Brighton & Hove City Council

Health Overview & Scrutiny Committee

Date: **24 November 2021**

Time: **4.00pm**

Venue **Council Chamber, Hove Town Hall**

Members: **Councillors:** Moonan (Chair), Deane (Group Spokesperson), McNair (Group Spokesperson), Brennan, Grimshaw, John, Lewry, Meadows, West and Wilkinson
Invitee: Frances McCabe (Healthwatch), Caroline Ridley (CVS) and Michael Whitty (OPC))

Contact: **Giles Rossington**
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AGENDA

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12 MEMBER INVOLVEMENT **5 - 22**

To consider the following matters raised by Members:

A written question has been received from Cllr Grimshaw relating to a complaint made about Child & Adolescent Mental Health Services (copy attached)

Date of Publication - Tuesday, 16 November 2021

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For further details and general enquiries about this meeting contact Giles Rossington, (01273 295514, email giles.rossington@brighton-hove.gov.uk) or email democratic.services@brighton-hove.gov.uk

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Item 12 Member Involvement

Member Question from Cllr Grimshaw

Mascot has brought the issue of its complaint to Sussex Partnership NHS Foundation Trust (SPFT) to me and asked me to raise at the HOSC (see attached documents from Mascot).

mASCot
Managing Autism Spectrum Condition Ourselves Together
Supporting Local Families

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4 October 2021

Sam Allen, CEO Sussex Partnership NHS Foundation Trust
Geoff Raw, Chief Executive Officer, Brighton & Hove Council
Adam Doyle, ICS Leader & Chief Executive Officer, Sussex Health & Care Partnership
Deb Austin, Executive Director Families Children & Learning, Brighton & Hove Council
Service leads & organisations working with children & young people in Brighton & Hove

Complaint in relation to the commissioning and provision of services from CAMHS Sussex Partnership NHS Foundation Trust ("CAMHS SPFT")

mASCot Formal Complaint

The Directors of mASCot C.I.C and the mASCot membership wish to draw your attention to serious concerns with CAMHS SPFT and call for an urgent and immediate response into how these ongoing concerns will finally be resolved.

mASCot is a local parent led organisation who support families on the journey to and after their child receives a diagnosis of autism & neurodiverse related conditions. We have been an established support network for 15 years and have a membership of over 1,000 families. We provide day to day family support and work alongside the Local Authority, Health Service, and schools to improve services for our neurodiverse families.

Within our large community we continue to hear daily accounts of systemic failures involving CAMHS SPFT. Whether families have been seeking help for years or are new to the service, the **same** problems that were documented in the 2014 Services for Children with Autism Scrutiny Panel report continue.

Neurodiverse children and young people are the largest cohort requiring help from CAMHS SPFT. As such, many of our mASCot families have been referred to or will need to access CAMHS SPFT as it is the only service with statutory professionals who can help with their age group and neurodiverse conditions.

CAMHS SPFT is therefore the gateway for many of the interventions our neurodiverse children need, whether it be assessment, diagnosis, medication, or therapeutic support. It has become a bottleneck and families are being refused assessment, and access to help is being declined or significantly delayed.

mASCot feedback issues, via parent representatives on boards and panels. Our collective voice is important because parents & carers need to focus on their children and may not have the capacity to individually fight for the care their children need and deserve, nor should they have to. Many of our

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families are at breaking point because of the struggle to have their children's specific needs acknowledged and catered for. The main areas of concern experienced:

- Disjointed communication & assessment process
- Lack of ASC & neurodiverse appropriate therapeutic intervention
- Poor management of medication
- Disrespectful & insensitive attitude towards families – culture of 'Parent Blame'

mASCot led in the initiation of the 2014 Autism Scrutiny and have been involved in the re-planning and development of the new Neurodevelopmental Pathway from its inception. This new pathway has been referred to many times as the 'answer' to the problems highlighted within CAMHS SHFT, however this pathway has been in the planning stage for five years. Its incompletion, and/or the acknowledged national underfunding of mental health services for children & young people, can no longer be an excuse for why these longstanding issues with this specific service have not been resolved.

mASCot Directors and the mASCot community membership submit a formal complaint with associated evidence linked to this letter. Please respond to info@asc-mascot.com to acknowledge receipt of this complaint within 14 days of the date of this letter.

