



# COVID Feedback from Kent July 2020



# Monthly Summary report July 2020

## **Background**

Throughout July, Healthwatch Kent have worked with the Kent User Forums to gather direct feedback from 156 people about their experiences of the Covid 19 pandemic and life under social distancing. We have combined this with anecdotal feedback from 22 organisations who support a wide range of Kent residents including people living with mental health, physical disability, sight loss and impairment, carers and those suffering domestic abuse. Its purpose is to enable decision makers and planners to understand how people are coping during the COVID epidemic.

# **Methodology**

We have been running a series of social media adverts promoting an online survey. People were also encouraged to share feedback with our Helpline, either by phone, email or text.

To ensure more than one method of gathering data, Healthwatch staff and volunteers have established a regular phone interview with organisations. These calls enable us to capture the feedback that the organisations are hearing from their own clients and/or members. It is particularly important as it enables us to hear from communities who may find it harder to share their feedback such as people living with Dementia for example.

We have been sharing regular insight reports to provide a timely snapshot of how people are coping. These reports are shared directly with decision makers to help support their emergency and recovery planning.

This report aims to summarise and reflect the changing experiences of people living and working in Kent during the Covid 19 pandemic. If you require more detailed reporting on a particular theme, please contact us, this is the forth monthly report that we have produced. Our April, May & June reports can be found on our website.

This is a monthly snapshot of feedback. Wherever possible we are raising issues and sharing feedback directly with relevant organisations.

You may read some worrying stories in this report. Some of these have come directly from the public and if they have given us contact details, we are following up with them and escalating if necessary. However, not everyone will give us contact details. Where organisations have shared concerns with us, they are following their own safeguarding and escalation protocols.

PLEASE NOTE: The comments in italics are direct quotes from the public about their experience. They are peoples' personal views, not the view of Healthwatch Kent. Other comments are anecdotal pieces of feedback from organisations

Thanks to everyone who contributed!

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# **SECTION 1. The impact of lockdown**

## There were 11 themes within this topic area:

- 1. Government guidance
- 2. Furlough
- 3. Shielding
- 4. Lockdown
- 5. Finance
- 6. Access to food
- 7. Social distancing
- 8. PPE
- 9. Eating out
- 10. Religious services
- 11. Public services

## **GOVERNMENT GUIDANCE**

- "The Government said that children can have playdates must MUST NOT use paddling pools. Why then, are we now allowed to go back to using swimming pools?"
- "Why are so many services opening again in October but the Government are also telling us to prepare for a 2nd wave in the winter?"
- An organisation supporting carers told us they think that once shielding stops on 1st Aug arrives, people will feel more confident about going out. A lot of the older people were worried what will happen if they break the Government's rules.
- An organisation supporting veterans told us that some of their calls are about the confusion around the guidelines. People are unsure of what it means. However a lot of the clients are elderly and vulnerable, so are still shielding.
- Kent Autistic Trust told us that some autistic adults are still confused about the restrictions lifting: the Government messages are confusing. Where can they go/not go now, who are they allowed to see/not see. It changed from 2m distance to 1m, but it's only 1m if you keep precautions in place. It's not always clear, and others don't observe this.
- One Age UK centre told us that they still receive an average of 40 calls per week asking about the regulations because people don't understand them, eg where can people go, what shops are open, how many people are allowed to be in a shop



#### **FURLOUGH**

• "they need to end furlough as soon as possible. It's not a state funded holiday. These people are going to the beaches and spreading infections"

## **SHIELDING**

- "I've been shielding since the beginning of March. It's very difficult to stay safe when your other half is the main breadwinner and has to go back to work in August in an environment where masks can't be worn. I also have a son studying A-levels going back in September. We have accepted there is nothing we can do except our best to stay safe. Our support network (priority shopping slots, pharmacy deliveries) will also end soon, forcing us out"
- A cancer support organisation told us that some families are still shielding and have been declining a visit.
- An Age UK centre told us that many of their clients are still depending on volunteers to collect their medication because they don't want to leave the house.
- Another Age UK centre told us that many of their service users are scared to go out.
- "I've found the guidelines about shielding very confusing. I've been told by the government that I am vulnerable and have to shield but don't really understand what that means and they send through a lot of mixed messages about what I can and can't do."
- "I have been shielding for 4 months and have to return to work in August. I work in an opticians and have to be face to face with the public. To say I'm worried is an understatement as the letter from the government said in essence, I may not survive COVID and was told to pack a bag for a hospital stay, which included details of next of kin."
- "I've been shielding for months and am perplexed that I have been assured that I no longer need to be shielded from 1st August and can go to my place of work if my place of business is COVID-safe. I work in a secondary school, how can that be deemed COVID-safe? Am I one of the masses that will be sacrificed for herd immunity?"
- "We had shopping help but that has now stopped and as we are on the very serious list, we need to continue to shield but I can't as have no one to help now. I have to go out myself and I have autism so going out alone for me should not happen! I feel really let down and alone, I have tried all the place to get help, but they tell me it's stopped now"



## **LOCKDOWN**

- "This new world, or whatever it's called is terrifying, I just want to get back to the way things used to be, or some sort of normality"
- "Why is north of England, places like Manchester, in lockdown whereas I'm from Kent and we can celebrate Eid?"
- An organisation who support ethnic minority groups told us that service users have been telling them that they are starting to relax their attitude towards Covid; they have stopped wiping down the food that they buy in supermarkets and they are trying to get elderly parents out and about again.
- A mental health support group told us that carers reported that when visiting clients during lockdown, many were very edgy about the visits and did not understand exactly what lockdown meant. Each visit took longer in the early stages as explanations were needed and given. Some clients continued to feel uneasy about it. As lockdown got longer, the clients started to realise that they could go on with life and go out for a walk as daily exercise and for food shopping.
- A Community Hub told us that over half of their service users would like to continue with ongoing welfare checks. Many people who didn't want a welfare check told the Hub that they had left the house to go to the hairdressers or the supermarket for the first time and things weren't as bad as they expected. They are now ready to do their own shopping and collect prescriptions themselves. The service users do want to keep the Hub number close by in case they need anything.
- An organisation supporting veterans told us that since guidelines changed, the initial panic in theory is over as such, they are not having panic phone calls. People are calmer and have come to terms with the new guidelines. The pressure has eased since they are now allowed to meet people in parks.
- "has the 1st wave ended? Hundreds are still dying but people are desperate to get back to work, pubs, cinemas. This isn't normal"
- "everyone needs to build up their immune system, especially vulnerable people. They need to get out for emotional health and physical health!"
- "I was so supportive of the government back in March but now I think the house of cards is falling.

  Too many mixed messages and a pre-recorded message at this time just shows a lack of respect to a nation"
- An organisation supporting people with visual impairments told us that they have seen an
  increase in contacts around the resumption of health and social care services this seems to
  be triggered by shops and restaurants reopening as for some service users there is now a
  perception that things have returned to normal. They have also seen a few enquiries about
  local lockdowns and concerns around the impact of restrictions being eased.
- We heard from a support group that the autistic community are aware of the increase in cases in Ashford and Medway areas, so there is a concern that cases will rise again in other parts of Kent. They are also worried about a possible influx of infections after September when schools go back. This has been discussed on various zoom calls/online groups that the support group have.
- An Age UK centre told us that their demand peaked in April and has slowly tailed off since the end of May (particularly when lockdown restrictions eased) however, many of their clients are still very nervous and anxious about going outside and mingling with people

