on a weekly basis
34	Easier GP access
35	Son eats a restricted diet which was awful during lockdown when preferred foods were not available. We would benefit from more money to pay for his preferred takeaways more often. We would also benefit from seeing an ASD-specialist dietician

Appendix D - Social Care

Q.10 Social Care (children and adults) - is your family getting the support that it needs?



Yes - we feel well supported	24
We are having some issues, but we're doing OK	9
Things are quite difficult and extra support would be helpful	10
No - we don't feel supported at all	12

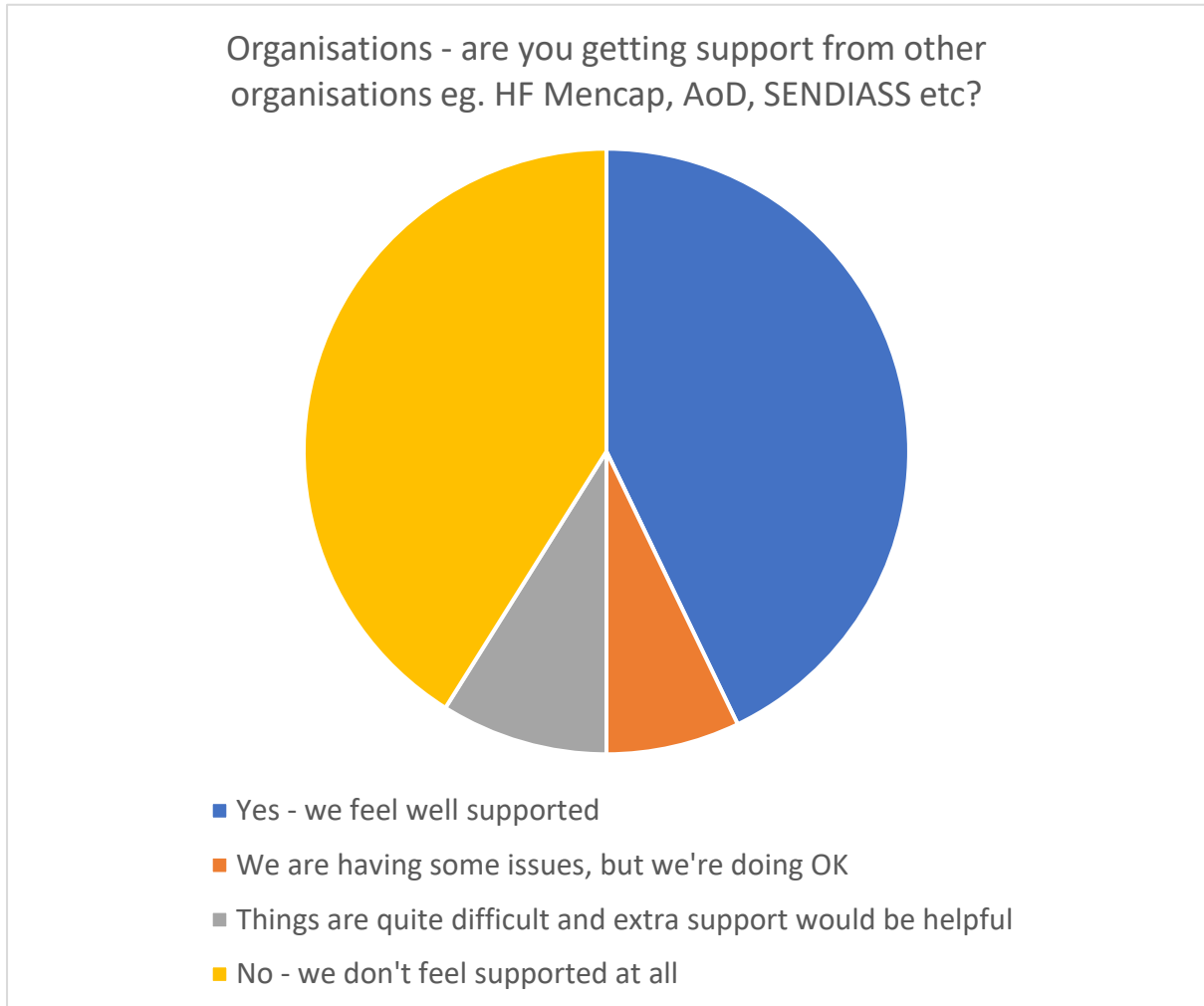
Q.11 Social Care (children and adults) - what do you feel will help? – comments received:

1	We don't know about this.
2	More information for a start as to what support is available and then more respite or activities my child could do
3	n/a
4	n/a
5	Does not apply
6	Note: We haven't used any Social Care resources but haven't felt like we have really needed them. (You might want to add an answer choice to this effect in your survey)
7	EVERYTHING IS ONLINE DUE TO THE PANDEMIC ONLY SMALL GROUP SESSIONS ARE TAKING PLACE IN LOCAL AREA.
8	Access to facilitated online group activities; an online forum for families; a single point of reference for information and inspiration.
9	Moving from a hostel (sharing bathrooms with other families) to self-contained accommodation
10	Case workers are not consistent and had no contact for 9 months
11	Good
12	not applicable
13	Need more clarification on what DP can be used for also Kayla's short breaks package is due for renewal next month and I have yet to be contacted.
14	Assessments done quicker without having to constantly chase
15	We have struggled to get our usual agency carers in but the LA has been helpful and we are accessing carers from SWC - the quality of his carer has been very high.
16	Mobile profiling bed should be provided at the SWC, in order that wheelchair users can be taken out of wheelchair and quickly taken to the designated suction area without having to be hoisted back into wheelchair. Plus it's safer in general than being on a mat on the floor, and a disabled children's centre should have this In any case
17	Care agency placed my child in danger but health/ SS refuse to change them. This has been going on for years. My child will probably die at their hands before anything is done

18	We need a key worker we have had no support the hole of lockdown.
19	We don't get any support other than at school for them! Which is very difficult as we've no family nearby.
20	More concerned social workers and actual concrete help rather than talk about it
21	Our current living situation is a nightmare as we are currently living in a tiny flat with 4 adults and my son and I am pregnant (high risk) with the baby due in August. We have no outside space and very minimal space inside. My son has no understanding of danger so we have to keep the majority of the doors locked and windows barely open. Two of the adults are unwell. One being retired with health problems and the other also with health problems and needs surgery soon. In addition we have been asked to leave by December and the council are not helping at all - they're ignoring my emails / phone calls, giving me the wrong information constantly regarding my account / reference and the CMA are not helping either despite letters from my sons doctor.
22	I think from September kids should have much more Speech therapy , ot and Physio in order to catch up .
23	Not applicable
24	No social care support
25	We didn't seek help yet.
26	We do not have or need social care
27	Social Care haven't featured - their advice has been " use your direct payments " We are totally reliant on Queensmill
28	We do not use this service yet.
29	Support with transition to adulthood
30	Social worker has contacted us a family on several occasions and PPE provided

Appendix E – Organisations

Q12. Organisations - are you getting support from other organisations eg. HF Mencap, AoD, SENDIASS etc?