Regards

Sam Bayley Director
mASCot Directors & mASCot membership

www.asc-mascot.com

cc:
Caroline Lucas MP
Lloyd Russel-Moyle MP
Peter Kyle MP
Hannah Clare, Chair of Young People & Skills Committee
Sue Shanks, Chair of Health & Wellbeing Board
All Councillors
Anna Gianfrancesco, Assistant Director Children's safeguarding & Care
Jo Lyons, Assistant Director Education & Skills
Georgina Clarke Green, Assistant Director Health SEN & Disabilities
Dr Rick Fraser, Chief Medical Officer
AMAZE
PaCC
Healthwatch
OFSTED
CQC

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Complaint in relation to the commissioning and provision of services from CAMHS Sussex Partnership NHS Foundation Trust ("CAMHS SPFT")

Please respond to info@asc-mascot.com to acknowledge receipt within 14 days of this letter and to confirm the dates by which the answers to the various concerns will be addressed. This should be within a reasonable time-period and no later than one month from the date of this letter.

You are respectfully requested to pass this letter to your legal advisors to respond formally and to set out the steps to be taken to remedy the situation as a matter of urgency.

CAMHS SPFT has a duty of care towards those it is empowered to serve. CAMHS SPFT is in breach of its legal duty of care towards service users and potential service users (neurodiverse children and young people in need of mental health support and diagnostic services in Brighton & Hove and Sussex). This breach is unacceptable, inexplicable and must be remedied. We look forward to your formal response to the concerns in this complaint.

For families, there is a history of poor service from CAMHS SPFT. The Services for Children with Autism Scrutiny Panel report April 2014 *[*Scrutiny Report*]* prepared by Brighton & Hove City Council, set out recommendations which CAMHS SPFT are fully aware of, but to date, many mASCot members feel few positive improvements have been made.

Individual service users and parental groups have continued to raise concerns/complaints, to numerous professionals within CAMHS SPFT and via PALS, both as constructive feedback or official complaints, both in writing and via meetings and these have not been acted upon adequately nor satisfactorily responded to. Concerns have also been raised by the Healthwatch report 2014 (Sussex) ** Healthwatch report* and the Parents and Carers' Council report 2017 ** PACC report* together with Brighton and Hove Clinical Commissioning Group's own Autism Scoping Report 2016 ** ASR report*

Notwithstanding being on notice of this and the impact of these failures. We seek clarification of:

- why not all the Scrutiny Report's recommendations have not been implemented,
- what grounds CAMHS SPFT has for failing to adopt these practices sooner,
- what steps CAMHS SPFT will take to adopt those practices,
- the timescales for doing so.

Clearly time is of the essence as these inexplicable failures have seriously adverse impacts on those affected.

In addition to the Scrutiny Report's recommendations there are additional issues that we wish to formally

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draw to CAMHS SPFT's attention so that they can be incorporated into the necessary changes currently in construction in standard practice and standards and guidance for CAMHS SPFT professionals and staff as part of the current re-design of the Neurodevelopmental Pathway.

There is always the opportunity to change the management of the work culture and ethos of CAMHS SPFT. mASCot members have reported serious ongoing concerns in the following areas which are summarised below with full responses linked.

1. Disjointed communication & assessment process

The attached lived experience/anecdotal evidence demonstrates that families overwhelmingly feel there is lack of consistency and transparency in the assessment process within CAMHS SPFT and that it is not fit for purpose and serves only to waste time and increase stress for both staff and service users.

Neurodiverse families are aware that over the last 5 years, work has been undertaken to consolidate a new Neurodevelopmental Pathway. However, until this new Pathway is implemented with the whole service adequately staffed and trained, the mental health, wellbeing and educational attainment of all children awaiting assessment for all neurodiverse conditions is extremely compromised and strategies to support these children and their families remain unclear and unmet.

Following the COVID pandemic the NHS has adopted effective communication portals which means that there is much scope for guidance from within the NHS on setting up such information, communication and tracking services. An efficient, effective service provider always sets up clear lines of communication to end users and reduces the time potentially spent by CAMHS SPFT staff dealing with personal case enquiries and all general enquiries.