- "Things have piled up on me since the lockdown I have not been able to see my close family, until last weekend when the lockdown was eased. It's been really difficult getting along without seeing anyone. Things with my family are not usually easy, because things in the past have not been properly resolved"
- An organisation supporting older people told us that volunteers are still unable to make home visits however, their clients are overwhelmed with the requirements of application forms and need someone to help them fill it out. Many of their clients have no access to a computer or the internet so still rely on paper forms, but require help understanding how to complete them.
- An organisation supporting veterans told us that before Covid they had many calls and meetings helping with paperwork etc. People are now trying to book in time with the organisation to get help with paperwork and other admin. However due to this still being done over the telephone, everything is taking twice as long to sort one individual out.
- An organisation supporting people in isolated areas told us that one older lady hadn't ventured further than her front gate. Another service user said that things were good when they "clapped for carers" on a Thursday because she got to see her neighbours from her doorstep. Now that it's finished, she hasn't seen anyone from her community.
- An Age UK centre told us that some of their clients have said "nothing will ever return to normal"

## Life events

- "we postponed our wedding from July 2020 until July 2021. My partner and I are both key workers. Working every single day throughout the pandemic while rearranging our entire wedding has been extremely stressful and exhausting. I feel there has been a distinct lack of support and information for us. I don't mind waiting if it means our guests will be safe, but it hurts that we seem to have been forgotten in this"
- An organisation supporting people in isolated areas told us that a service user felt very
  isolated in the village. They lived on the outskirts and didn't see anyone passing by. They
  were desperate to move house nearer to the centre of the village but had not had any
  interest from buyers.



## **FINANCE**

- "My housing provider wrote a letter demanding more rent. My benefits have been reduced since a PIP assessment last year. This PIP assessment failed to recognise the debilitating effects of my mental illness, and my benefits income was reduced. I am barely managing to survive on my current benefits. I rely on food from the foodbank. I am trying to communicate with my housing provider about how to get through this, by paying what I can realistically afford. This is yet another worry about things I have no control over"
- A group supporting disadvantaged families told us that many of the families that they support have been hit financially by the COVID situation. Some people, who were on zero hours contracts, have lost jobs altogether. A few families have had their hours reduced (in one family their working hours went from 17 to 10 per week). The impact on the families is huge, and over half of the families can't claim any benefits due to their partner's income. Their financial situation means that they can't cope on one income alone. One family has run up a credit card bill of over £6k to get their child diagnosed, and are unable to repay this without two incomes.
- An organisation supporting families with special needs helped 6 families who have now been successful in being awarded the full £150 of council tax COVID fund
- One organisation supporting disadvantaged families told us that they were supporting one family to get approval for the Covid-19 council tax hardship fund; the process started on April 6th and it took 7 phone calls, 6 emails and 2 applications to get approved.
- An organisation supporting disadvantaged families told us about one family; one parent was admitted to hospital with Covid-19 and has now returned home. They still need to use oxygen when they move around, and there is still shadowing on 1 lung but doctors have advised to be very cautious. The family are struggling to cope with statutory sick pay, and with the parent signed off for at least another 3 weeks, they are facing huge financial challenges. They secured a bounce-back loan from the bank but will have to start paying it back in October, they don't have any spare money at the moment so they are concerned about what happens when the loan repayments start.

## Welfare

- An organisation supporting older people told us that clients are struggling to get through to the Government helpline for benefits; the line is ether engaged or gets cut off after it rings out. Clients are giving up trying to call.
- An organisation supporting carers told us that they have been calling managers at the Department of Work & Pensions to get help for carers; the DWP cannot do assessments at the moment and some carers are reporting problems and confusion with filling out the form

#### **ACCESS TO FOOD**

## **Community support to access food**

- "I have been offered food parcels from NHS responders, but I am coeliac, and they don't do special diets so it's no good for me"
- A voluntary organisation told us that some clients are no longer requesting volunteer's help with emergency shopping, but with their larger, weekly shopping.
- An Age UK centre told us that staff are still doing shopping for clients although they think that the clients are getting a "large shop" from family or online, and using Age UK staff to "top up" to prevent them from having to leave the house

## **School vouchers/meals**

• "My son's school have been offering hampers instead of free school meal vouchers; I collected one on Monday and it's all a bit stupid really. I received 2 cloves of garlic, 5 mini cartons of apple juice, 3 apples, 1 potato, 2 tins of chopped tomatoes, a tin of soup, a jar of jam and 6 morning rolls. What am I supposed to make him with that combination?"

## **Supermarket Shopping**

- "The only way to get a priority slot at the supermarket was to register with the government as not having support and needing a "Boris box". Then I registered with the supermarkets to get my shopping slot. Then I cancelled my Boris box because I don't want their food"
- An Age UK centre told us that they are still using volunteers to go out to buy shopping for their service users who cannot manage to do it themselves.

#### **Foodbanks**

A mental health support group told us that one of their service users contacted the foodbank to
ask for a food parcel during lockdown as they had no money due to being unemployed and their
benefits being stopped. The service user was refused a food parcel due to having a couple of bags
of pasta in the house which therefore meant that they had food and would not go hungry (in the
foodbank's words).



## **SOCIAL DISTANCING**

- "My daughter was shouted at in the supermarket as she accidentally knocked into someone; she has learning disabilities. People are so edgy at the moment and paranoid, then I got shouted at by the shopper and told not to let my daughter out of the house!"
- "I work in a primary school and all I've seen in children running around, holding hands, playing, cuddling etc. Schools aren't taking social distancing seriously, or even trying to enforce it"

## **PPE**

## PPE in the workplace

- "I've been on furlough from my job as a care assistant in a care home as I have asthma, and I also don't have any childcare for my toddler. During lockdown I've found myself in the happy position of being pregnant again. I returned to work last week but I have concerns regarding my health and new pregnancy; a lot of my co-workers in the care home aren't wearing PPE and I was made to feel like a problem because I asked for gloves and a mask when I was at work. I just want to be safe, especially since my home did have an outbreak of COVID, but I'm now worried that if I make too much of an issue about the staff not wearing PPE then I'll lose my job"
- "I got bloods done in clinic and they had full PPE. They said they had to fight to get it thought because initially they had none, and they refused to work without it. The phlebotomist was however concerned that the masks were slightly out of date"
- "My physiotherapist has still not opened and is struggling to get appropriate PPE (mask, gloves, gowns, visors), but the premier league physio was on TV the other night with only gloves and a face mask. It's a farce"
- A college teaching practical skills courses told us that all students are wearing gloves, masks and aprons when they come into contact with a patient. Students were surprised to learn that they might need to wear PPE for possibly another year.

## **Face masks/coverings**

- "I don't want to wear a mask. I will just say I have asthma so I can't wear one...no one can prove it"
- "I have no problem in wearing a mask, but this should've been done 4 months ago. It's too late now"
- "If you can't wear a mask due to your own health reasons then don't go out and put yourself at risk and others. Why would people even put themselves at risk if the virus hasn't gone away. It wouldn't be coming into law if it was for no good reason"
- "Given the complete lack of masks in Canterbury today I doubt people are going to adhere to the new facemask rules. It's a shame because all of us who have been shielding and those key workers that have worked so hard in the last few months have done their very best to protect people"
- "If masks are being made compulsory then the government should be handing them out free of charge"

- "Other countries just accept wearing a mask, you don't see them harking on about asthma, anxiety, autism etc. British people don't like being told what to do. The same people who hoarded food are probably the ones refusing to wear a mask"
- "I'm not going to wear a mask, I haven't done for the past 4 months so I'm not going to do so now. I follow the rest of the guidelines though".
- "If facemasks are effective (which they're not) why has the government only now made them mandatory when the virus is on its last legs in UK?"
- "The prime minister must lead by example. He and the rest of the cabinet should be actively wearing masks, it's their civic duty"
- "Some will have valid reasons not to wear masks, but most are hypocrites who clapped for NHS workers but don't think it really concerns them. No wonder Ashford, Folkestone and Dover had the highest coronavirus deaths last month"
- "We have been told for months we don't need to wear masks due to them being constantly touched, we are now being advised to wear them but the amount of people saying that the mask moves up the face to the eyes and then moving them back down again! People are moving masks down to still lick fingers to open carrier bags and bank notes to separate them and then handing to cashiers all the time! Social distancing is still in place too although a lot of people seem to have forgotten this already too!"
- An Age UK centre told us that they had received many calls from service users who were concerned about their own lack of PPE. People had heard on the news that facemasks would be mandatory but they didn't know how to access masks.