Yes - we feel well supported 24

We are having some issues, but we're doing OK 4

Things are quite difficult and extra support would be helpful 5

No - we don't feel supported at all 23

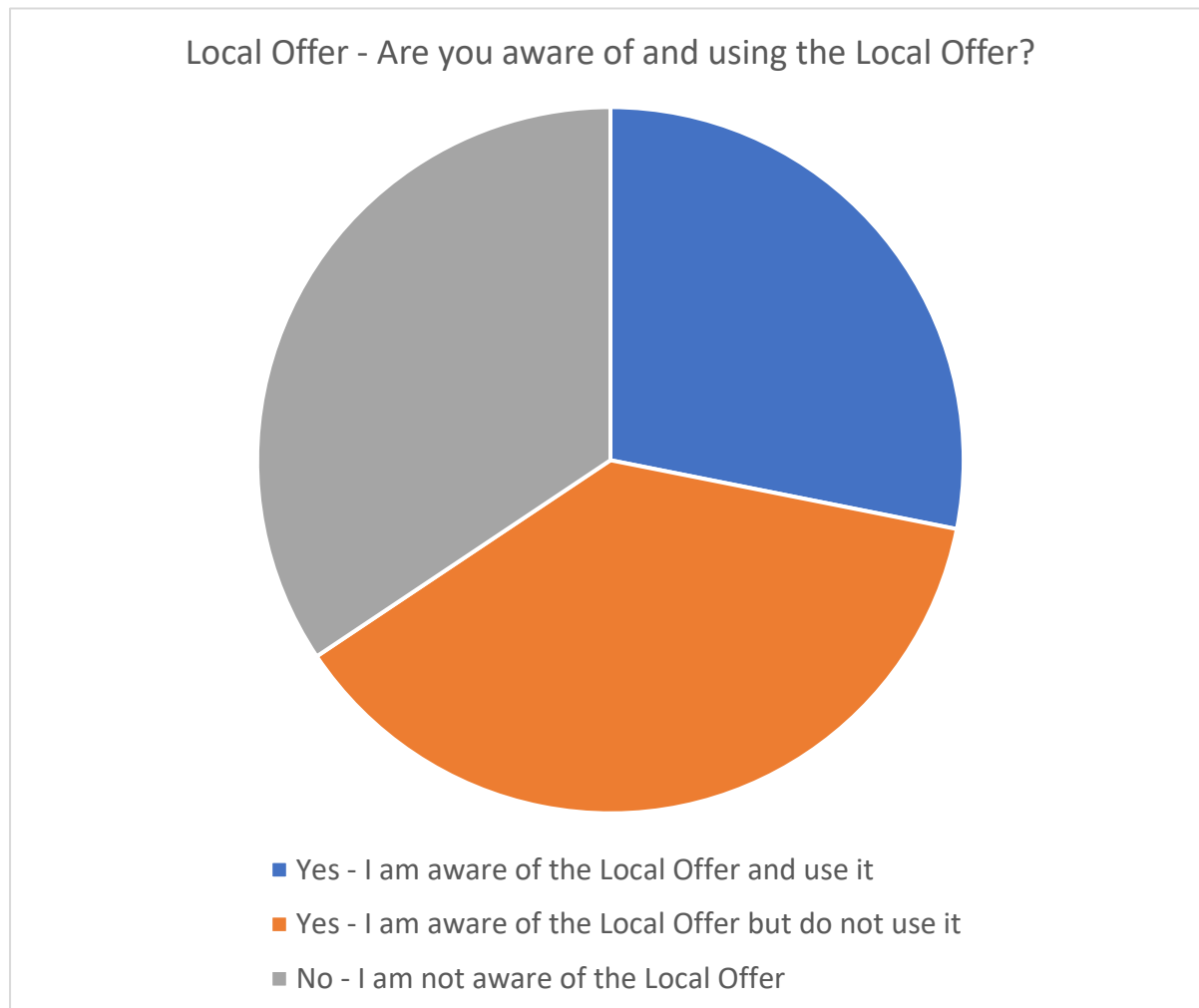
Q13. Organisations - what do you feel will help?

1	I recently joined Parentsactive. I feel I can rely on them especially on issues about my child wellbeing.
2	We are fortunate to have contact with Parentsactive and PlayAssociation but otherwise not had any input from any organisation. Parentsactive have arranged various virtual meetings. If some of the other organisations could find a way to open and offer activities out of the house that would be useful.
3	the only support is from Parentsactive
4	HF Mencap/Parentsactive have been in regular contact
5	Thanks to Parentsactive who have been brilliant
6	We have lots of support groups outside of the educational settings
7	More mental health support.
8	I only get information emails from parents active. There has been no contact from any other charity, organisation or department. As above, it would helpful if those organisations were more proactive with generating and sharing information for these times.
9	Not sure what they do
10	Good
11	Nandini has been amazingly supportive. We are very lucky indeed. She has helped with lack of contact from SEND, during the pandemic and her regular emails are so wonderful and informative.
12	I didn't know about these organisations. Maybe we can get an email explaining what these organisations stand for and how they can help.
13	We have been accessing AoD youth club virtually and this has been fantastic both from a social engagement point of view but also for Barney to do some physical activities.
14	We don't not currently need support from outside agencies
15	never heard of them as we don't need support
16	Any help would be good.
17	We are desperate for respite - help with days away/holiday camps would be so helpful as we don't know how we're going to get through the summer

18	More support to help us with our son's needs
19	I am only receiving help from my key worker with schools and housing forms and my sons ECHP
20	Never heard from any organisation so I don't know what sort of help they may be able to offer.
21	Have received excellent support from Parentsactive and SENDIASS in the past
22	Yes
23	Possibly Centaur horse therapy at Richmond Park
24	ASCEND
25	SENDIASS
26	Can't use other services - not safe - without TESTING. Vulnerable Parent shielding at home.
27	We do not use this service yet.