This is now standard practice in other private and public service providers and government websites and has been for many years. For example, one can access medical records via the NHS APP; order medication and communicate with GPs directly via surgery portals (thereby releasing the staff/GP's time); track the status of an applicant's application for a driving licence or passport. One can even check the status of a conveyancing transaction with a legal services provider via their portal. This is now basic, standard procedure. The Local Authority use computer communication for all reports/assessments/conversations regarding a child and it is inconceivable that CAMHS SPFT cannot adopt this practice to release time dealing with enquires (or more to the point, ignoring enquiries presumably due to time pressure) and for staff to undertake work to progress applications.

This will also help resolve some of the current problems identified in the attached evidence:

- referrals lost or acknowledged received and then lost,
- the long wait between assessment and receiving the written report which delays all other interventions from schools and services,
- delays in assessment or and discharge with no explanation,
- reports not being written,
- reports being sent to the wrong people,

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- inaccurate information being recorded that takes months/years to amend resulting in cases mistakenly being closed,
- long waits with no communication,
- phone calls unacknowledged or not returned,
- poor case hand overs involving CAMHS SPFT,
- case notes not being read before meetings thus wasting time,
- parents having to chase CAMHS SPFT to visit schools to complete assessments,
- referring families to private support agencies that charge,
- failing to accept private diagnosis and then failing to refer to the appropriate pathway,
- assessments not tailored to communication or ability level of the child,
- failure to inform/update service users of important information relating to staff absences that may affect provision nor explain temporary changes to, or the reshaping of, services.

As such, the outdated communication system in use by CAMHS SHFT has additionally resulted in parents only able to gleam 'off the record' information regarding the assessment process, for example, from professionals during parental workshops. Whilst parents were glad to receive information snippets, it is inappropriate to expect parents to disseminate vital service information to the parent community in this way; workshops are designed to be a support for parents and not for individual parents to be a channel for statutory service information sharing.

Furthermore, regarding Covid-19 and lockdowns, parents and agencies have questioned why CAMHS SPFT closed its doors to families in January until March 2021. There was no point of contact within CAMHS SPFT at this time for families regarding their children's assessments, nor how to access medication and no therapy provision was provided.

We are fully aware of the impact Covid-19 has had on all statutory services but are confused as to why voluntary organisations, such as mASCot, PaCC and Amaze as well as Seaside View and private assessment clinics have still been contactable and available to SEND families throughout multiple lockdowns. When CAMHS restricted/reduced its service this caused extreme distress to many families.

CAMHS SPFT is in breach of its legal duty of care towards service users and potential service users and we seek clarification of:

- how, future service provision and related information will be communicated to the public, as a matter of urgency, and if not, the justification for this,
- what legal basis it felt entitled to restrict and suspend services,
- what emergency 'disaster recovery' plan did CAMHS SPFT have in place as all services are required to do. Please provide a copy. This is not a confidential document.
- what factors affected CAMHS SPFT's ability to comply with this emergency plan,

We propose that the latest reasonable date for setting this up is 6 months from the date of this letter.

"They are dangerously incompetent, and my family has no trust and no confidence in their service. Our relationship with them began in 2014, and it has continued to erode ever since".

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"The lack of cooperation and empathy is disgusting. Got told to speak to PALs and that was it".

"Respond to distressed parents when they ask a question! Have a telephone line where someone actually picks up".

"Lack of understanding or any excuse to not assess - My son was referred for an ASC assessment by a professional and myself. It was refused on the grounds that he had friends".

"They literally dumped us from one list to another with no help, support or advice".

"We all understand that Covid brought up massive issues for CAMHS, but the lack of communication was extremely stressful, and was a problem before covid came along. Only being able to access an answering machine (and one where the recorded message essentially told you that they wouldn't be calling you back if your query was regarding stage 1 or stage 2 assessments!) and not hearing back was incredibly stressful and would have been made much easier if we'd just been kept in the loop about what was happening. Just be open about it. Being able to continue with assessments over video call. We had video appointments with many other departments over lockdown/covid, including assessments with NHS Occupational Therapy and NHS physiotherapy, and video appointments with The Wellbeing Service. We managed to co-ordinate with educational psychologists and assess and make an entire EHCP".

Parental evidence

2. Lack of ASC & neurodiverse appropriate therapeutic intervention

The attached lived experienced/anecdotal evidence demonstrates CAMHS SPFT discriminates against children & young people who have co-occurring diagnosable and severe mental health difficulties, as well as their ASC or/and ADHD. This is an extremely serious matter that must be remedied as a matter of urgency.