## **EATING OUT/RESTAURANTS/HIGH STREET**

- "I went to a restaurant on Friday, trying to support local businesses. There was a "sign in" sheet by the front door, diners were asked to give their name and telephone number (for tracing purposes). Sensitive information was on full view to anyone who walked in the door, isn't that a breach of data protection?"
- "I would love to get out and "eat out to help out" but I'm still furloughed until October and I'm on the brink of redundancy"

## **RELIGIOUS SERVICES**

 An organisation working to support BAME groups told us that although the Sikh Temple was open, they are not seeing as many people as anticipated. The Mosque opens this week, and will have strict measures in place, such as limited numbers, bring your own prayer mats, no ablution - basically come in with your mat, pray and leave. The organisation noted that that there are more channels available to take part in worship from home - for example T.V, internet etc.

## **PUBLIC SERVICES**

- "Until I am able to browse at my library, I won't be going. I will stay away. There is no point in ordering books just for me to collect from a library that is further away, my local library isn't going to be opening"
- An organisation working with the BAME community told us that the numbers of calls they are getting are decreasing but still coming through, mostly about when services and councils are going to be reopening.

## **SECTION 2. Mental health & wellbeing**

## There were 7 themes within this topic area:

- 1. Mental health
- 2. Addiction support
- 3. Domestic
- 4. Impact on young people
- 5. Impact on the workforce
- 6. New parents
- 7. Vulnerable groups

## **MENTAL HEALTH**

- "The crisis team have been amazing since I had an episode a month ago. They have been to my house every day since. Some of the workers are better than others, but the ones that are good are amazing. They really listen to me. The only thing is that I don't know how they're actually going to help me. They helped with my medication and are listening to see if I need to go into hospital which is good"
- An organisation supporting carers told us that carers are having difficulty getting mental health help; they cannot get a passive referral from the GP because they do not meet the needs of the Single Point of Access. Carers told the support group that they feel that their mental health is declining week by week.
- A community hub told us that they have seen a deterioration in the mental health of large numbers of people they are calling through their befriending service in recent weeks
- An organisation supporting veterans told us that the mood of service users has improved however the impending second lock down is bringing up anxieties.
- A breastfeeding support group told us that there are concerns around new mothers and fathers experiencing post-natal depression due to not being able to attend the birth, being isolated at home and not receiving support etc.
- An organisation supporting parent's rights told us that the number of mental health related calls to their helpline is still on the increase
- An organisation who support carers told us that they received 55 calls from carers who had been trying to access mental health support. They said that 1-1 support is still unavailable.
- An organisation supporting adults with autism told us that they believe mental health issues will rise soon, there is already a demand since SLAM closed their services to people in Kent. A mental health support organisation in Kent have decreased their number of staff so there is already a noticeable drop in support available.

#### **IAPT**

A service user with a mental health support group spoke about their experience with IAPT services; they said that the cognitive behavioural therapy (CBT) that they received was not what they expected for ASD. They said that they felt that the psychologist understood them, but that the communication skills that make all the difference for their condition were not recognised. The service user said they felt manipulated and deflated, and that there was no ASD awareness. They described the psychologist as "amazing" however nothing in the outcome report was about ASD and how it affects the service user's life.

#### **CAMHS**

- "One of our neighbouring local authorities are no longer taking autism diagnosis referrals for over 5 year olds. This is apparently due to chronic underfunding and based on the idea that all but "mild" autism will show up before a child is 5 years old. It seems to be a way to prioritise resources for the most severe cases. It disadvantages girls, who are likely to mask for many years and remain undiagnosed. Is this going to be a common process across other local authorities? Kent already has a huge waiting list and I am concerned that they will be more strict and have tighter control about accepting referrals"
- An organisation supporting families with special needs told us that 4 new families have contacted them with children under 8 years who have had ASD assessments put on hold.
   Three of these children are due to start school in September. The organisation gave all of the families a copy of the new handbook for families.
- A mental health support group told us about a client was informed that a referral would be made to CAMHS back in March 2020 for her daughter who is 8 years old, via the school. Her daughter has been suffering with severe mental health issues for a period of time often stating she does not want to live anymore. Due to the school being closed, she has not been able to find out whether the referral took place. Due to lockdown the situation has become more difficult as she is not being supported by any service. She had one session with a school counsellor before lockdown. Her symptoms are extremely distressing for everyone and they are concerned that she will come to harm.
- An organisation supporting families with special needs told us that kids are struggling with their mental health. The organisation have had a few families who went to their GP to get CAMHS help but didn't get anywhere. They are looking to pay privately for therapy for their children to treat their anxiety
- A different organisation who support families with special needs told us about one family
  whose child has started to develop "tics". The family were advised contact CAMHS and to
  make a list of tic related behaviours, including if the tics are visible movements or verbal, how
  they change in situations, how long they last for, and to try and video them. Apparently
  CAMHS need this list of information in order to look at diagnosing tic disorder/transient tic
  disorder/Tourette's. Without this information, they will ask you to go away, make a list and
  return in 3 months.
- The same organisation told us that 8 families that they help have received new diagnoses during lockdown, 1 via a hospital appointment, the rest have been via a phone call or zoom call following either a face to face or zoom assessment. None were given information about what to do now or what they need to know about the diagnosis (the diagnoses include EDS, ASD, Dyslexia and GAD)

## **Community Teams**

- A mental health support group told us that one service user was told in March that they would be receiving weekly phone calls from the CMHT for support during lockdown. This has been sporadic and, as of mid-July, they haven't been contacted for 3 or 4 weeks.
- A mental health support group told us that one service user was seen every 3 months at their CMHT usually. The service user had not had any contact with the CMHT so called for an appointment, the doctor told them that they were doing video calls at present, but the service user wasn't given a video appointment or any dates for the future for a video appointment.
- "I've been in the system for a couple of years and I don't think I've seen the same person twice. It's incredibly distressing having to go through the same issues with each of these people and having to relive the trauma that caused my PTSD over and over again."
- A service user of a mental health support group said that they were meant to have an
  appointment at XXXXX but due to shielding they couldn't attend so cancelled the
  appointment. The service user has been chasing them up, but no one has got back to them
  to rebook.
- A service user in a mental health support group said that their first appointment with the psychiatric nurse at XXXXX was good; they felt heard, listened to and understood. The service user felt as though someone believed them for the first time in 40 years.
- We heard from a mental health support group that one service user is struggling to get through to their designated support worker through the 1-1 phone support at XXXXX. The service user is particularly anxious during this Covid period and needs support.
- "I need help to contact XXXXX because I get too nervous. Some of the duty team are scary and I can't get hold of my care coordinator. Sometimes they phone me and sometimes I don't get the call when I'm meant to and I'm feeling some suicidal thoughts at the moment"
- A mental health support group told us that following a diagnosis of EUPD and PTSD, a
  service user was instructed by XXXXX to stop taking all but one of their medications as they
  were not used to treat these conditions. There was no weaning period, they only informed
  the service user that they would experience some withdrawal symptoms. Fortunately, the
  service user's GP's was very supportive and weaned them off the medication properly with
  support.
- "I've left multiple messages with XXXXX on multiple occasions for them to get back to me about a service user that I'm supporting, and they haven't got back to me."
- A mental health support group told us about one of their clients; XXXXX were calling him every day but for three weeks now no one has called. He was on the red board but he must have been take off an no one has told him. His care coordinator was also calling him everyday but hasn't called him in three weeks, He doesn't know what is going on.
- "I got referred to XXXXX. I showed my self harming and talked about feeling suicidal and I'm really struggling with my BPD symptoms, but I was discharged to primary care, who didn't accept me. They said I need more than the sessions that they have available and I need more support"
- A service user of a mental health support group contacted their CMHT and the lady they spoke to was very rude and unhelpful. The service user joined the support group due to being discharged. They have been left feeling unsupported and they reached out to the support group who cannot offer clinical support

## **ADDICTION SUPPORT**

• A mental health support group told us that one service user has been being supported by an addiction support group for quite some time. Once lockdown began, they were getting weekly welfare calls with their support worker. This then went to once a fortnight until the service user didn't hear anything from them for some time. They were then called by someone else to inform the service user that their support worker was on long term sick leave and that, because of that, they would no longer be supporting the service user as they felt that they were doing okay and didn't need the support. The service user was left feeling let down and left hanging because of this and is currently not accessing any support for their addiction.