Appendix F – Local Offer

Q14. Local Offer - Are you aware of and using the Local Offer?



Yes - I am aware of the Local Offer and use it 18

Yes - I am aware of the Local Offer but do not use it 24

No - I am not aware of the Local Offer 22

Q15. Local Offer - if you answered 'that you do not use the Local Offer' to Question 11, why, and what can be improved? – comments received:

1	Discussion. What is this and how it will help us.
2	The links don't seem to work so tend to not bother. If it was functioning properly then could use
3	Have not needed to.
4	Have not felt that we have needed it at the moment
5	because of the pandemic ...
6	I'm not aware of the local offer? Do you mean mental health?
7	Not sure what they do
8	Good
9	I used it to find activities however what I found was centred around very young children particularly preschool age.
10	Send reminders by email of added info or explaining how the website can give a variety of information about different subjects
11	Visibility and clarity. SWC location is not ideal for us and I don't feel the offer is relevant and I would want for me (parent) not to have to go in so in-home care/respite is much better.
12	My child has complex needs and access services already
13	I don't know what this is
14	I'm not entirely sure how to go about things myself on the local offer. As i usually get told a professional needs to refer me which takes time.
15	More information on the areas it can help with.
16	Whatever organisations are in the area they should get in touch with special schools and special mainstream units to offer they help (how parents can know about it different way ?)
17	Don't understand how to 'use' it
18	Currently no need, but would make use of local offer if required

19	Yes
20	Not aware of the local offer
21	Check it occasionally but don't often find anything suitable.
22	I don't know how to avail it.
23	I am not using local offer
24	REGULAR TESTING Special Summer provision for young adults should have been organised. Many families have had no support during this pandemic. The local offer has not been functioning normally because Covid 19
25	We will start to look into it now and see can be useful for us to get involved in.
26	I have the provision in place

Appendix G – Impact of the current situation on your family

Q16. How has the current situation impacted on your family situation including siblings?

