

12 January 2022

Summary of Acronyms and Abbreviations

Acronym	Meaning
ADHD	Attention Deficit Hyperactivity Disorder
ASC	Autistic Spectrum Condition
BHCC	Brighton and Hove City Council
BHISS	Brighton and Hove Inclusion Support Services
CAMHS	Children and Adolescent Mental Health Services
CCG	Clinical Commissioning Groups
EHCP	Education Health Care Plan
HEE KSS	Health Education England Kent Surrey Sussex
JSNA	Joint Strategic Needs Assessment
mASCot	Managing Autism Spectrum Condition Ourselves Together
MHIS	Mental Health Investment Standard
ND	Neurodevelopmental Disorder
NDP	Neurodevelopmental Pathway
NICE	National Institute for Health and Care Excellence
PaCC	Parent Carer Council
PALS	Patient Advice and Liaison Service
PHSO	Parliamentary Health Service Ombudsman
SCFT	Sussex Community NHS Foundation Trust
SEN	Special Educational Needs
ToR	Terms of Reference

Dear Ms Bayley,

We are writing in response to your complaint dated 4 October 2021 regarding Children and Adolescent Mental Health Services (CAMHS).

This response is made jointly by Sussex Partnership NHS Foundation Trust (SPFT), Brighton & Hove City Council (BHCC) and Sussex Clinical Commissioning Groups (CCG). It follows the meeting that a number of senior representatives from these organisations attended with you on 29 October 2021.

We would like to thank you for attending a meeting on 29 October 2021 with John Child (Chief Delivery Officer for SPFT), Fran Boulter (Interim General Manager for Brighton and Hove Children Adolescent Mental Health Services at SPFT), Georgina Clarke-Green

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Issued by Brighton & Hove City Council, Sussex NHS Commissioners and Sussex Partnership NHS Foundation Trust.

(Assistant Director for Health, SEN and Disability at BHCC) and Jessica Britton (Executive Managing Director, East Sussex CCG and Sussex Commissioners Executive Lead for Mental Health). Colleagues found this meeting very constructive and enabled all present at the meeting to confirm the issues that would be addressed within this response.

We do welcome your feedback and we hope you feel we have listened and responded to your concerns and this is reflected in our response to the issues you have raised with us.

1. Training & workforce for Neurodevelopmental Disorder (ND) pathway

All staff are required to undertake statutory and mandatory training, which varies according to their role. For clinical staff, this will include activity required for continuous professional development and to maintain registration with their professional body (such as the Nursing and Midwifery Council).

Compliance is monitored through supervision and annual appraisal meetings, where future training and development needs / requests are also reviewed.

Training sessions on Autism, Attention Deficit Hyperactivity Disorder (ADHD) and Attachment and Trauma are included within the induction programme for all new CAMHS staff. Inpatient staff are also required to attend an autism awareness course; compliance with which is monitored through the SPFT governance systems.

2. Development of an effective communication portal between parents and SPFT CAMHS

We apologise for the communication issues that families have experienced from CAMHS, and the impact this has had upon parents seeking information about waiting lists for neurodevelopmental assessments.

During the Covid-19 pandemic, CAMHS has experienced pressures on clinical and administrative capacity. In the light of this, a telephone message system was introduced to ensure queries were passed to clinicians to respond. This did reduce the ability to speak immediately to a member of staff. We appreciate this increased feelings of anxiety and frustration for some parents seeking advice and information.

We have reviewed our telephone system and there is now in place a duty system to respond to any queries. This is staffed by experienced clinicians who are working in the neurodevelopmental pathway.

We are aware that in the meeting you held with representatives of our organisations, it was collectively agreed there were areas of service development which would benefit from working closely together to co-design. Communication with parents is an area in which we would like to work with mASCot and other support groups to improve what is currently available. It will be extremely valuable for us to work alongside organisations such as yourselves, to enable us to have a greater understanding of what you feel an effective portal would look like and what we, as a service, would be able to provide. Our colleagues in Hampshire are currently implementing a digital service, and learning from this will be taken

into consideration for local service development in East Sussex, West Sussex and Brighton and Hove.

We would like to assure you that the newly developed Neurodevelopmental Team within Brighton and Hove CAMHS, and the recruitment of a Clinical Service Manager to oversee the team, will significantly improve timeliness for providing assessment reports and response times regarding queries and requests for information. The new team has a dedicated administrative resource to provide families with a central contact point for information (9am - 5pm, Monday - Friday), with additional support from clinicians available as needed.

3. "When will the list of private assessment clinics / diagnostic centres whose reports will be accepted by CAMHS and other services be available to service users wishing to pursue a private assessment?"

As agreed at our meeting on 29 October, the SPFT Minimum Clinical Standards document is attached.

We are confident that Autistic Spectrum Condition (ASC) / ADHD assessments provided within CAMHS are compliant with NICE guidelines. To support equity of provision, and to base ongoing intervention on a clear understanding of the assessment process, CAMHS do accept NICE compliant diagnoses which are provided in private clinics.

Like all NHS provider organisations, SPFT is unable to provide recommendations for private clinics. The CCG operates in line with national guidance in relation to patient choice, this states that if a GP needs to refer you for a physical or mental health condition, in most cases you have the legal right to choose the hospital or service you would like to go to. Referrers are able to identify clinically appropriate providers which have a commissioning contract for the service required, that is, which have been commissioned by a CCG or by NHS England to provide that service.