Your attention is drawn to the regrettable fact that there is a practice, whether a formal or informal policy, of refusing to provide an appropriate service and treatment that caters to those who present with both severe mental health difficulties as well as ASC or/& ADHD.

Therapies and interventions must be adapted to the neurodiverse needs of the individuals. **NICE Autism spectrum disorder in under 19s: support and management paragraph 1.1.5, 1.1.8, 1.4.2.*

At present a one size fits all approach is practiced. This is discriminatory as offering options that are unsuitable for someone with ASC or/and ADHD and not adapting to their needs is a breach of CAMHS SPFT's legal duty of care to provide services to those individuals.

Perhaps this is not clearly understood by staff and training is required. As a result, they are unable or unwilling to tailor their service and approach to meet these young people's needs and so, to discharge their legal duties towards them.

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An example, the regular occurrence of families being threatened with being removed, or being removed, from the service list due to a failure to attend one or more appointments without taking into consideration that the child cannot attend or manage appointments due to anxiety, fear, agoraphobia, or other reason related to their autism.

Evidenced here

In addition, a high percentage of emergency referrals to CAMHS SPFT are refused due to difficulties being identified as purely 'autistic behaviours' requiring support. There is a lack of autistic behavioural specialists within CAMHS SPFT, and this lack of specialism must be addressed. If CAMHS SPFT is not the appropriate service to provide this, who are these families being referred to?

Both these current approaches result in hundreds of autistic youngsters without access to appropriate/impactful early support via CAMHS SPFT identified in the linked evidence:

- high risk/complex/acute needs being referred to CAMHS SPFT from other agencies being declined as told not meeting their threshold that result in child being left with no support to deteriorate,
- being inappropriately referred on to other services,
- families seen by underqualified or inappropriate staff thus wasting time or returning family to long waiting lists for appropriate staff,
- professionals not keeping appointments, families arriving with no staff to see them,
- what little intervention offered is often not appropriately adapted for neurodiverse service users,
- if child fails to engage, due to lack of adaption, case then discharged with no further support,
- lack of help in-between assessments,
- post diagnosis limited intervention/support for families or failure to provide the support promised,
- often not enough flexibility in approach with service users.

It is vital that the new SEND strategy 2021-2026 *[*SEN Strategy]* formalises a non-discriminatory approach, supported by the new Neurodevelopmental Pathway. Please confirm this will occur.

The discrimination and breach of legal duty must be remedied forthwith. Please respond within 1 month of the date of this letter with your proposals for training of staff and the tailoring of services appropriately.

> ***"There is no support or provision afterwards anyway! Why are we making our kids jump through hurdles for??? Just to get medication or strengthen an EHCP application".***
>
> ***"Calling, no one getting back, still waiting for help, not in school, no friends, in bedroom, She has been abandoned and absolutely anything could have happened to her, and nobody would have known".***
>
> ***"The anxiety group for YP is not autistic friendly and don't capture the experiences of autistic experiences of MH issues. Their response is the CCG requires them to do this, doesn't explain why they can't use additional measures designed for ASC young person".***

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"CAHMS are like an impenetrable fortress. They don't even explain to the YP why they aren't offering any help".

"ASC or/and ADHD young people receive little if any adapted therapies yet require adaptions in education etc".

"Lost count of being told CAMHs aren't commissioned to work with autism… YP can't access the standard therapies delivered by CAMHs, then seen as not engaging".

"Therapies are siloed into different teams with little interaction or note sharing between them".

Parental evidence

3. Poor management of medication

The attached lived experienced/anecdotal evidence demonstrates the shocking situation that CAMHS SPFT clinicians are failing to prescribe or authorise renewed mediation in a timely manner. Our member's evidence shows that this has resulted in families experiencing the sometimes traumatic and often debilitating circumstances of running out of medication due to the unavailability of clinicians or any administrative staff at CAMHS SPFT to respond effectively to the problems identified in the attached evidence:

- lack of permanent staff in psychiatric positions, posts not filled,
- delays in reviews or renewing medication due to 'admin issues', with serious consequences of lack of appropriate treatment leading to suicide attempts or detention under the Mental Health Act,
- failure to inform families of waiting times for medication reviews or give advice between check-ups,
- parents having to chase prescription renewals with GPs having to bridge gaps,
- lack of flexibility in available medication to suit child's ability to take,
- failing to work in collaboration with private practitioners.

