

## Waltham Forest Parent Forum Consultation on Services and Support during COVID-19 Lock-down – May 2020

### Consultation

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) were consulted via an online survey about services and support. The results below come from 85 responses from 24th April to 13th May 2020 during COVID-19 lock-down. Considering the huge additional demands on families' time, energy, and priorities at the moment, this is a significant response. We intend to continue the survey and adapt it to changing circumstances so that we can contribute as effectively as possible to services' ongoing need to understand how best to support families.

### Background



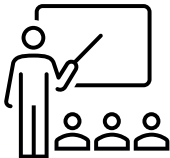
Waltham Forest Parent Forum) is a collective of parent carers from over 1,100 member families across Waltham Forest. In addition to this, FWFPF has an online community of over 1,500. WFPF has been the strategic voice of parent carers working in partnership with Waltham Forest Council (LBWF) and the Clinical Commissioning Group (CCG) and other health partners since 2008. It is funded through a direct DfE grant (administered through Contact) and by LBWF.

### Questions

Parents were asked a series of questions. Some were multiple choice and some simply required parents' thoughts.

Below are the questions, the responses in terms of the % of parents who responded and the number of parents that equated to.

### The summary findings are below:

	<b>High levels of stress and anxiety:</b> COVID19 is clearly causing a high degree of anxiety and worry to both children and young people with SEND and their parent carers 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/respite, child's worsening mental health or behaviour, worrying about loss of income/employment, impact on siblings etc
	<b>Worsening of child and family mental health and wellbeing for most:</b> Having CYP w SEND at home 24/7 is exhausting and challenging, especially without access to other support services, respite, the outdoors or other activities. This is impacting negatively on many children's (and their parent carers') wellbeing and behaviour. This is coupled with anxiety as to how child(ren) will re-integrate back in school after lockdown
	<b>Parents need more help to support home learning:</b> Many parents said they are not getting the support they need from their child's school. Some parents said they don't have the capacity or skills to support their child's learning, or that the work the school is sending home is not differentiated or appropriate to their child's needs. Many would appreciate virtual lessons to relieve the pressure on them, even if for a short time.



**Concerns about their child's progress or plans for the future:** Several families said they are concerned about the impact of delays to their child's diagnosis or assessments and therefore referrals into services. Some families are concerned that their CYP with SEND will be falling (even further) behind in school which may make re-integration back into class harder.

Parents also have worries about their child's transition to a new setting in September 2020- how can they prepare the child/young person for a new setting or how can they choose a new school for their child when it is not possible to visit potential schools

## FULL SURVEY QUESTIONS AND COMMENTS BY INDIVIDUAL PARENTS

### 1. What kind of setting did your child attend before lockdown?

Type of provision	% of responses	Number of responses
Early Years	2.35	2
Primary Mainstream	34.12	29
Secondary Mainstream	12.94	11
College -Mainstream	2.35	2
Special School	31.76	27
Specialist College	3.53	3
PRU	0	0
Home Schooled	2.35	2
Other- including NEET, Day Centre	1.18	8

### 2. Which professionals have been in touch since schools closed?

Who?	% of responses	Number of responses
SENCO	42.35	36
Class teacher	63.53	54
TA/LSA	24.71	21
Head/Deputy Head	24.71	21
SALT	7.06	6
OT	4.71	4
Physio	4.71	4
Psychiatrist/clinical Psychologist	11.76	10
GP	11.76	10
CAMHS	17.65	15
Social Worker	16.47	14
Educational Psychologist	3.53	2
SEND Officer	24.71	21
No-one	1.18	1

## Comments

- 1 I contacted SALT myself- I don't think they necessarily would have been in contact otherwise
- 2 We received one call from the class teacher back in March and a few emails with links etc. A telephone appointment with his psychiatrist as scheduled previously. An email from his SEND Officer 10 days ago, quite vague as the SEND officer is new, to which I sent off a reply and still awaiting response. Not enough support and no concrete decisions towards any kind of respite has been very disappointing
- 3 Whitefield Special school and short breaks Tony and the team has been amazing for calling
- 4 The Head contacted after I made a complaint about the lack of interaction and a focus on core subjects on a computer which I didn't agree with. They have now made changes and offered creative curriculum options which is good
- 5 None of the above except the Paediatrician for the yearly review. I expected the school to keep in touch but not one call from them
- 6 The tutor has been in contact regularly and great although couldn't help with a loan of a laptop for remote access. The EHC person centred review fell in April (pre organised) so had contact with the senior and send officer, although neither have followed up since either on the plan or on COVID lockdown support, so not really sure if counts as them 'checking in'- we haven't got a laptop and they know we've been struggling yet no follow up.
- 7 SENCO not much help and SLT suggested I help my son's social skills by getting him into online gaming. Both SLT (school) and SENCO contact appeared to be a tick box exercise
- 8 Speech therapist, she said she will have an online session, but I haven't heard again.
- 9 We have a supportive school and as he is also under CAMHs they are in good contact with him
- 10 LA officers have been in touch re on going care and appointments scheduled pre-lock down. School have made 2 welfare calls (deputy head) 1 email specifically about my son from SENDCO and a couple of generic from SENDCO
- 11 We don't use Ed psych normally, but I got in touch and they have been supporting me