However, it is important to be clear that assessments provided by independent sector clinicians will not speed up access to CAMHS intervention. Once the young person reaches the top of our waiting list, CAMHS will request copies of any reports completed by private sector clinics to ascertain what is needed in order to provide NHS follow up following a private diagnosis.

Please see below the information that is included in letters sent to parents:

"It would be inappropriate to prioritise a child with a private assessment over that of children or young people who have waited longer or who present with greater clinical urgency.

If the child is receiving medication or follow-up privately, parent(s)/carer(s) may wish to continue with this privately whilst the child remains on our waiting list for an NHS follow-up.

Please be reassured that the child will be held on our waiting list and that when they are at the top of that list we will write to the parent(s)/carer(s) with an appointment."

4. Response during the Covid 19 pandemic

CAMHS have continued to operate throughout the pandemic, providing both face to face and online virtual appointments according to clinical need and risk.

Non-urgent neurodevelopment assessments were paused for a period of time between June 2020 and February 2021.

Young people deemed to be at significant risk to themselves or others were seen on a face to face basis. A Decision Support Tool (attached) was developed that supported clinical staff in this process. The aim of this guide was to inform decision making about the approach to take when considering face to face or remote contact with children and young people. It was an aid to help decision-making and not intended to replace clinical judgment. Children and young people and / or families contacting our duty teams were supported in the usual way.

There was a reduction in the number of children and young people seen who were waiting to be assessed for both autism and ADHD. This was because it is difficult to assess for autism without face-to-face contact and the requirements for Personal Protective Equipment, including face coverings, to be worn makes this more difficult. Services were also required to consider the safety of both patients and staff in relation to taking measures to prevent the spread of Covid - 19. There was also the need to maintain a high quality of assessment as there is significant risk of false positive or false negative outcomes if assessments do not follow evidence-based practice. Disruption to the education system also prevented observations of the child / young person taking place in school. In the light of this experience, we have revised our assessment process to reduce reliance on direct observations and replace this with information provided by the school. This information is used alongside clinical information to inform a decision on diagnosis which is compliant with NICE standards.

We did not do enough to communicate with families about the challenges we were experiencing during the pandemic to provide families, children and young people with timely assessments and the action we were taking to respond to this situation. We are very sorry for this and will ensure we avoid the same mistakes in future. We would value the opportunity to work with you - as well as with other organisations, families, children and young people - to explore how we can continue improving the way we provide clear, timely and relevant information to people about our services.

The Sussex Community CAMHS Business Continuity Plan is attached as requested.

5. Communication

Having considered the communication aspect of your complaint, rather than state how we will communicate future service provision, we feel it would be better to work together with mASCot and other parent / carer groups, along with the SPFT communications team, to agree what would be the most helpful approach moving forward. We hope this would ensure that all key stakeholders can be kept up to date and share the information as required.

During the meeting on 29th October 2021 it was discussed how mASCot could be involved in service planning, and we welcomed your offer to work with us on this. We recognise you and your members have thoughts and suggestions as to how services can be improved /

changed for the better and we are keen to hear about these. We would propose discussing this further with you early in 2022 and potentially establishing a series of forums to further seek the views of your members to co-produce service changes and improvements.

We also discussed how it would be beneficial to develop a closer relationship with the Trust's CAMHS services, recognising that families are often directed to mASCot by the CAMHS team. You explained it would be helpful to have a clear link person in CAMHS to help getting timely responses to issues, which can then be shared with young people and their families. This would in turn reduce the need for numerous communications or enquiries via the Patient Advice and Liaison Service (PALS). The General Manager for Brighton and Hove CAMHS has agreed to take on the role of link person at the current time.

6. The letter states that there is a policy of 'refusing to provide an appropriate service and treatment' for young people with severe mental health difficulties as well as ASC / ADHD

CAMHS provide a range of therapies and interventions to children and young people with ASC/ADHD and co-morbid mental health diagnoses. We are currently not commissioned to provide a service, beyond assessment and diagnosis to children and young people presenting with ASC who do not also have a co-morbid mental health diagnosis.

All young people who are given a diagnosis of ASC will be supported with signposting to local alternative services, educational material and peer support groups.

For ADHD, we provide an assessment and treatment service to all children and young people meeting our threshold. As part of our new pathway we will be providing additional workshops to families whose children and young people receive a diagnosis, and this will include topics such as medication and behaviour support.

7. 'Families are removed from the waiting list due to failure to attend and the service doesn't consider reasons why'

CAMHS has a clear policy which covers the actions that clinicians should take when a family does not attend a scheduled appointment. This includes making direct contact with families to discuss if they do not attend. Families are also sent a leaflet describing what happens if their child or young person is not brought to a CAMHS appointment.

This information should be included with all initial appointment letters (document attached).

The Sussex CAMHS General Manager, Safeguarding Nurse, and Clinical Service Manager are reviewing compliance with this policy in the light of the concerns you have raised with us.

Further to this information being provided to families in their initial appointment letter, contact is always attempted with families on more than one occasion before closing a case.

Clinicians are able to discuss cases either in Multidisciplinary Team meetings, supervision or directly with their line manager. In line with Trust Policy (Active Engagement including Did Not Attend Policy and Safeguarding Children Policy and Procedures, documents attached) when children are not brought to appointments, their appointments are regularly cancelled or

rearranged a consideration of the impact on the child should be made in each individual case.