This is a clear and serious breach of their legal duty of care to provide a medical service. All other medical services provided emergency services at least during lockdown. This is, frankly, negligent. It is most definitely a breach of the duty of care owed by CAMHS SPFT and the individual clinicians and staff resulting in quantifiable distress and harm to patients and their families.

CAMHS SPFT is asked to provide an explanation as why this occurs. The discrimination and breach of legal duty must be remedied forthwith. Please respond within 1 month of the date of this letter with your proposals for rectifying these breaches.

"CAMHS then went on to say that they cannot give any timeline for any type of discussion re. medication as they currently have no psychiatrists who can prescribe".

"After my son had been started on his medication there was a delay of 2 weeks in between the first month's prescription and the second due to "admin issues" which meant he was then

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restarting the process of his body getting used to the medication, further delaying our follow up medication review which was supposed to take place after he was on the medication consistently for 2 months".

"Perhaps my situation was rare but in the event of moving the transition of notes from one local CAMHS to another should not take a year, especially when a patient is mid-way through a medication trial".

"We were told medication advice would be put in a letter. I have chased and chased this and after 4 months was told no letter was ever written/ dictated and the psychiatrist has left the service. We are now at 6 months and have been told to wait for transition to adult services for medication advice, and not to go to the GP".

"I was told they had a locum psychologist, so they were only prioritising review of meds for people that were on them as covid had triggered lots of reviews and they had massive depletion of staff".

Parental evidence

4. Disrespectful & insensitive attitude towards families - culture of 'Parent Blame'

The attached lived experience/anecdotal evidence demonstrates that CAMHS SPFT customer service and communication culture is not fit for purpose.

Any family attending CAMHS SPFT, whether they be neurodiverse or neurotypical, will require clear and supportive information, guidance and support from clinicians and their support staff. Staff must consider the communication needs of **all** their users to ensure differentiation and inclusivity for all families.

Families understand the lack of resourcing in mental health services for young people, but this is no excuse for the lack of customer care most mASCot families attending CAMHS SPFT experience. CAMHS SPFT is formally notified that training is required in customer service across all staffing levels, from reception staff to professionals involved with all families.

Clinicians and their support staff frequently fail to provide clear communication, or effective support and guidance, often combined with a lack of positive regard or basic courtesy:

- parenting still being scrutinised as causing their child's difficulties, even when a child has a diagnosis, EHCP and/or attending a special school,
- failing to offer positive regard or empathy toward service users, staff routinely adopt an abrupt/belittling or patronising attitude, families not feeling heard/ cared for,
- talking inappropriately in front of child with no sensitivity about diagnosis,
- staff do not respond to phone calls for updates or information, creating frustration and stress for families wanting help and advice, other agencies then having to intercede to obtain response,
- cases refused or dismissed with no information provided of why,
- retelling stories to multiple teams is re-traumatising,
- inadequate complaint procedure that is not user friendly.

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There is still a perceived culture of **'parent blame'** which was highlighted in the 2014 Scrutiny Report. The outdated and unacceptable perception that parents are responsible for their children's difficulties/disabilities and additional needs is wholly unacceptable and it continues to risk obscuring the condition and/or medical needs of the child and devalues the legitimate concerns of parents, eroding their wellbeing.

There is no excuse for this attitude as much work has/is being done to educate professionals, for example *A Time For Autism* a resource for professionals to improve their awareness when working with autistic families.

In conclusion, we stress that CAMHS SPFT requires a parental approach based on respect and that this is a vital element of service provision. This discrimination and breach of legal duty must be remedied forthwith.

Please respond within 1 month of the date of this letter with your proposals for the training and monitoring of staff and the tailoring of services appropriately.

"Young person detested going there, felt patronised way spoken to YP. Hated it. Parent feeling undermined and cross examined and one time called a liar by practitioner".

"The input of CAMHs was an extra trauma".

"Parent told not to take notes as would get a report in 2019, not heard and then told wouldn't' be getting a report due to a backlog and someone had left".