### 3. For what reasons have professionals been in touch?

Reason for contact	% of responses	Number of responses
find out about the wellbeing of your child and how they are coping with self-isolation and social distancing	73.49	61
- check that your child is able to access their schoolwork and if any adaptations are needed to meet your child's needs	48.19	40
check that your child is able to access their schoolwork and if any adaptations are needed to meet your child's needs	21.69	18
help build a structure for your child's day	36.14	30
find out from you how they could support your child better	43.37	36
find out from you how they could support your child better	36.14	30

Provide relevant schoolwork	43.37	36
provide work broken down into smaller steps or differentiated to suit your child's needs	14.46	12
provide equipment or technology to enable your child to do school work at home	6.02	5
provide a plan or timetable to do schoolwork	14.46	12
provide useful and appropriate resources to do their schoolwork e.g. special grip pencils, large print books etc	2.41	2
support your child's emotional well being by providing video contact with the class teacher/class friends	8.42	7
provide live lessons	7.23	6
provide video contact rather than just phone calls	12.05	10

### Comments

1. Whilst the school SENDCo has provided some useful resources, the main job of differentiating work to meet my son's needs has been left to me. I have had to spend a lot of time going through suggested work, selecting appropriate tasks and then differentiating them. At times I've felt completely overwhelmed with it all - particularly as we've also been receiving work to do from a charity for children with Down's, who provide SLT and OT support. It feels like we've been tasked with the impossible!
- 2..To check whether my child can socially distance and provide help with any reasonable adjustments
3. Very limited and only after we made contact.
4. Whitefield special school has provide my autism daughter an ipad to use at home. 😊
5. My child does speech and language live on zoom every Thursday and he's really looks forward to it.
6. Only the class teacher who is trying her best to differentiate but often it looks like worksheets frantically taken from twinkl in a hurry that don't match the learning objectives for the main class work
7. Told school 4 times that child needs video content from school--they are now 'thinking about' doing something on Zoom. Really disappointed.
  8. We speak to his TA each week via video- this is to keep her familiar and for him to see her in school- they just chat and do magic tricks. Educationally they sent out packs, but he does his own style of work. There has not been SEN / personally adjusted work for him.
  9. Therapy via video

### 4 So far, how well do you think your family is coping with lockdown?

Who	Very well % (number)	Well % (number)	Fairly well % (number)	Badly % (number)	Very badly % (number)
Your disabled children	10.59(9)	15.29 (13)	54.12 (46)	14.12 (12)	5.88 (5)
Other siblings	4.76 (3)	28.57 (18)	55.56(35)	7.94 (5)	3.17 (2)

<b>you</b>	4.76 (4)	23.81 (20)	54.76 (46)	14.29 (12)	2.38 (2)
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### Comments

1. Siblings also have asd/adhd and are introverts- but answering questions for youngest child still in school. Siblings happier in lockdown than in normal" times.
2. Child - is getting a bit frustrated and stir crazy from lack of freedom outside I'm finding there are just not enough hours in day (and night) to get everything done and feeling overwhelmed
3. We are a shielded household due to parental illness. This is making things much harder.
4. Lockdown has magnified my son's anxiety and challenging behaviour, most of the things that relax him and he enjoys gone (trains, cinema, nature trails, pubs, bowling, eating out), as well as his friends as he is being shielded with us, away from his supported living. No respite for us, trying to juggle working from home, thank god for his (young adult) younger brother. And the uncertainty of not knowing when it will be safe for him to return. We are getting some behaviour support now though and having his care package reviewed.
5. It is difficult having all children home and school work pressures!
6. It fluctuates depending on mood of disabled child as it affects us all negatively
7. We started well, but the past 2 weeks have been extremely challenging for both myself and my SN child. He has become very unsettled.
8. I would say more generally it's been very up and down emotionally for all of us. Good days and very bad days
9. We are all coping very well as we moved in with my mum so that we have extra help and support each other. I could not cope with the kids alone and I knew that was not an option. My sons mental health is the best it has been in 2 years since being out of school and with closet family support around. He is also getting regular support form CAMHS
10. She copes well in the day to day but she is struggling with relationships beyond the family and I fear she had become far too dependent on me for feelings of security and safety.
11. We are doing our best some days are awful and others pretty nice- it's never going to be easy when normally you have several professionals supporting who you see weekly and then nothing it all stops overnight and I'm in charge of all therapies all education all nurture all discipline- I can only do my best