8. 'A high percentage of emergency referrals to CAMHS are refused due to difficulties being identified as purely 'autistic behaviour'. And there is a lack of autistic behavioural specialists within CAMHS

CAMHS are commissioned to undertake assessments for ASC/ADHD and provide intervention/therapy for young people experiencing moderate to severe mental health issues. The teams support young people who have a mental health need and who also have autism. CAMHS staff are trained in supporting children and young people with an autism diagnosis, but our services are unfortunately, not commissioned to provide support to children and young people diagnosed with autism but who present without a mental health need. However, we are aware of the need to have good knowledge of autism, and relating supporting strategies, in order to benefit those young people with a diagnosis of autism who also meet our threshold for a CAMHS intervention. SPFT has recently secured 5 places on the Health Education England Kent Surrey Sussex (HEE KSS) ASC training programme. Further information can be found at:

www.annafreud.org

These trained practitioners will enhance the service's knowledge of ASC and will provide both training to the wider CAMHS teams and one to one intervention to children and young people.

We will be evaluating the impact of these roles by gaining feedback from young people about the extent to which these interventions have had a positive impact on them.

We have begun the recruitment process and anticipate having 5 trainees who will work across Sussex as part of their training next year and who will then be able to join the service permanently from January 2023 on completion of their training programme.

9. Management of medication: -

a. Failing to prescribe or authorise renewed medication in a timely way due to unavailability of clinical or admin staff

There is a Shared Care Protocol in place, between SPFT and Primary Care (GP's) for the prescribing of ADHD medication in Brighton & Hove. This enables GP's to prescribe medication in individual circumstances on the advice of Consultant Psychiatrists. This is currently undergoing review with a move towards a Sussex wide protocol. The current protocol sets out responsibilities between GPs and secondary care doctors for the prescribing of ADHD medication. In summary, under this agreement, the medication is initiated and prescribed by the specialist service (CAMHS) and then when the young person achieves stability and the dose of medication is optimised, the responsibility for prescribing is transferred to the GP where prescriptions are continued and monitored along with specialist support. In these circumstances the young person would remain open to CAMHS to enable the specialist monitoring and eliminate the need for future referrals.

There are occasions when primary care do not prescribe treatment under the Shared Care Protocol and in these circumstances, which occur rarely, the responsibility for prescribing medication would remain with CAMHS.

In keeping with the national position CAMHS have experienced significant medical workforce challenges which has had an impact on service capacity.

However, we feel confident this situation has improved recently due to additional resources now being available following the recruitment of locum psychiatrists who are offering a combination of face to face and virtual contact with young people. We acknowledge that this may have caused many families and young people distress and we wish to apologise for this.

We have sourced locum psychiatrists to support during this period and we are continuously reviewing additional locum availability. There have been occasions when all of the medical staff working in the service have been unable to work in the office for a variety of reasons linked to government restrictions. This has led to some increased delays in completing prescriptions which have now been resolved due to the recruitment of additional medics.

The Trust has recently tendered and procured an electronic prescribing & medicines administration system (EPMA), with a view to rolling out across our inpatient and community (including CAMHS) services. Initially the EPMA programme will support digital prescribing and recording of medicines administered, as well as clinical decision support software to ensure safer prescribing and alignment to formularies. This will be rolled out across our inpatient units in turn from the first quarter of 2022 over a 12-15 month period. Following roll-out to our inpatient units, we then aim to roll-out the system to our community (including CAMHS) services from early 2023. This is a planned 2-year roll-out programme in total across all inpatient and community services, but is also subject to further system and national developments during this period which may impact on implementation dates. Currently there are no approved EPMA programmes that will directly send electronic prescriptions using the Electronic Prescription Service to community pharmacies (similar to GP practices), this is currently awaiting NHSX approval. Once this is approved nationally, we have assurances from our EPMA providers that the new Trust EPMA system will support this functionality. This was one of the factors for the phased roll-out plan above.

b. Medical recruitment- update on medical vacancies in Brighton

There have been a number of challenges recently regarding the medical workforce in Brighton CAMHS, this is in keeping with the national shortage of psychiatrists. We are actively recruiting to both substantive and locum posts. The situation is now more positive: we have recruited to medical vacancies across Sussex and the number of vacancies has decreased. As a result of additional funding, work is underway to improve neurodevelopment support for children, young people and families in Sussex. This includes eight new clinical roles which are currently being recruited to. Interviews are also taking place for a new consultant psychiatrist role in January 2022.

c. Delays in reviewing / renewing medication

Young people on medication are offered an appointment, usually face to face, one to six months after their previous appointment. This is in line with NICE Guidelines.

Prior to being accepted for treatment, young people remain on a waiting list to see a psychiatrist or non-medical prescriber, for initiation of medication. Whilst they are waiting for this appointment, we have initiated psycho-educational workshops for young people newly diagnosed and they will commence in the new year. We will confirm the exact date to parents as soon as possible.

During the pandemic, we have prioritised that the continuation of these reviews in line with NICE guidelines. On occasions, we acknowledge we have had limited capacity or flexibility within our clinics to offer alternative appointment dates if the initial appointment has not been offered at convenient times. However, we have endeavoured to see young people as quickly as possible.