"Lack of empathy was overwhelming CAMHS actions towards parents when their child is in crisis (A&E for self-harm or suicide attempts) can be at best considered dismissive, and at worst, contemptuous. We left feeling horrified, unsupported, and quite frankly we were all far more distressed than when we went in. We haven't been back since. Instead, we spend the majority of X's DLA money on a private doctor"

"If they were less contemptuous of the role of parents in (x)'s care, I truly believe that the outcomes for children would be more positive".

"Continued pressure from me re appointments led to suggestions I required parenting support".

"I found CAMHS personnel to be rude, disrespectful, challenging and inclined to blame parenting for all issues despite the clear and multiple diagnoses including autism, anxiety, alexithymia etc".

"My son had a very traumatic experience when we went to CAMHS and got so upset by the questions being fired at him he cried and froze. He has not seen or spoke to anybody else since this happened, we have had no support at all from them throughout the whole of lockdown ".

"Very scary experience, feel very intimidated as though you're lying….We should feel like they are on our side and support us but it's not like that".

"I felt dismissed and patronised, and it left me in a state of humiliation and betrayal (as I had opened myself up, giving detail of my family history, which at times was traumatic, in the family therapy process,

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for it to come to nothing in helping my boy)"

"I have been totally alone in dealing with the boy's mental illnesses and he has become totally depressed and abandoned. The whole process is like being on an eternal hamster wheel as a parent".

'Someone then phoned me up and was really rude and told me off for chasing. She was so rude I was in tears".

"It was like we were going through a sheep dip or a sausage factory. Diagnosis being dumped on us and then we were forgotten about. It was a very bad experience".

"Employ people who can be nice and kind and sympathetic of situations and people".

Parental evidence

In summary

Improved communication via efficient use of IT, improved customer care, seeking and responding to feedback, creating bespoke/differentiated packages for the individuals under CAMHS SPFT's care, will result in an improved service which embodies good practice and positive outcomes for young people which sadly is not currently there in many cases.

We have set out several questions above which we seek responses to along with a copy of the emergency procedure document. For your ease of reference these are summarised below:

We seek clarification of:

- why many of the recommendations of Services for Children with Autism Scrutiny Panel Report 2014 have not been adopted?
- what grounds CAMHS SPFT has for failing to adopt these practices?
- what steps CAMHS SPFT will take to adopt those practices?
- timescales for doing so and justification for those timescales,
- set up a case tracking service,
- set up communication of service information via the Local Offer or similar portal,
- set up training and tailoring of services for ASC, ADHD, and neurodiverse service users with mental health issues,
- set up specialist behavioural staff for those without mental health issues,
- provide an explanation why failings in medication prescription occurred and what will be put in place to avoid delays in future,
- what steps CAMHS SPFT will take to adopt appropriate staff training on customer service to all families and particularly tailored to the requirements of ASC or/and ADHD and neurodiverse conditions?
- what legal basis it felt entitled it to suspend/impede services over lockdown?
- provide a copy of CAMHS SPFT 'disaster recovery' emergency plan for the provision of services which should have been triggered by the pandemic and explain what factors affected CAMHS

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SPFT's ability to comply with this emergency plan. We will revert to you on consideration of this with any further queries we may have on compliance with this document.

In addition:

- what is being done to lessen the backlog of assessments that have built up during Covid-19 and how will the timeframe for assessment, currently being quoted as a 2 to 3 year wait, be reduced?
- will assessments be outsourced to private clinics to reduce waiting times as in other counties and, if not why?
- when will the list of private assessment clinics/diagnostic centres whose reports will be accepted by CAMHS SPFT and other services, be available to service users wishing to pursue a private assessment? as currently CAMHS is both gatekeeping and monopolising service provision.
- we need a new complaints procedure, that links parents directly to service leads rather than families being directed to PALS, as PALS this proven ineffective in resolving these longstanding and ongoing problems.

We have set out above the numerous breaches of CAMHS SPFT's statutory duty of care towards children and young people across Sussex. These breaches have resulted in qualifiable financial loss and harm to health which were foreseeable results of such breaches such as:

- individual daily suffering,
- self-harm (due to insufficient treatment),
- suicidal ideation (due to insufficient treatment),
- significant loss of education with resultant loss of potential earnings,
- loss of potential earnings for parents who must provide care without the support they are entitled to from CAMHS SPFT,
- parents have been obliged to incur the cost of private medical diagnosis/treatment to obtain support and medication to protect their children's welfare in the absence of CAMHS SPFT.