#### **DOMESTIC**

- An organisation who support ethnic minority groups told us that their helpline is hearing less covid-related issues, but are receiving stories about workplace problems, domestic violence and planning permission.
- An organisation supporting families with special needs told us that the end of the school
  year was very emotional for families as there is a lot of uncertainty about what will happen in
  September with schools going back, and they are also concerned about the isolation that the
  summer will bring. The fear of having no support is massive, with schools closed and support
  groups only funded to provide help during term time. The group told us that this has caused
  a new level of panic in the last couple of weeks of July with families realising how isolating the
  next few weeks will be.
- An organisation supporting parent's right told us that getting access to children is still the
  main reason for people to contact their helpline. Although lockdown easing has meant that
  most parents who had been prevented from seeing their children, there are still cases where
  this is being used a reason to keep children apart from parents
- The same organisation told us that they see 2 or 3 cases of emotional domestic abuse calls per week
- An organisation supporting families with special needs told us about one family who were currently in crisis, their child was displaying very challenging behaviour, ASD, ADHD, selfharm and was disruptive. Mum was struggling to talk about the issues as her child was angry that she was talking to someone about him. He was aggressive towards her when she was on the phone, but the organisation managed to pass over their details (with permission) to the duty team at CAMHS.
- The same organisation told us that people are calling looking to see what respite might be available over summer, short breaks etc. Parents are struggling with being at home with kids all day long, everyone needs time apart from each other, even just for 1 day.
- The same organisation told us that it has been a challenging few weeks for families who were previously doing well; children are arguing over the slightest little thing, anxiety has really grown and become a big issues for siblings as well as others. The organisation help families with techniques to help manage children's behaviour and there are a lot of families who have lost the skills learnt and are exhausted now so are not managing situations and behaviours that they previously could. The organisation are trying to help with the parent's anxieties in order to manage the child's and suggesting ways they can calm down and take time out in order to talk and manage behaviour in a more positive way. The change in weather massively effects family life for a number of them and lots have been out less for walks etc which impacts on behaviour

## **IMPACT ON YOUNG PEOPLE**

- "My 18 year old daughter is having difficulty with all this COVID-19 pandemic and the guidance (she's on the spectrum). She has become somewhat of an expert in this but now has not gone with the latest guidance so she is now petrified of doing anything, which includes going out. What makes it worse is that she expects us to do the same. This has led to tears and major meltdowns. Her mental health is really poor and she panics if we open the front door, she is absolutely refusing to leave the house"
- An organisation supporting families with special needs told us that the end of term is always
  a busy time for them, as they have lots of queries about transitioning. Lots of children have
  not had the chance to meet their new teacher or classmates. This has resulted in a high
  number of calls to the organisation seeking advice on how to manage anxiety.
- An organisation who support families told us that many kids are struggling with separation anxiety; it's becoming an increasing issue especially among the kids that have not yet returned to school. They think there will be a marked increase at the end of August/Start September when kids have to prepare for school. They told us of one child who ran across the road from their house when they realised that their mum had popped across the road to drop something off for a neighbour. The child was screaming and had a meltdown.
- "my 5-year-old daughter is struggling to remember her teachers and friends at school. Her risk assessment has said she cannot return to school for the foreseeable future. I asked advice on how to keep school memory alive and I was told to print photos of the children off the class website and create a scrapbook. Feels a bit weird to do this without other parents' permission"
- An organisation supporting families told us that there are lots of issues with siblings, many are fighting with each other, they are getting bored at home and it's difficult to take them out because they don't understand social distancing. Older siblings are desperate to see friends.



## **IMPACT ON THE WORKFORCE**

- "I'm a teacher and been working throughout lockdown. I've been called horrible things on social media; told I'm a crappy mum because I had no choice but to go to work. I was told I'm putting kids in danger by not socially distancing from terrified, traumatised children who are scared that their parents might get sick and die (I was working when only key worker's children and vulnerable children were in school)."
- "I line manage staff at work and since the pandemic I am spending a lot more time emotionally supporting the staff that I manage. The extra strain that lockdown has placed on households has led to a marriage breakdown and her husband has moved out of the marital home. This has severely impacted the mental health of my team member as she is now juggling child care as a single parent whilst also working at home to fulfil her work commitments (as well as dealing emotionally with the breakdown of her marriage). As we have to work remotely due to our office being closed, supporting this individual has been more difficult than it would have been in other times. We use Microsoft Teams but my team member does not like to use the video call function, so from a safeguarding perspective, it is more of a challenge to truly make sure that she is coping ok as you can gauge a lot about someone's wellbeing when you can see them"
- A charity in North Kent told us that they have referred some members of staff to local mental health services; the strain of lockdown and an uncertain future has exacerbated a pre-existing health condition for one person. Another worker feels like they are just going from one emergency situation to another.
- "I work for KCC and they have released a policy this week that states that if you travel to a foreign country that requires a 14 day quarantine upon return, despite the fact that I am currently working at home (and have been for 4 months now), I will NOT be allowed to work at home during the quarantine period and MUST take it either as annual leave, or unpaid leave. I find this ridiculous as there is no good reason that I couldn't work upon return from holiday especially if I continue to be in good health, but I am being made to not work. I do not have sufficient annual leave to take three works off work, nor can I afford to take unpaid leave"
- A voluntary organisation in Thanet told us that 50% of volunteers were happy to loosen restrains and start to visit clients again, but the other 50% said they were uncomfortable doing this.
- "I have a 14 year old daughter and I am a keyworker. I have been told to go back to work but school won't let her back as they say she's old enough to stay home alone. She's not been diagnosed by the doctor, but she suffers so much with anxiety. I need to work, I worry about my job security if I refuse, but school are not letting me put my child back in their care"
- "I work as a carer and I just had to self-isolate because I came in contact with someone who had covid symptoms. I was isolated for 2 weeks and I was paid SSP. I won't get any help with the money that I lost from not being able to work. What happens if I have to self-isolate again? My bills won't get paid on SSP, and it's not even me that's sick!"
- An organisation who support adults with autism told us that some employment disputes are
  cropping up; adults with autism don't like to say "no", so when their manager asks if an
  employee can take on an extra shift they just agree. Some people are at breaking points,
  they are working so much, possibly have family/domestic issues, the public are not
  observing distancing rules. Some people have had outbursts at work, leading to
  disciplinaries.