We acknowledge that there have been delays in offering medication initiation appointments due to limited medical resources which is being addressed. Again, we do acknowledge the frustration this is likely to have caused and we apologise for the impact this has on children, young people and families.

To address some of the issues that have developed as a result of the extended waiting times we are setting up psycho-educational workshops to offer support to young people whilst they are waiting to be seen. Children, young people and families will be notified in writing about the dates for these workshops as soon as they have been finalised.

We are also refining our processes in regards to our liaison with GPs to ensure that prescriptions are more easily available for families. This is an ongoing piece of work that is being led by our ADHD team.

d. Lack of flexibility in the types of medication available for children, teams not considering their ability to take this.

We work clinically to support children to take different types of medication. As such, the service does sometimes try to encourage young people to practice swallowing tablets as opposed to having medication in a liquid form. We are able to provide information about how to do this most easily. We do recognise that this does not work for all young people and are able to make changes where needed to enable different preparations to be offered.

10. 'Customer Care'- example given of poor communication and behaviours. Letter raises concerns of 'parent blame'.

Thank you for the feedback you have provided and the content and tone of our correspondence to families. This is clearly an area where we need to improve. It would certainly never be our intention for parents to feel blamed and we apologise that has been the case in some situations.

Our new Neurodevelopment Pathway Lead for Sussex, who starts in February 2022, will be responsible for reviewing the training programmes we have in place to support clear, timely and relevant communication.

11. Covid backlog- 'what is being done to lessen the backlog of assessments that have built up during Covid'-

During the Covid-19 pandemic, there has been an increase in the number of young people awaiting a specialist CAMHS assessment.

We are very sorry for this and the impact it has upon children, young people and families. Our work to address this situation as a matter of urgency includes the implementation of our new neurodevelopmental team (as highlighted earlier in this response). It also involves commissioning additional independent provider support to address waiting times.

In relation to our CAMHS neuro-developmental pathway, we have reviewed our care pathways and streamlined our ADHD and ASC assessment models including:

- Joint screening procedures
- Full use of QB tests (for ADHD)
- Use of multi-disciplinary meetings to confirm diagnosis.
- Use of psychoeducational group to initiate medication for those diagnosed with ADHD (as opposed to 1-1 meetings).

12. Waiting times- ' how will the timeframe for assessment be reduced?'

Reducing waiting times is complicated by the increased levels of need that specialist CAMHS are experiencing (illustrated by 21% increase in referrals in the last year).

Our plan to respond to this situation involves £6.2m extra funding being invested in Sussex CAMHS this year (taking the overall level of investment to £31.2m). Priority areas for investment identified our ADHD and ASC assessments and the provision of Cognitive Behavioural Therapy. Other action being undertaken, as highlighted earlier in this response, includes commissioning additional independent sector support to reduce ASC waiting lists.

We are currently undertaking a comprehensive review of the milestones we will set out to meet to achieve and sustain a reduction in waiting times. We would be happy to share and discuss the outcome of this piece of work with you as soon as it has been completed.

13. Following from the above 'will assessments be outsourced and if not, why not?' -

Both SPFT and CCG have contributed to this response.

As noted above we have recently been in a position to agree this and young people with no additional mental health needs will be offered the option of a private assessment for ASC. We are actively planning for this and hope to be able to implement this action in early 2022. This is likely to be in the region of 150 assessments in Brighton and Hove and 520 in total across Sussex.

14. Issue relating to the SPFT complaints procedure

SPFT provides a combined Complaints and Patient Advice and Liaison Service (PALS) which encourages and welcomes the views of patients, family and friend carers, other organisations and the local community to support continued improvement of the quality of care and services we provide. Our guiding principal is that the complaints procedure should be informed by the needs of the complainant. Any concern or complaint should be seen as an opportunity to learn lessons and improve the quality of care and services we provide. The Complaints and PALS team are unable to influence the clinical decisions of teams. Through our Lead Nurse we can support the teams to review outcomes and facilitate communication with complainants.

We believe it is important to promote a just and learning culture to help us continuously improve care, treatment and support for the local communities we serve. This involves ensuring that complaints are processed effectively, handled sensitively and used as a catalyst for service improvement. We are committed to making sure that the complaints process is fair, open, flexible, and easily accessible. It is essential that people are treated with respect, and that they feel confident there will be no adverse consequences as a result of raising a concern or complaint.

We endeavour to adhere to the Parliamentary and Health Service Ombudsman's (PHSO's) Principals of Good Complaints Handling (2018), My Expectations (2014) and the draft NHS Complaints Standards (2021) namely:

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right
- Seeking continuous improvement

The SPFT Complaints Policy has recently been reviewed. A new policy will be introduced in 2022 (by end of June at the latest). This places increased emphasis on early resolution, in which clinical teams will be encouraged to contact complainants to reach an amicable resolution to the issues raised in a timely manner.

As part of the development of this new policy we have also reviewed our training package with the support of Experts by Experience. Additional investment in the complaints function will also enable us to introduce informal 'drop in' session where people who use our services will have the opportunity to discuss their experience with a member of the team.

15. 2014 Children with Autism Scrutiny Panel Report

Your letter raised specific concerns regarding the Brighton & Hove City Council's 2014 Children with Autism Scrutiny Panel Report with particular reference to the progress made against the published recommendations.