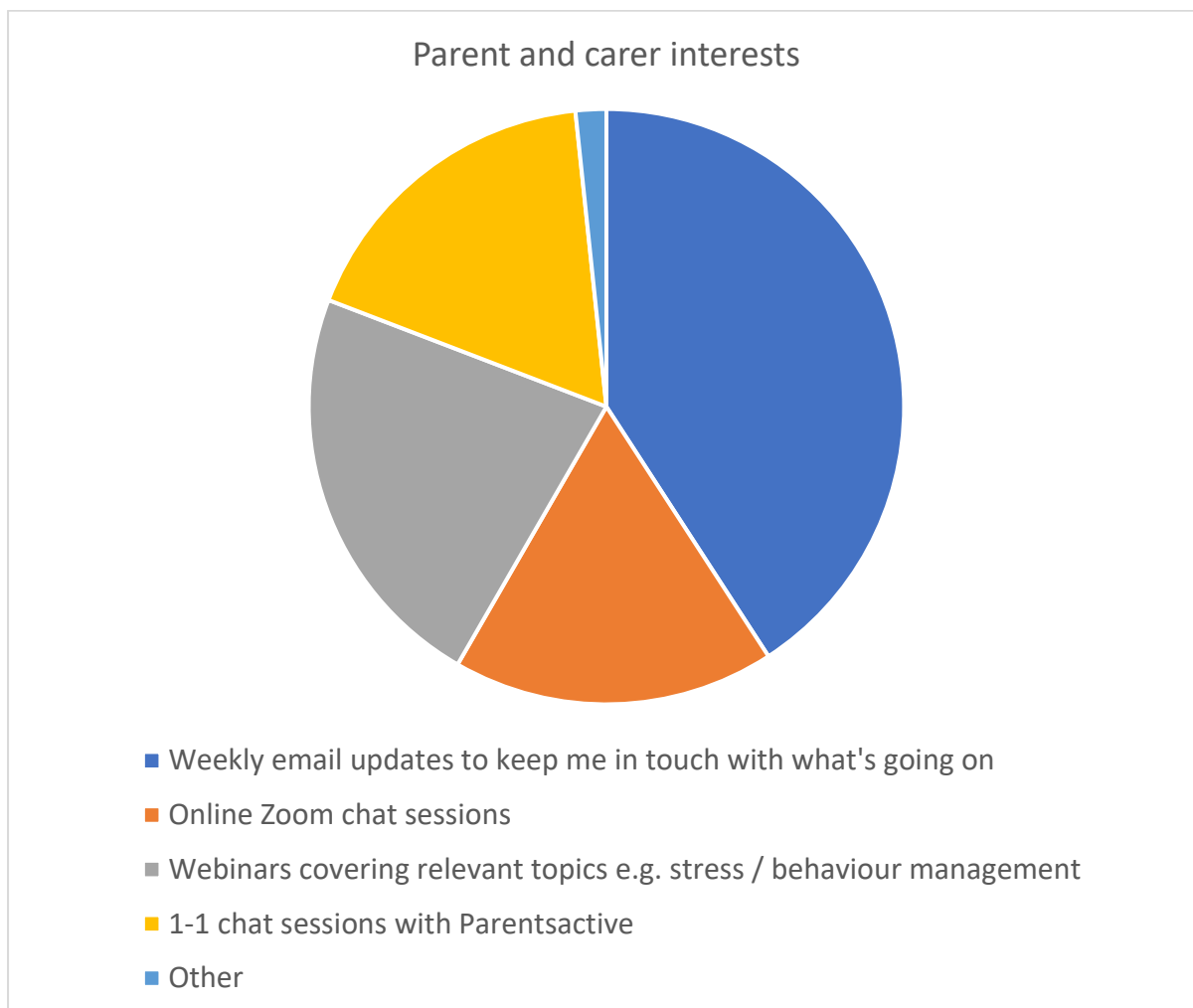
1	It's difficult to raise an autistic child. It's new to us. We don't have family or relative or friends with this condition to ask in times of difficulties.
2	We are stuck in doors. We do not have extended family so have restricted going out to a minimum as worried if one or both of us gets ill who will look after our child and also if our disabled child contacted the virus what would happen.
3	Everything is good
4	We feel very isolated indeed. The lack of contact from the school has made us feel very alone
5	The COVID situation has made us feel very isolated and alone. We have received no direct communication from the School other than a very rare email, maybe 3 during the course of lock down and direct contact from the SENCO, teachers, or anyone to ask if we are ok. We have just be left to get along with it and it has affected us all badly.
6	It has had a big impact. Money worries, school worries are ever present.
7	the school have completely neglected my child's educational and emotional needs.
8	My younger daughter finds it very difficult to be around her older sibling. Frustrated and stressed at Charlottes mental health issues and illness.
9	It has put a lot of pressure on our whole family and has been extremely disruptive and hard to handle.
10	All my 3 children are now back at school, which makes our family life better. It was difficult living in one room all the time.
11	My son's anxiety is very bad again. He is unable to complete any work at home therefore missing education. Lack of therapies is seriously affecting his physical and mental health
12	Good
13	Its stressful because you don't have that break when they are at school or you're at work.
14	Less hecticness and multitasking, less stress which is positive. More social isolation and less academic progress.
15	My children feel far more safe and secure than they do outside and always have. They enjoy staying at home although they are beginning to miss their friends.