## **Working from home**

- A breastfeeding support group told us about one woman who is a new mother at home, she
  has no support from her family due to corona. She is isolated at home with her husband
  however she is worried that the baby will make too much noise and disturb her husband
  who is working from home.
- "One of my employees is Autistic and is now terrified of coming back to work. Everyone has been working from home for the past few months and we are now starting to come back into the office, on a rotational basis. She has become so used to working from home and feels a lot calmer, she doesn't enjoy social interaction. I do not know if I can allow her to work from home as a "reasonable adjustment" to her autism, or if it will create tension among the other workers who are coming in. At the same time, it would be good for her to come in perhaps twice a week so that she can build up her social interaction skills again. I don't know what do for the best, but she's insisting on working from home from now on"

## **NEW PARENTS**

- "my baby is now 3 months old and was born during lockdown. I'm struggling to keep sane at home, as a first-time mum I had all these plans to be going to baby groups, baby yoga, singing classes, making new friends. It hasn't been able to happen. I've entered a new phase of my life being a mum and I haven't been able to experience it properly yet, I'm just at home with a baby that needs stimulation, as do I".
- A group supporting new parents told us that at the beginning of lockdown lots of mothers
  with older babies were calling to say they were missing being able to interact with other new
  mothers to discuss things such as teething etc. Some people worry about complaining about
  things such as teething during a pandemic.
- A breastfeeding support group told us that new mothers are struggling as they aren't allowed to have midwives come to their homes to help. Midwives can only assist by making phone calls to the new mothers. There aren't enough midwives doing video calls to assist with breastfeeding. They struggle to use video content as everyone's problems are different and unique.

## **VULNERABLE GROUPS**

#### **Homeless**

 A District Council running a community hub told us about 6 homeless people who should have been on the shielding list but they had no address to receive a letter. One of these clients was found to have end stage cancer and passed away during lockdown at their temporary hotel accommodation.

## **Abuse Victims**

 A district council told us that they have seen an increase in domestic abuse calls now that lockdown has eased slightly as these people have been able to get out of the house to seek help

## Other vulnerable groups

- An organisation supporting older people told us that one of their volunteers had to visit a client to read a letter that was received in the post; the client is unable to read and could not understand the important letter that had arrived.
- An organisation supporting independent living told us that 20 people in the past few weeks indicated that they are managing their lives at present but the phone assessments are not able to provide the client to person home visits. They believe they are being deprived of the essential advocacy service to support them in their individual chosen life path.

An organisation who support people with autism told us that it has been hard for families who are shielding and are being careful about how they start to go out into public again. We heard about one family who have 4 kids (2 who have a diagnosis and 2 who don't have a diagnosis but are likely to be ASD), Mum and Dad are also on spectrum; it's hard to get kids to abide by the rules of social distancing. People look at you "funny" and judge if you can't abide by the rules. If they had a more visible & clear disability then the public might not bother as much, but ASC is a hidden disability.

## SECTION 3. Access to medication & physical health

## There were 4 themes within this topic area:

- 1. Access to primary care
- 2. Ongoing treatment
- 3. Access to medication
- 4. Maternity & post-natal care

## **ACCESS TO PRIMARY CARE**

- "I had a problem contacting my GP for an appointment; they gave me a phone consultation even though I'm deaf and can only lip read. I have sent an email to my surgery to tell them this so I hope that I get a video consultation and I can try to lip read"
- "I have had 2 consultations with my GP during this period using technology. It's been excellent, no dirty waiting rooms! Let's hope virtual consults remain"
- "My son has been suffering from a mild, but long term, health condition so I recently phoned our GP for an appointment. The only option available is to phone up on the day and request a telephone consultation. It took a long time to get through. I rang many times before I eventually got into the call queue. I left my details and was told that a doctor would call later that morning, which they did, but unfortunately at that moment I was unable to answer the call in time because I am working at home and looking after two children. I phoned them back instantly and was told rather abruptly that if I did not answer the call then I have lost my place and they will not call back. I was even told that I should have sat by the phone all morning so that I didn't miss the call! The only option available to me was to phone back at midday, which is when they release the afternoon appointments, so I did this (and repeated the whole saga of trying to actually get to speak to someone)"

- "I've been very impressed with my GP. Normally I have to go and see them to get my prescriptions but I've been able to do it over the phone. It's been a life saver. I hope things don't have to go back exactly to the way it was before and we can learn from this and do things differently in the future."
- "I phoned up my GP to get an appointment and was very upset by the receptionist who told me "don't you know people are dying out there". I know that my problems aren't as bad as what's going on out in the world but that doesn't mean I don't need help to. It was very distressing."
- "My GP has been really good. I phone up, get a prescription and within an hour it's ready to collect at Boots. So much more seamless than it used to be."
- A mental health support group told us that a service user was informed by text message that he would need a face mask to attend the GP surgery, they purchased a mask and attended the GP surgery to find it was still closed. This was quite a distressing experience for their mental health.
- "It's been awful, I'm unable to make Drs appointment at XXXX and the situation still continues. We're not able to use the technology they are using to substitute for face to face. My husband had a phone call from the GP in June to be told by phone he has heart failure, which is cruel to a man of 77, it left him worrying with no further contact or reassurance"
- "I had to send a photo of the area in question to the GP surgery's general email address which I feel is unacceptable as presumably all staff could see it. For many issues I would be happy to have a phone consultation but if I wanted a face to face I would not want to be made to feel that I was being difficult. The consultation via phone was acceptable"
- "For my 87 year old father, he has had a mixture of experiences accessing his GP. He has had many contacts with the practice. He does not use a mobile phone and was told the call would be anytime in the next 12 hours, and it was 10 hours of waiting by the house phone!"
- A Council running a community hub told us about 4 homeless people who were living in tents and had been placed into a hotel temporarily; the service users were registered with a GP but now the GP no longer wishes to have them on their books now that they have temporary accommodation. The Council reports little support from primary care for this cohort of patients.
- We heard from a support group that a lot of autistic adults have found the new way of
  contacting GPs much better for them. They prefer the video calls to having to go into the
  surgery and sit in a waiting room, with all the sensory issues that brings with it. They feel
  that the video calls are the way forward.
- An Age UK centre told us that they received 10 calls this week from clients who asked if they were "allowed" to go back to the GP, these clients all have pre-existing health conditions.

#### **GP Referrals**

- "I always thought I had something "different" and couldn't understand what it was. I've been looking into ADD, and I filled out an application via my GP for an appointment regarding an ADD referral. I missed the call from the GP to follow up on my application. Because I missed the call, I got a text from the surgery saying that they have sent the referral off straight away, I didn't expect him to send the form off without talking to me about it"
- A mental health support group told us that a service user saw their GP in May, who made a
  referral to the Community Mental Health Team. The service user is really struggling with
  their mental health and called the GP to follow up the referral, who told them to wait an
  additional 2 weeks.

## **Practice Staffing**

 A mental health support group told us that when a service user contacted the GP about their medical conditions, the receptionist began to tell them about their own personal family crises that they've gone through because of COVID and the service user felt like the receptionist was having a go at them and that their problems weren't important because of everything else that was going on.

## **ONGOING TREATMENT**

- An organisation supporting families told us about a client who is having problems getting radiology services to respond to them. Their child is one years old, not mobile and has left sided weakness. There is a lump on the side of their head, which is growing and the child cries as if in pain. The child was seen in hospital and Padua Ward put in an urgent referral for a head scan; 5 weeks later the family have not heard anything. No one has answered the phone at the ward, ultrasound department or CT department. Messages have been left with secretaries, but the family are still waiting. The GP and health visitor said that nothing can be done until the scan is completed.
- An organisation working with disadvantaged families told us about a child that they support
  who has been transferred to the PICU in the Evelina, with Kawasaki disease. The child is
  stable now, but very critical. The child's mum has been unable to leave the hospital ward due
  to the COVID restrictions.
- "I've just been to have a blood test. The nurse didn't wash or use hand sanitiser before blood
  withdrawal and didn't wear gloves. She was handling the phone, computer and tablet before.
  While taking the needle out of my arm, there was a bit of an accident so the blood started pouring
  on my arm and she put her naked & unwashed finger over it to stop the blood. Needless to say, I
  rang her supervisor shortly after the incident and had a long talk with him about infection control"
- "I went to the XXXXX hospital, but didn't expect to stay in for five days with pneumonia and I didn't take my medicines with me apart from a couple I keep in my bag. I realise now that I should take a small sealed bag with my meds and prescription with me. Also it would be helpful for the discharge form to include times that you have taken medication in case of overdosing. This is why I try to write a record of what I've taken and when, because when poorly, we can easily forget"
- An organisation supporting carers told us that carers have reported that local hospitals are much better at referrals and communicating with them, compared to the start of lockdown