At the meeting between mASCot and SPFT, the Council and the CCG in October it was agreed that the recommendations would be reviewed collectively with mASCot colleagues. This meeting took place on 11th November and involved representatives from BHCC, the CCG, mASCot, Parent Carer Council (PaCC) and Amaze and the responses below reflect those conversations. We would like to express our thanks for completing this review collectively.

We have grouped the recommendations and the current position via the organisation which has provided the response.

Brighton & Hove City Council

a. 'Send Strategy 2021-2026- request that the strategy formalises a non-discriminatory approach supported by the NDD pathway'

BHCC and the CCG will commit to ensuring that the 'Send Strategy 2021-2026 formalises a non-discriminatory approach supported by the NDD pathway'. This will be addressed through the two Priorities in the SEND Strategy 2021- 2026: Priority 1 Inclusion and Priority 3 SEND pathways. The strategic actions in both priorities will specifically address any inequalities in the system and the SEND Partnership Board will be monitoring closely the progress on these priorities as part of the governance structure.

The following section refers to the response of BHCC on the Scrutiny Panel paper for Services for Children with Autism (2014).

The key elements of the 10 recommendations that require action from Brighton and Hove City Council are:

- All schools in the city are fully signed up to being 'autism-aware'. (Rec 11)
 - All Governing Bodies of Schools must undergo SEN training - which should include autism awareness training. (Rec 12)
 - The Director of Children's Services ensures that this report is drawn to the attention of all Governing Bodies of schools in the city. (Rec 13)
 - The Director of Children's Services considers increasing the funding of the ASC Support Service. (Rec 14)
 - Regular monitoring reports are produced detailing progress on the Transitions Strategy, the Adult ASC Strategy, the Children with Autism Plan, and the work on the Education, Care and Health Plans to ensure there is no duplication or gaps. (Rec 15)
 - An Autism Champion is appointed for the city. (Rec 16)
 - The Director of Children's Services draws this report to the attention of the head of the Family Law Courts in the city. (Rec 19)
 - The Youth Service and/or Youth Collective considers whether there is enough demand to merit the creation of a youth club aimed at young people with autism, and if so, which organisation may provide this. (Rec 20)
- b. RECOMMENDATION 11: All schools in the city are fully signed up to being 'autism-aware'.**

There is a team within Brighton and Hove Inclusion Support Services (BHISS) dedicated to support children with an ASC diagnosis, as well as ASC teachers, this team also has SEN Practitioners dedicated to Family Support.

There is an opportunity for all schools to undertake the Autism Aware award across the city and a 6-week Autism Champion course for all schools is offered annually by ASC Team. ASC Training for schools provided by the BHISS team ranges from introductory modules to specific cohorts e.g. gender and autism, girls and autism.

There has been an increase in provision for children with an ASC diagnosis in the city such as the Callum Centre and the Social Communication Resource (a co-produced resource with mASCot members). There will also be an increase in the number of ASC specialist educational placements created across the city within the next 5 years. This development is part of the SEND Strategy under Priority 6 SEND Sufficiency. Parents and carers will be invited to be part of this workstream and be part of the decision-making process regarding the commissioning of this new provision.

In addition, BHISS provides training to schools on Social Emotional Mental Health needs which is focused on understanding what behavior communicates, this includes autism awareness for undiagnosed/children on the neurodevelopmental pathway.

There is also a new neurodevelopmental pathway complex needs panel for making multi-disciplinary decisions that take in information beyond what is seen in clinic. Representatives from Seaside View, BHISS and CAMHS attend.

c. RECOMMENDATION 12: All Governing Bodies of Schools must undergo SEN training - which should include autism awareness training.

SEND Training is now provided to Governors. We are committed to working more closely with parent groups on the delivery of this training and we would like to work with (PaCC), Amaze and mASCot to explore how this training could be co-delivered in the future.

Currently this is what BHCC Governor Services offer:

1. We provide all new governors with the National Governors' Association's 'Welcome to Governance' book, which has a section on SEND that includes the governing body's responsibilities in relation to this.
2. As part of the eLearning prior to the induction session, they have to read this, and then they discuss a SEND scenario in the induction session with the trainer.
3. A termly SEND Forum led by the Assistant Principal EP who leads on ASC
4. The Governance Handbook for SEND and Inclusion (NASEN) sent to all SEND governors

Governor Services have also been in communication with the author of the NASEN handbook, with a view to commissioning him for extra training. They are particularly interested in his 'Introduction to SEND for Governors and Trustees' course, which they are exploring and hoping to add to the SLA for April 2022.

BHCC currently have a 'Governance Journey' for governors, that lists how to prioritise their learning. The SEND course will be part of the recommendations for their first year (along with Governor Induction, safeguarding & finance).

Unfortunately, BHCC cannot make any training mandatory, but we do target governors for induction and other key training.

d. RECOMMENDATION 13: The Director of Children's Services ensures that this report is drawn to the attention of all Governing Bodies of schools in the city.

BHCC are not aware of whether this occurred in 2014 following the report. The Director of Children's Services who was in post in 2014 has now left the Local Authority.

e. RECOMMENDATION 14: The Director of Children's Services considers increasing the funding of the ASC Support Service.