16	Impacted on one of the children but all ok
17	It is exhausting - personally I feel overwhelmed and stretched. I'm dealing with a child who did not get to sit his GCSEs, a child doing first year of GCSEs and feeling she is falling behind and then a disabled child with learning difficulties. I do feel I don't have enough time to support everyone, my 'able' children (especially my daughter) needs emotional support as she has found home learning very difficult and feels isolated and missing her friends. With my disabled son we have been glued to the hip of each other as I have to explain and help with every learning task. I feel like I am a mother, teacher, physio, speech therapist and OT all in one. It's exhausting. I'm trying to be kind to myself.
18	As we are stuck inside more than usual, my son has not got the space to have a quiet time.
19	Depressing, isolating. We don't wish to use zoom or video calling apps
20	We have been stuck at home with criminal neighbours. SS protect them so they can be as criminal as they like. Parents active are complicit also
21	We are very lonely it just us in a flat on the 3rd floor. We can't go out much to help the boys with OT, we really get minimal support
22	It haven't impacted on my family that much as we doing fine keeping safe and have lots of thing to keep them entertain
23	With 2 autistic children in family, we are quite emotionally tired. Primary school kindly offered place for our 7 y.o Special secondary school (Cambridge school) is closed and our 13 y.o son is home-schooled by us.
24	It's very difficult as we've no outside space and have very limited space in our flat which is very difficult when the children need their own space.
25	We are all the most exhausted and desperate we have ever been. We have had very little help from anyone and have had to spend our savings on getting people to help look after our SEN child for the odd hour at a time. The school closed, we were left alone. Our NT children have been ignored for months on end while we've struggled to cope with our SEN child and hold down our jobs on reduced pay.
26	Family is very stressed, tired. We have good days, but the sleep is catching up on our energy.
27	It has been very difficult, and we have been helped greatly by our social worker but would have benefited from more support from school
28	As a mother with 2 boys both with additional needs I have found it quite difficult
29	It has broken my son's routine greatly and has stopped his development greatly. It has also caused a lot of problems at home as during the main lock down we were all under

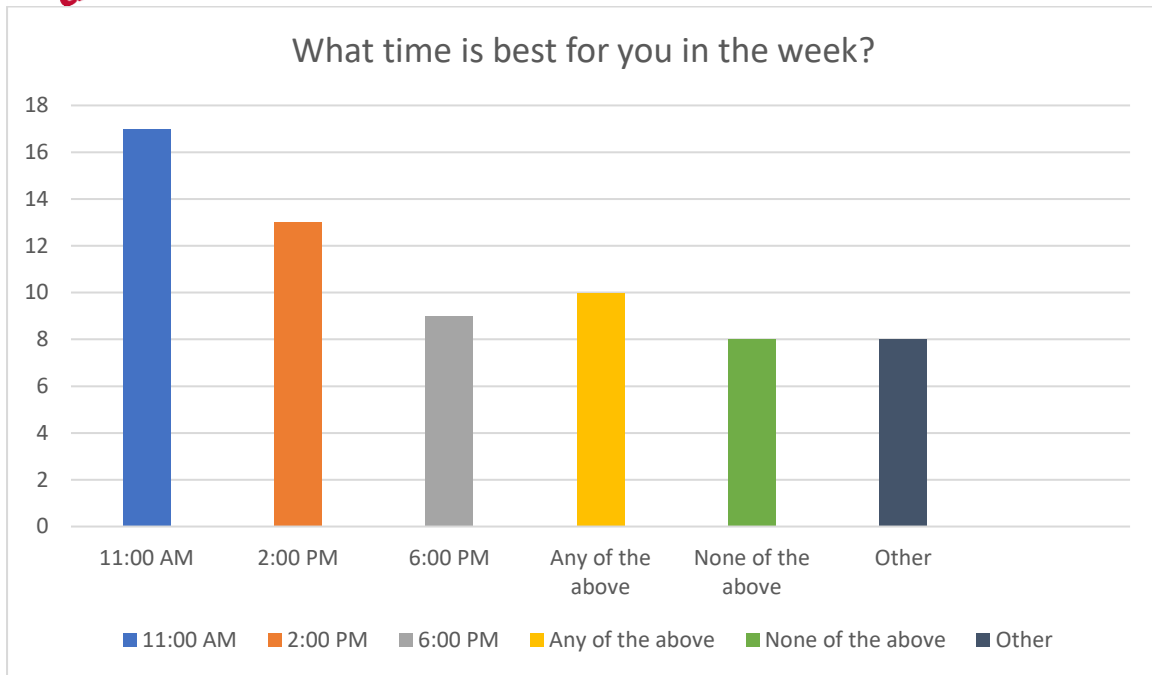
	one roof with no outside space and my partners parents can not tolerate my sons behaviour at the best of times let alone with this all going on.
30	My kid is autistic , the whole situation has made him again being afraid of going to shops , meeting people on the street, me speaking to neighbours.
31	Horribly. Each organisation says a different thing and then blames each other.
32	We've been coping without support from OT/SLT
33	We are all upset by our eldest daughter's difficulties. Husband very traumatised by our daughter's difficulties and younger sibling also upset but coping better than husband She has moved out of the house aged 19
34	Created more pressure and an increase in mental health and behavioural issues. It has completely changed the familial household dynamic.
35	It's been very difficult.
36	We're all going quite mad frankly... it's so challenging to have lost access to our regular school routines (which stabilises the children and gives me time to get things done) and main emotional regulation activities (Eg, gym, team sport, martial arts). Spending far too much time together in our tiny flat has given us cabin fever: We're more irritable with each other and generally much lower mood and sluggish/ unproductive. I can't get the kids to do their work in this situation so the sooner schools restart in significant amounts of time, the better for all of us
37	Anxiety occurred to me.
38	As I suspect the same with other families who is in our situation, you tend to give all your focus on your child with special need and feels guilty that you are not able to give the same amount of time to your other child. It is a struggle.
39	Couldn't manage, couldn't have managed without support from Queensmill.
40	Very stressful time with a new baby as well as a 6years old child to look after and support with his home learning. It has been very challenging.
41	Quite tasking challenging. Safety concern and hygiene are always at the back of my mind for us all and sometimes I feel paranoid, but things are improving now.
42	My daughter is residential. Only parents allowed to visit not siblings which difficult.
43	Tremendous stress and worries
44	It's been hard but managing