### 5 What are the top 3 things you are finding most difficult in lockdown?

The format of this question proved difficult and not everyone answered correctly. Therefore, the results are not accurate enough to produce in full here. Below are the results of only those parents who did answer in the required manner

	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>
<b>A lack of support with caring</b>	8	4	5
<b>Managing home schooling</b>	10	9	5
<b>Difficulties of putting infection control measures in place in the home</b>			1
<b>Problems accessing remote appointments and support</b>			2

Loneliness made worse			
Child's behaviour getting worse	7	4	1
Additional pressure of child's behaviour or mental health	2	12	7
Fear of getting the virus and who will care for my child/ren if I'm ill	3	2	3
Fear of how the virus might affect my children	2	2	
Lack of space/home environment	3	1	2
Access or cost of food	1		
Getting medical treatment			2
Getting medicine or prescriptions		1	1
Explaining the lockdown/change of routine to child	1	1	5
Being away from family/friends	3	4	9
Managing remote work and home schooling and care	7	5	1

### Comments

- 1 My child is high risk and so is my husband so having the prospect of being out of school for long periods of time. He is a school refuser so difficult weighing up medical risks V psychological risk
- 2 Lack of schooling is a killer
- 3 Not to being able to support my child in his development as this crucial stage.is difficult
- 4 Constantly anxious of my child, or one of us getting infected, we can't lockdown for ever!
- 5.accessing safe green space outside where my child can exercise - local park and Walthamstow Wetlands are SO OVERCROWDED and my child doesn't understand how to keep his distance from other people and will run into them, therefore we are unable to let him move freely and have to hold his hand tightly - in turn he becomes very distressed by lack of freedom. Only thing he enjoys is sitting on his dad's shoulders for walks - which means he ends up getting no exercise at all. He is then stir-crazy at home as he hasn't been able to move around enough outside
6. My own wellbeing and mental health.

### 6.What support would you like now and in the coming months to help your family cope better?

1. I think wellbeing checks for parents. As time goes on, I'm starting to struggle with demands of family life, 24hour caring responsibilities and trying to continue with work. For some we are having to become full time carers without our normal formal and informal support mechanism e.g. families, friends and schools. Although there are services open like talking therapies it would be good to have checks with families / carers on how they are doing. It can be really isolating and it's easy to think that you're doing a really bad job in managing all aspects of life.
2. Help so my children are able to get some fresh air and go outside. Doing this without help would lead to fines of and breaking social distancing measure as my Autistic son has no understanding why he is at home and not in school

3. One to one therapy provision - SALT, PT and OT to continue and not to be another thing offloaded to parent. Local playground/green space/large indoor space with appropriate games and equipment to be open at set times for limited number of SEND children to be able to exercise and play safely and freely. To be managed by SEND Team.
4. As my asd son is isolated anyway, even before this, some kind of respite to socialise will be great. Also, I think it is extremely important for home not to lose physical contact with school, so online lessons /sessions with his teacher will be very good.
5. School reopening
6. Schools not generalizing the situation and been more specific based on my child's needs
7. Remote access to speech therapy, remote classes or learning. Consistency in teaching staff.
8. Access to testing (Covid-19 and antibodies) for child, family and all his support workers; more than adequate PPE in supported living; special hyper social distancing times in cinemas and pubs; safe respite care until he returns back to supported living; really effective, well fitting, colourful face masks (I can't sew); telephone or online trauma counselling for parent carers!
9. I want my son to get full access to the curriculum, as per my view he is very much able, but activities and timetable provided by school is not much stimulating for him. Instead of having a blanket approach schools should tailor activities according to child's ability.

#### 10 SALT

11. Family support therapy
12. Online video lessons with teachers and classmates
13. Have someone to talk to when stressed and anxious
14. Help for my child to cope with lockdown. She doesn't understand why everything is closed
15. Transition support - it's been decided he won't continue at college (not coping) but no support plan for when he leaves. Support for Planning independent living and housing options
16. More support on strategies for home learning from school and educational psychology. My main worry is that my son will fall even further behind. We have had zero contact from his 1-1 LSA, that would have been helpful early on. Transition is also a big worry considering the number of SEND kids at his school,
17. Help and advice with children behaviours
18. Mental health and behaviour support
19. 1:1 online support for our child's mental health
20. Zoom class every day, even if just for short time, so she can see friends without getting overwhelmed.
21. We would like to have better learning support for my autistic daughter, right now the homework she's getting is not suitable for her needs.
22. Video link once a week with school and also I need to get/borrow a more updated laptop/computer also report from teachers to let me know how the home school is going.
23. I would like for my child and me to be able to have a break from each other and have the possibility of returning to a fairly normal routine. Being just the 2 of us has been extremely challenging in the past few weeks.
24. Resources/access for young people to talk about how they've felt during/after the lockdown
25. Reassurances that year 10 students will have exemptions made for tutoring time missed. My son doesn't cope well with home/independent learning. We would like some kind of online face to face teaching if schools remain closed
26. Restoration of respite service at 99 Leyton green Whitefields to open
27. More input from school re video lessons on zoom or Google classroom. Regular telephone calls to my son offering support and guidance re school work. The psychiatrist has not been in touch since lockdown and so follow up from Camhs would be helpful too. More input from school re video lessons on zoom or Google classroom. Regular telephone calls to my son offering support and guidance re school work. The psychiatrist has not been in touch since lockdown and so follow up from Camhs would be helpful too.