There has been an increase of £225k into the ASC Support Service this includes 1.6 full time equivalent Specialist Teachers that sit within the BHISS team and the provision of the Social Communication Resource provision from financial year 2020/21.

f. RECOMMENDATION 15: Regular monitoring reports are produced detailing progress on the Transitions Strategy, the Adult ASC Strategy, the Children with Autism Plan, and the work on the Education, Care and Health Plans to ensure there is no duplication or gaps.

A new ASC working group will be established as soon as possible in 2022. This will include representatives from the CCG, SPFT and Senior Officers from the Local Authority including from Safeguarding and Care as well as parents and carers. The Terms of Reference (ToR) have yet to be agreed for the new working group and these will need to be co-produced with all stakeholders. However, it is expected that part of the remit of the group will be to receive and monitor regular reports that detail the progress on all strategies across the organisations, that support children and young people with ASC and their families.

Currently there is no Adult ASC Strategy, the Director of Adult Social Care has committed to working with the SEND Community to co-produce this piece of work in 2022.

g. RECOMMENDATION 16: An Autism Champion is appointed for the city.

It was agreed at the meeting with mASCot in October that BHCC with the CCG will explore an Autism Champion post that can work across organisations. The scope and grade of the post will be informed by the job description already sent to the local authority and through further discussions through the ASC working group. Part of their role will be to ensure that a coherent approach is taken with strategies dovetailing and not duplicating other work that is ongoing.

h. RECOMMENDATION 19: The Director of Children's Services draws this report to the attention of the head of the Family Law Courts in the city.

In discussion with mASCot, PaCC and Amaze it has been agreed that the Police will be invited to one of the ASC working groups once they have been established. The purpose of

this will be to discuss with the Police and the Court System the training needs for these organisations and agree how this training will be delivered.

- i. **RECOMMENDATION 20: The Youth Service and/or Youth Collective considers whether it there is enough demand to merit the creation of a youth club aimed at young people with autism, and if so, which organisation may provide this.**

In January 2022 a meeting will be convened with the Head of Service for Integrated Team for Families, Youth & Parenting and with mASCot, PaCC and Amaze to discuss further. The youth providers who are currently being commissioned will also be invited to attend.

Recommendations that have been responded to by SPFT, CCG and BHCC are the following:

- A clear pathway needs to be created for children and young people who have autism but neither learning disabilities nor mental health issues. (Rec 2)
 - The Panel recognises that a key gap in services provided is in the area of home support. The Panel strongly recommends that funding is reconfigured to include home support packages. (Rec 3)
 - There is a clear and unambiguous statement of where the responsibility lies for the performance of all tiers of CAMHS and the systems in place for addressing any problem areas. In addition, the Director of Children's Services, after consultation with the CCG who are ultimately accountable for Tier 3 CAMHS, must work to ensure that an Annual Report is produced detailing performance against a clear and relevant set of indicators. Parents and young people should be actively involved in determining key performance indicators and contributing to the assessment and monitoring against them. (Rec 6)
 - Any assessment of a child's needs must not be purely clinic-based but also include assessments in the home and social environments. (Rec 7)
 - The CCG, Public Health and Children's Services work together to put a strategy in place to ensure there are strong and coherent links between Health Visitors and GPs across the city. (Rec 10)
 - The Panel recommends that the ASC Working Group takes a proactive role in monitoring the implementation of the recommendations in this report. (Rec 17)
- j. **RECOMMENDATION 1: The Panel recommends that both Seaside View and CAMHS should have a nominated Keyworker specifically to help parents and carers of children and young people with autism. This named person would be the first – and final – point of contact for people using the services of either Seaside View or CAMHS.**

The General Manager for Brighton and Hove CAMHS will be the nominated keyworker at the current time on behalf of SPFT and will be a point of contact via either 0300 304 0061 or their Personal Assistant on 07917053414.

This action point is also linked to the work that the CCG are undertaking regarding the new neurodevelopmental pathway. Sussex Community NHS Foundation Trust (SCFT) and Seaside View have confirmed that they are committed to the model and working to develop

the pathway to have keyworkers / family support in place to offer this support to children and young people and their families in line with our Sussex wide pathway improvement work. However, in the meantime, they have Child Development Centre Coordinators, who can be contacted via telephone or email. The young person also has a named Pediatrician once they have been assessed who, although not directly contactable, can be contacted by arrangement.

k. RECOMMENDATION 2: A clear pathway needs to be created for children and young people who have autism but neither learning disabilities nor mental health issues.

This is now happening with a Specialist Advisor from the CCG leading on this piece of work. The place-based neurodevelopment pathway is under development and explained fully below.

l. RECOMMENDATION 3: The Panel recognises that a key gap in services provided is in the area of home support. The Panel strongly recommends that funding is reconfigured to include home support packages.

This is outstanding, but nevertheless it is an urgent piece of work that needs to be undertaken. This will be driven forward through the new ASC working group that will be established. The PaCC parents survey is to be used as intelligence to inform the model. BHCC, CCG, SPFT and parents / carers will scope out the ASC working group.

m. RECOMMENDATION 4: Current service providers such as Seaside View and CAHMS need to examine the strategies they have in place to ensure parents are at the centre of their services. This should include looking at new ways of getting feedback from service users – particularly parents of children with autism – and reflecting this in their services. This feedback should be open and transparent and externally monitored.