45	increase in meltdowns, many violent, from our son as he is overwhelmed by all the change. Did zero home-schooling as couldn't cope with it at all. Spending far too much time on a screen; he's terrified and doesn't want to go out
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Appendix H – Parent and carer interest and availability



Weekly email updates to keep me in touch with what's going on	49
Online Zoom chat sessions	21
Webinars covering relevant topics e.g. stress / behaviour management	27
1-1 chat sessions with Parentsactive	21
Other	2



Appendix I - Other Comments

1	If it wasn't for Parentsactive I would feel very isolated
2	It has been difficult because of covid19 & the lockdown just like everyone but college reopened & he goes two days a week Monday & Tuesday then the rest of the week he goes to Play Association. But then one of the parents was diagnosed with cancer so from the 23rd May a plan had to be set up & thanks to Lesley from play association did a plan & sent it to Matt which he agreed with so while the parent was in hospital they new things at home would be ok & there is still a plan ongoing until the 3rd of July which will be looked at once the parent gets the results & given more details of what the next step is. We don't have a social Worker at this time as she has left so Matt Simpson is the first port of call if the family need anything. At the moment his hours have been extended since the 27th of May so after college he goes from there to white city till 6 then from Wednesday until Saturday he's there from 10 to 6 was doing Sunday until 4 which has now stop this week because parent is slowly getting better after op
3	I am happy with the support has been given.
4	Thank you for being the voice of parents
5	I feel isolated as the NHS does not know how to support Charlotte who gets agoraphobia which is extreme and affects the whole family. Her multiple food intolerances affect her eating profoundly and this is very stressful for the family. Also, the lack of engagement from Charlotte is upsetting for all of us.
6	In these changing times, life is not fitting into a regular time slot so even more important to have access to information and possibly summaries of what has been discussed shared online so I can access it at my convenience.
7	Thank you Parents Active. You are brilliant.
8	I like the support provided by Parentsactive but find it hard to attend meetings as no free time at present.
9	I'm aware of the many options of online support offered by PA and the play specialist at kaleidoscope which is useful should we wish to partake in online activities/meetings in the future
10	No
11	Thanks for trying.
12	Parents active have been very helpful especially during lock down
13	Would be brilliant if webinars were recorded

14	None
15	Parents active is a very helpful organisation for families like us who felt lost and don't know where to start. They have been brilliant in guiding us what to do. I wish I have known their existence very early on.
16	Thank you Parentsactive for all you have been doing especially now with the zoom session. It has helped me feel involved and participate in information and discussion that affect me and my family especially at this time.