## **ACCESS TO MEDICATION**

- A service user of a mental health support group said that they continue to have issues with their pharmacy. The pharmacy 'mess up the dosset boxes' and they are now considering changing pharmacy as this is having a negative impact on their mental health. They said the thought of changing pharmacy is daunting, however it 'needs to be done'.
- "My pharmacist is having a lot of delays at the minute. I know that there are a lot of pressures and it's a difficult time for everyone but I've been left without my meds for 3 days and without them I'm starting to go downhill really quickly."
- A mental health support group told us that one of their service users contacted their GP regarding pain relief. The GP will not review the medication as it wasn't them who originally prescribed the medication. The hospital were the ones who originally prescribed the medication and the service user was not aware if the department was operating during lockdown, this led to a decline in mental health. The decline in mental health has led to an increase in pain meaning the service user can't use stairs as they live on the 7th floor and the lift is often out of action, they are often unable to get out for walks.
- We heard from a sup-port group who said that a lot of autistic adults have found that
  collecting prescriptions is easier, they don't have to collect it from the surgery and then make
  another trip to the pharmacy; the prescription is going straight to the pharmacy and it's a
  smoother way of dealing with things.
- "The difficulties I have had getting the right medications from my chemist, have been added to by the pressures on staff at the chemist in XXXXX. While some staff are caring others seem poorly trained in customer services. Last week on of the staff had a go at me because their payment system was not working properly, so they had to complete refund form. They then complained that I was buying things I was not allowed i.e. perfume. Then said I was making her feel dirty, because I did not use the stores pen, but used my own pen to complete the refund slip."

## **DENTISTS**

- "I was due to have 3 fillings on Tuesday, but the practice cancelled as they don't have any PPE. I don't know who should be providing it? One tooth that was due to be filled in broke in half yesterday so I doubt it can be filled now, and it's one of my front teeth, great!"
- Our Helpline took 11 enquiries within 2 weeks from clients who were looking for dentists
  and required treatment. One client told us that their dentist closed at the beginning of the
  year. Another client told us that they had guaranteed dental credit but cannot find a local
  dentist taking on NHS patients. We heard from one client that they had phoned quite a few
  dentists, but they were only interested in taking on private patients. The 11 enquiries came
  from various areas of Kent including Dover, Canterbury, Maidstone, Gravesend and
  Tonbridge.

#### **MATERNITY & POST NATAL CARE**

- "I had my baby right before lockdown started. I was still able to visit my GP surgery for her to have her jabs at 9 weeks old. My family still hasn't met their new grandchild, but she's kept me so busy that the last few weeks have flown by. It would have been better if I was able to get out to baby groups and visit the local children's centre, I feel that we've both missed out on something but I know that we're safe at home"
- "I'm meant to be under the consultant due to having multiple miscarriages but I don't have a clue, I've not heard from anyone and when I do try chasing it up I just get the 'someone will ring you back'. I'm not fussed but I've already been made aware I have a bleed around the sac, and I've bled twice already during this pregnancy..."
- "I'm a first time mum. I had loads planned for my maternity leave but it's all cancelled now. I'm finding the time at home alone with a newborn tough"
- "There are no local baby groups running at the moment and I don't know when it will be safe enough to start them up again. I'm climbing the walls at home, and my baby is now 7 months old, we need to get out!"
- "The first 6 months of parenting are the hardest, and yet the most precious. It has been completely changed by Covid, we didn't get to do our antenatal classes, visit the hospital where I was going to give birth, meet any new expectant parents. Now that the baby is here, we haven't been to any new mum groups"
- "I'm 13 weeks pregnant on Saturday and I've yet to hear from a midwife. I had my booking appointment at 5 weeks and that's the last I heard from anyone... I've had my 12 week scan but I've had to refer myself for the scans etc."

## **SECTION 4. Care & support packages**

## There were 7 themes within this topic area:

- 1. Care homes
- 2. Hospital discharge
- 3. Community services
- 4. Community services restart
- 5. Service coordination
- 6. Increased need
- 7. Future planning

## **CARE HOMES**

- "My mother-in-law died of COVID-19 after being in a care home. She died in hospital and they put her on end of life care on day 4. We thought the care home could have done a lot more to help, and she was in a reputable home. We weren't allowed to go to hospital with her and we didn't get to be with her when she died"
- An organisation that support carers told us that some of their service users have considered removing their family member from their care home and bringing them back to their own home. The support group told us that the carers don't understand how much help they will need, and the wrap around care that they assume they will have is not available.
- One person told us that "at the end of the day it's down to the care home to accept or refuse entry into their homes. Accepting without testing is a failure of their duty of care"
- "[I think that] The prime minister is so wrong for blaming care home staff for the errors he has made which cost the lives of tens of thousands of people. Take some responsibility"
- "I work in a care home and NO staff or residents have been tested, even though the government say that we have"
- "thanks to the fantastic commitment of eradicating this awful disease and shutting care homes to visitors, the deaths were fewer than they could have been. My heart goes out to those who lost a loved one. How Boris Johnson can blame the care sector for the government failings is beyond me. Until the government take responsibility, they have lost my vote"
- "I challenged the fact I have had not seen my mother for over 3 months so a week later they put in place an out-door visiting plan in place so people can book a 40 minute slot. It's only helpful if the weather is nice"
- "I've been working in a care home during the outbreak and I actually feel safer there than outside with all the muppets not following social distancing etc"

## **HOSPITAL DISCHARGE**

Care staff at a support organisation shared feedback about the lack of hospital discharge
care packages in place for people when they leave hospital. It is difficult to quantify at the
moment as the organisation say they aren't supporting that many people who have recently
been discharged from hospital, but when they are involved they have noted that people are
being discharged home without proper support in place.

## **COMMUNITY SERVICES**

 A mental health support group told us that a KCC Community Warden came to visit one of their clients following a short stay in hospital and the client said it was quite an unpleasant experience. The client said that the warden didn't really explain who they were, why they were there and asked what the client feels were irrelevant and probing questions about family without explaining why these questions were being asked.

## **COMMUNITY SERVICES RESTART**

- A voluntary organisation in Thanet, providing support to elderly clients, told us that 99% of clients want to have home visits reinstated. Following a risk assessment and polling of volunteers, the organisation has ruled out doing home visits at present.
- An Age UK centre told us that their service users are questioning why the centres are not back open again, but pubs, shops and restaurants are.
- Another Age UK centre told us that clients were calling because they need help with their benefits, getting a TV licence and other issues. They need centres to open again so that they can access the help provided by volunteers.
- Age UK told us that clients are pleased to have services such as gardening and domestic cleaning back
- The same centre told us that clients are "delighted" and have lots of positive feedback about the resumption of key personal care services such as bathing and nail cutting

## **SERVICE COORDINATION**

- "I currently access a number of services including GP, Older mental health services, respiratory services, social services, help at home, carer, and I notice the system is not joined up. No one person is taking responsibility for my care and I have had to hire a private advocate to oversee and co-ordinate my care because no-one is overseeing it. In the past it would have been the GP"
- A Community Hub told us that a "meals on wheels" driver identified a client who had fallen at home. They were helped after pressing their lifeline, but it shook their confidence. The Hub carried out a welfare check the next day and contacted the Intermediate Care team (ICT) because the client asked for more assistance. The ICT arranged for a community nurse to visit and establish what support was needed.