Brighton and Hove CAMHS have recently appointed a Participation Manager, this is a new post. This person will start on 17 January 2022 and will be asked to lead on this piece of work as a priority. They will develop systems and processes for obtaining feedback from parents and carers which is open, honest and transparent and which will be reported quarterly to monitor the feedback to provide direction of further service development going forward.

In addition to this, the CCG are working towards introducing the Best Practice Target Operating Model which firmly has the patient and their family at the heart of the development. In particular plans include:

- Single referral hub and unified referral paperwork – so children and young people stop being referred to multiple services with no sequencing between services. Also ensures that all SCFT referrals to SPFT go through the same route and will be monitored as part of the referral hub.
- Moving to single assessments – so a child referred for a number of Neurodevelopmental conditions will not be required to wait for multiple similar assessments and their parents / schools / other professionals will no longer have to fill out multiple versions of the same questionnaire / undertake further observations.
- A Sussex-wide piece of work will be undertaken to ensure that communication with parent carers, children and young people is accurate, appropriate and helps them to

locate additional local support and help. We have already discussed the ongoing involvement of parent carers in this work with the PaCC chair

However, we acknowledge that we will need a plan outlining the timescales for implementation and delivery.

- n. **RECOMMENDATION 5: Monitoring is crucial. CAMHS and Seaside View must have robust and publicly available monitoring procedures. Working with parents and children, CAMHS and Seaside View need to review their monitoring procedures and put in place a transparent, comprehensive feedback system for parents of children with autism.**

CAMHS will develop an annual report which should be co-constructed with BHCC and CCG. This forum will be the opportunity for us to report what parents and carers are telling us using the mechanisms developed with the participation lead. SCFT have confirmed their agreement to this recommendation and will contribute data and feedback to the report.

- o. **RECOMMENDATION 6: There is a clear and unambiguous statement of where the responsibility lies for the performance of all tiers of CAMHS and the systems in place for addressing any problem areas. In addition, the Director of Children's Services, after consultation with the CCG who are ultimately accountable for Tier 3 CAMHS, must work to ensure that an Annual Report is produced detailing performance against a clear and relevant set of indicators. Parents and young people should be actively involved in determining key performance indicators and contributing to the assessment and monitoring against them.**

SPFT and the CCG work closely in partnership to maintain a continuous monitoring of clinical need amongst children and young people in Sussex. The systems in place allow for ongoing review and with national investment opportunities, service development is always part of these considerations.

Moving forward this will be referred to the new CYPH Oversight Board for discussion and agreement as to how the Annual Report should be produced and how the CCG and BHCC engage with parents/carers to make the performance indicators meaningful to families.

SPFT is commissioned by the CCG to provide secondary care CAMHS to the population of Brighton & Hove and Sussex. Performance within these services is formally reported to and monitored by the Sussex CCGs via the contract management and quality assurance structures. SPFT have internal performance reporting and quality assurance mechanisms and CAMHS performance is publicly reported via the Trust Board.

- p. **RECOMMENDATION 7: Any assessment of a child's needs must not be purely clinic-based but also include assessments in the home and social environments.**

This action will be included in the Target Operating Model and will be considered in the place-based priorities and actions.

- q. **RECOMMENDATION 8: The Panel believe that, where appropriate, private Educational Psychologists reports should be accepted by CAMHS as a valuable source of information, particularly if services are stretched.**

This matter has been addressed elsewhere within the response by SPFT and CCG.

- r. **RECOMMENDATION 9: The Panel recommends that consideration is given to allow for the council's Standards and Complaints team to act as a mediator between service providers such as Seaside View and CAMHS and complainants if appropriate, or refer complainants on to Brighton & Hove Healthwatch who have a statutory role as advocates for those going through the health system.**

All statutory organisations, including the CCG, SPFT and BHCC have robust complaints and escalation processes in place. This includes agreed processes on how the organisations respond to complaints which involve more than one stakeholder / provider.

BHCC has a formal complaints system through the Customer Feedback team. These are monitored through a quarterly performance board in Families, Children and Learning Directorate. Each complaint that goes through the customer feedback system is logged and responded to within specified timescales. The number, outcome and details of all complaints are set out in the report submitted to the performance board as well as the compliments the service receives. Any themes in the complaints are discussed at the board, however, this information could be shared with PaCC at the monthly meeting with officers which is also attended by the CCG. We will produce a joint annual report that can go to the PaCC Steering Group and mASCot that provides information on the themes of the complaints across both Health and Local Authority and how we are using that information to inform future planning of services.

- s. **RECOMMENDATION 10: The CCG, Public Health and Children's Services work together to put a strategy in place to ensure there are strong and coherent links between Health Visitors and GPs across the city.**

Work is continuing on this area and in particular around raising awareness amongst professional groups.

- t. **RECOMMENDATION 17: The Panel recommends that the ASC Working Group takes a proactive role in monitoring the implementation of the recommendations in this report.**

It has been agreed with mASCot, PaCC and Amaze to include this in the ToR of the new ASC working group.

- u. **RECOMMENDATION 18: In order to fully reflect the needs of children with autism in the city, the Panel recommends that the Joint Strategic Needs Assessment (JSNA) is updated to include a section on what services are currently available for children with autism, where the gaps are, and how they can be filled.**

The organisations are working with Public Health to determine how best this can be addressed and are in the process of identifying a timescale for the publication of an updated JSNA. A further update on this will be provided as soon as it is available.