In the light of the above serious breaches, you are respectfully requested to pass this letter to your legal advisors to respond formally and to set out the steps to be taken to remedy the situation as a matter of urgency. It is sincerely hoped that this matter can be resolved by negotiation and co-operation without the need to take further action. Representatives of mASCot and other appropriate parties are willing to attend meetings to discuss how matters can be improved for the benefit of service providers and users.

Please note, it is not acceptable for the response to cite:

- the national underfunding of mental health services for children and young people,
- the 'current ongoing redesign' of the Neurodevelopmental Pathways,
- or to imply that these problems are historic.

These have been excuses provided since 2014 and it is simply untenable to continue to cite this as grounds for dismissing this document, these breaches, and the failure to complete the required changes set out above, and in the Scrutiny Report of 2014. CAMHS SPFT has had sufficient time to complete

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these changes, retrain staff and remedy the situation. Any reference to these points only serves to illustrate the failure to appreciate the severity of the situation.

In addition, these failings have been combined with an apathetic, lacklustre and lip service attitude towards improvements needed.

This was evident at a PaCConnect meeting in 2014 when CAMHS SPFT service leads referred to "'we talk about things, but they go into black holes… we've been in a state of flux… what we say we are going to do we should do… there was talk about doing things, but little ever gets actioned" which led mascot to raise concerns with local councillor's mASCot's letter.

The work culture has not changed and shows no sign of changing. The circumstances in this complaint are live (mASCot evidence gathered between June/October 2021) hence the request for full details and the offer to assist to bring this unacceptable situation to a close as a matter of urgency. Time is of the essence for our families.

Please respond to the above email address to acknowledge receipt within 14 days of the date of this letter and to confirm the dates by which the answers to the various questions will be responded to. This should be within a reasonable time-period and no later than one month from the date of this letter.

Please note that whilst we are more than happy to attend positive meetings with a view to progressing change, we do require these answers to be set out formally in writing for our and our members' consideration and with our advisors.

mASCot Directors & mASCot membership

info@asc-mascot.com

*Disjointed communication & assessment process parental evidence
*Lack of ASC & neurodiverse appropriate therapeutic intervention parental
*Failure to engage parental evidence
*Poor management of medication parental evidence
*Disrespectful & insensitive attitude towards families - culture of 'Parent Blame' parental evidence

Member Questions: Response to Cllr Grimshaw's Question

The following response to Cllr Grimshaw's member question has been jointly provided by Sussex Partnership NHS Foundation Trust, Brighton & Hove City Council and Sussex Clinical Commissioning Groups.

HOSC will be aware that in early October 2021 Sussex Partnership NHS Foundation Trust received an open complaint letter from mASCot. mASCot is a parent led peer support network for families who have a child/young person with autism or neuro-diverse related conditions. The letter was sent to the Chief Executives of Sussex Partnership NHS Foundation Trust, Brighton & Hove City Council and the Sussex Clinical Commissioning Groups. It was also sent to the Executive Director of Children's Services at Brighton & Hove City Council.

Following receipt of the complaint representatives from all three organisations met with mASCot on the 29th October 2021. This meeting was attended by Sussex Partnership's Chief Delivery Officer, the City Council's Assistant Director for Health, SEN and Disability from Children's Services and the East Sussex CCG's Executive Managing Director and Sussex NHS Commissioners' Executive Lead for mental health. It was confirmed with mASCot they will receive a single, formal written response combining responses from all three organisations. As the committee will observe the complaint referenced the Council's 2014 Autism Strategy report and requested an update on the progress made on the recommendations within the report. It has been agreed with mASCot that a review of the recommendations and the associated progress will be completed jointly with members of mASCot- this is being led by the City Council and the Clinical Commissioning Group and the outcome will be included within the complaint response.

Additionally it has been agreed with mASCot that once the formal complaint response has been completed a further meeting will be convened between mASCot and the Trust, the Council and CCG to discuss the response and agree how all three organisations can work more closely together in the future to improve services to children, young people and their families within the City. This response is on behalf of Sussex Partnership NHS Foundation Trust, Brighton & Hove City Council and Sussex CCGs.