## **INCREASED NEED**

- One Age UK volunteer took an 80 year old client out for a walk in the park; they barely managed because their mobility had decreased so much during lockdown.
- A Community Hub told us that they made a welfare call to a client, who was reciting their
  poetry down the phone. 10 minutes after the call finished, the client called back to ask for
  hearing aid batteries (the client hasn't been able to get any for a while). The client called
  back again after another 5 minutes to chat about their sunflower, which has grown during
  lockdown. Many people in the area are depending on these welfare calls, and will continue
  to use them for some months.
- A district council told us that "long term repercussions from Corona and lockdown on people and families will go on for a very long time"
- Another community hub told us that people have decreased mobility, and they are worried that they cannot cope with changes to the outside world
- A voluntary organisation have been carrying out wellbeing calls and have identified 30 clients who now need a face-to-face volunteer for help at home.

## **FUTURE PLANNING**

- A wellbeing centre told us that many of their service users have expressed anxiety and concerns about the future after Covid. People have been unclear about what the future holds, including job security, financial stability, relationship problems, and ongoing support from the Department of Work & Pensions.
- One organisation told us that the voluntary sector is really fragile right now. They can't plan ahead and they know that funding is going to be an issue. They are a healthy, well organised charity but if there is no help they will fall off a cliff in January. At the moment the voluntary sector is disguising the impact of Covid as they are all picking up the pieces in the community but as voluntary organisations start to fold, these people will be returning to statutory services for help

## **SECTION 5. Education, Transport & Housing**

## There were 5 themes within this topic area:

- 1. Education
- 2. Transport
- 3. Blue badge
- 4. Equipment
- 5. Technology

## **EDUCATION**

- "My daughter is in her 4th week back before summer break. It's been great for her, she's not traumatised, her mental health has improved, and she's been doing actual work and learning. The school managed to have a little sports day which all the children loved. My older child is dying to get back to school too, but I think the separation has been good for them after months together with no time apart"
- "I think the Government are putting us all at risk with the way they have downplayed the virus. They tell us that schools are safe and threaten us with fines if we don't send them back in September, however they still won't hold their own conference in a large hall because of the risk. Why should we accept this contradictory message? We can pack kids back into a classroom but they won't get together in a hall? We are being led by people who don't wear facemasks and openly admit to shaking hands and caught the virus themselves. I won't put my child at risk. I won't put myself at risk"
- "My daughter's school have been extremely slow with reacting to everything, the home learning has been poor/non-existent and for some reason the school are closing on a Wednesday for a deep clean. Surely they can do this after school closes on an afternoon? The Government are not providing any additional funds for extra cleaning so schools are struggling to find the money in their budget to pay for a cleaning firm to do these deep cleaning shifts".

- "As a teacher, I have to accept that children are safer at home. My assumption is that parents are doing a great job with their children at home, much more than I can do with 30 at a time in the classroom with no support"
- An organisation supporting families told us that they had spoken to 2 primary school SENCOs and both have said that from September to October half term they will be calling these terms nurture terms and focusing on settling the children into their new classes, supporting mental health and doing a lot of pastoral care work instead of focusing on academic work so much. There is also a plan to carry out teacher assessments and see where children are now.
- A teaching college have reduced the number of students allowed in a treatment room with a patient; they are live streaming consultations so that few people are in the room and the students continue to learn that way.
- "my son isn't going back to school as it's too close to summer holidays for him to get into a routine then out of it again for 6 weeks"
- "there are increasingly more outbreaks in educational settings than care homes"
- An organisation who support families told us that they have heard so many school issues lately. They held a zoom meeting with a therapist because so many parents are upset with their child's anxiety. Parents are mostly concerned about the return to school in September, many schools have not contacted parents with reopening plans. Some schools are doing staggered opening times, so having set times for year groups. This doesn't help if you have a few kids in the same school but have to wait around for an hour before the next kid goes in to school. Also if your child needs to have the support of walking in the gates with an older sibling. Having a change to the start and end of the school day messes with the child's concept of routine, especially ASC kids. Other school haven't communicated any updates for parents regarding starting back in September. One parent called the school to ask about provision for their ASC child, the school said "you're just one child and we have a whole school to deal with".
- We heard from an organisation who support parents that one child has been confirmed to have Ehlers-Danlos syndrome not just hypermobility. The child struggles to walk around for the whole of play time so uses their wheelchair chair but their arms hurt more than their legs so they can't self-manoeuvre the wheelchair. The child sits and watches the other children play. Mum asked if children or staff could assist but was told no one can push the wheelchair without having the KCC wheelchair training as part of manual handling.
- An organisation supporting disadvantaged families told us that some families have been told
  by schools that children can wear their own clothes to school, but they must be in fresh/clean
  clothes daily. Many families cannot sustain the financial burden of buying new clothes, as the
  children do not have enough, and the parents are unable to leave the house to buy clothes.
  With children having grown since lockdown began, and schools insisting on fresh clothes
  daily, parents are under pressure.
- "my son is in year 11 and had no support since he left in March, no homework or phone calls. I have no idea how he's going to cope with college in September!"

## **Nursery Settings**

- An organisation supporting families with special needs told us that they are finding that nurseries have been giving out incorrect information around DLA and EHCPs, which has led to children starting school without the support they need in place. In one case the nursery had provided 1:1 support through the nursery manager and had not documented the child's challenges as SEN so when mum said her child has 1:1 support at all unstructured times because of their SEN needs, there was no supporting evidence in the transitions pack, no high needs funding applied for and no reports to support the behaviour issues. The impact on this has meant school have said they don't have staffing capacity to meet the child's needs so would need to put part time schooling in place until high needs funding granted. The Mum works and can't manage a part time timetable.
- "my nursery is still charging parents despite government support! I'm not sure why parents should be paying the invoice if the child isn't going to nursery because the staff have been furloughed!"

## **Home-schooling**

- "as parents we are doing our best but we are not experts. Children are struggling emotionally at the moment with not being able to see friends and with new routines or even have new routines. Give kids a break! They will catch up but right now it's about their emotional state, that's what's important, not engaging in schoolwork"
- "when you have to print out work for several children it gets expensive and I imagine not all children have the luxury of home computers and printing capabilities. The government were meant to be supporting children who were disadvantaged but it seems to have been all talk and no action"

## **Special Needs**

- "My son couldn't return to school before the summer holidays started; he has ASD but doesn't have an EHCP. He has been overlooked, as have many other children who don't meet the "criteria" for an EHCP but have an additional need or disability"
- An organisation supporting families with special needs told us that two schools within their catchment area have said that they can't take reception children in nappies as they have no care facilities to change the child, or no place to offer dignity for changing. The advice from the schools to the families was to contact the organisation and ask for support for toilet training or at least get the children into pull ups and teach them how to change themselves with prompting. The other proposal was a parent comes into to school to change the child. The organisation told us that no referral was made to the school nursing team or to look outside the box in terms of using a first aid room or buying a screen to allow privacy in the toilet etc. One child has a diagnosis of ASD, the other child is awaiting diagnosis.
- The same organisation told us that 6 children with SEN have had school suggest part time attendance from September. Some parents are happy with this suggestion, but for those who work, it is causing concerns. The schools had various reasons but the main one was that there were not enough staff to meet need.