28. Help for vulnerable family with a disabled child with life chronic illness
29. Regular contact with school More support group contact via zoom with other children/school friends Staff willing to use video camera on zoom
30. 1:1 support via video for son Sibling support group Parenting and psychoeducation support accessible to working parents - remote learning with fortnightly evening video groups for example - part time access to some school for socialisation / respite
31. Specific school work for my child's needs and abilities not just our own effort to find what to learn. As a parent I don't know where to access learning but wouldn't want to sit and wait for schools to open when we could have done and learned so much at home
32. Preparing for returning to school which is going to be really hard re adjusting

## 7. When and how should schools reopen?

	% of responses	Number of responses
in a phased manner?	22.89%	19
as soon as lockdown ends?	1.20%	1
I'd be comfortable with a July opening	3.61%	3
I'd be comfortable with a September opening	26.51%	22
Only when school is happy to do so	7.23%	6
Only when the government says it's safe?	19.28%	16
Only when there is a vaccination?	4.82%	4

### Comments

1. When scientists and school say it is safe
2. When it's actually safe and we are not used a Guinea pigs to test theories
3. Phased manner asap
4. Not at school any longer but NEU #Five Tests are reasonable. Maybe when there are no longer hundreds of people dying each day
5. When people stop dying
6. When the unions say special schools are safe to open
7. Schools should open asap but staff should have access to PPE and testing
8. When it's safe for the children and my family
9. When there are changes that will make it safe for staff, children and their families. Vaccines, provide masks, staggered timetables, small group teaching to allow distancing
10. In a phased manner from September
11. Whenever it's deemed safe

### **Additional Thoughts**

WFPP is a member of the National Network of Parent Carer Forums (NNPCF) The NNPCF is a network of over 150 Parent Care Forums from across England. As a network we come together, working to effect local, regional and national service improvement through participation and co-production with parent carers.

During this difficult time, the NNPCF steering group has been meeting regularly with the Department of Education and other government ministers to feedback parents' thoughts on life in lockdown. We too have fed into this work by sharing the thoughts of parent here in



Waltham Forest. Several of the concerns parents have here are also seen across the country.

Below are some of the thoughts that the NNPCF have collated from all the PCFs but which would also relate to services here once lockdown ends

### Concerns

- In preparation for an end to lockdown, we must make sure that early help services, especially mental health, behavioural services, counselling, and social care are primed and ready to respond if there is a spike in need.
- When lockdown ends, we must make sure that we do not forget that some medically vulnerable children may not return to school. We must not forget about these children and we must make sure that proper provision is made for them if they need to continue to be home schooled.
- We must not forget the children who do not have an EHCP but have SEND.
- Reasonable adjustments must be made for children on SEN support as well as those with EHCPs to ensure they can re- integrate effectively
- Many families will struggle to adjust as lockdown eases. They will need to be given support and time and not treated punitively. For example, we may see:
  1. An Increases in absences and school refusal (parents should not be fined for keeping children at home)
  2. Behavioural problems – school behaviour policies must reflect this (traumatised, worried or confused children should not be excluded or disciplined)
  3. Social care thresholds may need to be changed
  4. More people may choose to continue to home educate if they have found that it works for them
  5. Environmental factors (such as whether transport services are running and safe, whether cleaning materials / staff are available and whether PPE is available for schools that have to perform personal care) will be important before parents feel confident in returning to school.
  6. Social distancing may be very difficult for many pupils with SEND. They may not understand or adhere to it.
  7. The health inequalities suffered by SEND children must be recognised and it must be understood that these may have been exacerbated by the Covid-19 lockdown period. For example, annual health reviews missed, physio appointments missed leading to long term issues and discomfort.
- We need to make sure schools know how to access early help offers for things like anxiety, abuse, behaviour.
- Schools should think support, not discipline in this period. In particular, behaviour policies need to be changed to reflect the stress many children will feel. Disciplining and excluding those that act out will doubly penalise the most vulnerable.