- An organisation supporting families with special needs told us that some kids are just desperate to get back to school and get back into a routine. For the kids who did go back (with ASC), the school have thought it through and have made sure that the support is in place. They are able to handle the children and their needs well, and still try to meet their education requirements. Other families have not even had the chance to return to school. Many have not even had a call from the school since March! Even though they're on the SEN register they still haven't had any support at all.
- "what about SEN children and in particular, those that attend Special Schools? Will they be allowed back? Will they be able to catch up 6 months lost specialist education including speech and language therapy and other therapies?"
- "my son has ASD, he doesn't have an EHCP. He has been overlooked for a return to school as have many other children who don't meet the "criteria" for an EHCP but have an additional need or disability. I'm bitterly disappointed"
- "some children with disabilities can't see home as school. It is causing more stress for myself and my little ones. As much as I want to, we can't manage to do schoolwork at home"
- An organisation supporting families told us that some kids with special needs are likely to become school refusers, there may be an increase in kids who will not return in September.
   Parents are concerned because the Government have stated that fines will be charged for children who do not return in September.
- A support group told us that some children that they work with (special needs) are
  progressing from infant school to junior school in the next few weeks. No transition has
  been able to take place and the children are struggling to accept the idea of a totally new
  school without being able to see it. There are virtual tours available, but this is difficult for
  young children to understand.
- A different organisation who support families with special needs told us about a new referral that they received during lockdown; a 4 year old child (who is nonverbal and is in nappies) who has been waiting for an ASD assessment (which has now been postponed) but has been waiting for 2 years now. He is due to start at school in a few weeks however the school can only offer 1 hour a day until he gets EHCP (they can't fund a 1:1 for him and they also don't have a care suite to change his nappies). The nursery self-funded a 1:1 for him for a few years. Mum is going to appeal to get an EHCP for him, but the school should still be able to get higher needs funding without an EHCP. The school cannot legally put the child on a part time timetable without parental agreement, which Mum has refused to agree to. Mum has called XXXXXX for help but is still waiting for a callback.
- An organisation who support families with special needs told us that one high school SENCO
  made a call to a student who is leaving primary school. The SENCO had a chat with the
  student and their mum to discuss the transition into high school, mum was glad that her
  child hadn't "dropped off" their radar and that the school are trying to make it easier for
  them. The high school SENCO is going to arrange a day when the school is empty for the
  student to have a "walk through" to make them feel comfortable.

#### **TRANSPORT**

- "I asked KCC for a partial refund of my son's bus pass because he hasn't used it since March, and it was a huge expense for us. I haven't had any response back from the department yet, but I did get an email asking for next year's payment!"
- An organisation supporting people with visual impairments told us that enquiries have been about attending medical appointments e.g. hospital transport have increased.
- A voluntary organisation in Thanet told us that their transport team are restarting their service for medical appointments, due to demand
- An Age UK centre told us that clients have been calling to ask if public transport is safe enough to use.
- A Community Hub told us that one client took a bus journey that lasted 15 miles. They were the only passenger there and back. The client felt that people are still unsure of taking a risk by using public transport.

#### **BLUE BADGE**

 An organisation supporting independent living told us that a client was unable to renew their disabled badge because they couldn't obtain a photograph.

## **EQUIPMENT**

- A breastfeeding support group told us that they normally receive 2 enquiries to rent breast
  pumps per week however during lockdown it has increased to 2 enquiries per day. It is
  likely that this is due to not being able to receive support from midwives, so mums feel they
  have no other choice but to go to breast pumping, which can cause new mothers to not
  bond with the baby. The organisation said that it has been challenging to keep up with the
  demand, but they are also taking the time to support mums with their breastfeeding
  challenges.
- An organisation supporting people with visual impairments told us that replacement equipment and low vision aid queries and requests are ongoing

## **TECHNOLOGY**

 An organisation supporting independent living told us that 5 clients contacted them and were struggling because they have no internet and no technical devices to enable them to communicate properly.

## **SECTION 6. Testing**

## There were 4 themes within this topic area:

- 1. Testing
- 2. Track & trace
- 3. Precautionary isolation
- 4. Covid experiences

## **TESTING**

- An organisation supporting carers told us that their service users are more comfortable visiting A&E, they feel reassured that staff have been regularly tested for COVID.
- "I had a test last week, I had been unwell for a week. My daughter sent off for a test for me, delivered by Amazon. Took the test, arranged delivery for next day, picked up by post office. I got the results in 36 hours, luckily it was negative"
- "if I get sick I won't be going out to get tested, I'll be going to bed and self-isolating of course, not driving around looking for test centres"
- "I spent an hour trying to get a test after meeting my friend who tested positive and have been told that unless I have symptoms, no test for me! I failed the last step of verification online trying to order a home test....now I've started coughing"

#### **Sites**

- "The Folkestone and Dover test sites have now closed and the nearest one is Ashford or Ramsgate!"
- "Folkestone has 24 cases per 100,000, which doesn't seem much, but we're getting close to a localised lockdown. It's increasing in our area, but maybe that's because of the mobile testing site picking up lots of cases?"
- "I've heard that Thanet is another area that has a high number of cases but it's probably because of the new testing site at Manston"

## **Waiting for results**

- "my partner had symptoms, he did a home test and isolated for 2 weeks (he lost 2 weeks income as he is self employed). That was 3 weeks ago, we have never had the results and have been told that they are lost!"
- "I did a test 3 weeks ago, still waiting for the result"
- "I had a fever and requested a test a month ago. The fever has gone now but the test still hasn't arrived. Is that the way tests are counted? One request = a test, even when it hasn't been completed? I don't know if I had the virus or not, I spent 21 days in isolation for nothing"
- "As a keyworker who has no car, I asked for a postal test back in April. I'm still waiting...."

## **Antibody testing**

• "they need to make antibody tests available to everyone. There are so many people that were asymptomatic, it might make all the difference if they knew that they weren't at risk of catching it, they can get back to work"

## **Contracting the infection**

 An organisation working with BAME groups told us that they conducted a survey with over 700 responses. They told us that the evidence suggests that those from BAME communities are more likely to know someone who has had Covid 19 or died from Covid 19 than non BAME.

## TRACK AND TRACE

- "Once you enter track and trace, you commit all your friends & families details to the council and police's new powers under public health to detain and remove people for 14 days. I don't trust it"
- "if I am standing near someone who doesn't know that they have covid, how can I be traced and told to self isolate?"

## **PRECAUTIONARY ISOLATION**

• "My daughter returned to school for a week at the end of term as she is in year 5 and we were advised it was safe to do so. After only 3 days we were informed that one of the teaching staff in my daughter's bubble had tested positive for Covid-19 so now all of our household need to self-isolate for 14 days. This has impacted the whole family from a social perspective and my husband cannot go to work as he cannot work at home"



## **COVID EXPERIENCES**

- "I tested positive in April and was off work for 7 weeks. It started with sinus problems, headache from hell, then aching all over. Sore throat, bad stomach, diarrhoea and then the breathing problems started. I was on 3 lots of antibiotics and steroids then ended up in the hospital. I'm asthmatic so it made me extra wheezy and couldn't catch my breath. I never felt so ill. Now I'm back at work and feel much better but I still get very tired and wheezy. The doctor said it could take 6 months or more to fully get over it"
- "I suspect I had it at the end of January, I wasn't right until the end of March. Antibiotics didn't do much, but I think they prevented pneumonia"
- "I had it in February and was very ill but not hospitalised. I did end up having pneumonia as well and I still have difficulty breathing when I walk upstairs. I have extreme tiredness, bad headaches and not able to get on with things in general"
- "I am 28 years old and work in a GP surgery, we are still accepting some patients into our surgery who need to be seen in person. I contracted Covid at the start of June and I recovered within 3 weeks. I had breathlessness and fatigue that was very severe once I returned to work. My own GP referred me to a cardiologist who diagnosed me with dilated cardiomyopathy, he said it was a result of infected heart muscle from my stay in hospital. He is not sure if it is reversible. I'm too young to have a heart condition and I feel like my life is cursed now since this virus came along"
- A community hub told us that one client had recently been discharged from hospital after recovering from Covid (they were over 90 years old). The client said that they needed help with some shopping and prescription collection but felt guilty about having to ask for help. The client said they were usually quite self-sufficient and had been struggling with the effects of the virus.



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