16. The CCG have provided the following information in relation to the Send Strategy 2021-2026.

"Send Strategy 2021- 2026- request that the strategy formalises a non-discriminatory approach supported by the NDD pathway"

The Sussex CCGs, inclusive of Brighton and Hove CCG, recognises the Neurodevelopmental Pathway (NDP) offer across Sussex requires improvement. The Sussex CCGs' Learning Disability and Autism Strategy was published on 28th March 2021, which included our intentions and commitment in relation to the Neurodevelopmental Pathway. The full document can be found here: <https://www.brightonandhoveccg.nhs.uk/wp-content/uploads/2021/06/Sussex-LDA-Strategy-2021-2024.pdf>

The priority actions identified within the strategy are:

- To develop a Sussex-wide **target operating model for a Sussex Neurodevelopmental Pathway** underpinned by a common set of principles by April 2022.
- As part of the Sussex pathway to prioritise creating a **sustainable long-term plan for the development of diagnostic services** to include demand and capacity modelling, workforce requirements and planned investment by December 2021.
- To have **established a Sussex-wide keyworker model**, building on the current pilot scheme, for children and young people on the dynamic risk register who are at high risk of a hospital admission by April 2024.

Locally for Brighton and Hove, this means:

- **Prioritise immediate investment into diagnostic capacity**, including triage, through the realignment of existing contracts and investment from Learning Disabilities and Autism service development funding by September 2021. To include within this the ADHD pathway.
- Implement the **Sussex Neurodevelopmental Pathway target-operating model, as appropriate for local need** by April 2023. This could be through a collaborative framework with a range of providers including the voluntary and community sector. This pathway will address:
 - **Strengthen self-help and peer-led** approaches to support.
 - **Improve communication with parents, adults, referrers, and other professionals** to improve understanding of the current diagnostic process and sources of support.

By 2023-2024, it is the intention for the following outcomes to be delivered:

- To reduce diagnosis times for children, young people, and adults in line with National Guidance which is due to be published shortly.
- Reduce the proportion of the Sussex Adult Autism Population waiting for a diagnosis from 12% to 10% by April 2024.

- Reduce the proportion of the Sussex Children and Young People's Autism Population waiting for a diagnosis from 60% to 30% by April 2024.

Sussex CCGs remain on track to deliver the priorities and outcomes above. Given the importance of this work, additional resources have been invested into increasing the pace at which the Sussex Neurodevelopmental Pathway target-operating model is implemented and it is anticipated for this to be delivered ahead of the April 2023 target. We would want to ensure a non-discriminatory approach and would value further discussion with you to help us continue to shape the work.

17. Development of the Neurodevelopmental pathway from CCG perspective

Brighton and Hove and the Sussex Clinical Commissioning Groups acknowledge that the current commissioned NDP for Children and Young People is not comprehensive and requires attention. It also notes that the NDP and services have concentrated on diagnosis with very limited pre or post diagnostic support.

Whilst improvement work has taken place in Sussex, over many years, to develop Neurodevelopmental services, and we welcome mASCot's involvement in this from its inception in 2014, we understand that some of the pathway improvements have led to a more fragmented service for some, with increasing numbers of entry points that can be confusing (and frustrating) for both practitioners and individuals. This has, in-part, also been exacerbated by some of the NDP service improvements also being commissioned on a short-term basis only. We also understand that communication will be key to any pathway improvement.

The CCG has therefore been working with system partners, stakeholders, children and young people, service users and families to redesign the pathway. This is helping to rebalance the approach to place more emphasis on pre and post diagnostic social and community support, with improved communication between service providers, children and young people and their families. This has involved reviewing the strategic framework to bring together all aspects of care from clinical diagnosis and therapies, social care, education, SEND, employment support and community development to provide a 'joined up journey' built around individual strengths. The multi-professional stakeholder group involved in the pathway review noted that many aspects of the current pathway are fit for purpose, and as such, not everything will be new.

The updated Learning Disability and Autism Strategy for children and young people was approved by the Sussex CCGs Joint Committee on 21st April 2021, with a timeline that leads to mobilisation of the new NDP which will be underpinned by a common set of principles from April 2022.

The features of the proposed Neurodevelopmental Pathway for Children and Young People include the following:

Referral and screening

A standardised initial assessment signs and symptoms checklist to ensure a consistent and uniform approach to assessment of all Children and Young People, leading to:

- a single point of referral and united referral form
- a multi-agency panel, including SEND, educational psychology and children's social care, and nurse led triage.

Pre-diagnosis and assessment

A needs led multi-professional pre-diagnosis service and support working together to provide wrap around care to ensure:

- referral into diagnostic services, making sure each child and young person is allocated a lead professional
- referral for specialist assessment, for autism, Foetal Alcohol Syndrome, ADHD, Tourette's, and Tics, Global Developmental Delay and Developmental Language Disorder's.

Both of which will lead to either:

- No diagnosis – lead professional informs family, referring professional advised, referred into local support offer and advised when / if a further request to refer could be made.
Or
- A post diagnosis – strengths based multi-agency package of support - co-produced with the child and family.

Post diagnosis

The post diagnostic package of support will include:

- Family/ Carers Peer-to-Peer Support Network and Young People Peer-to-Peer Network
- Children's Social Care, SEND offer, Education Health Care Plan (EHCP), in education support (where appropriate)
- Training and Support – individuals, families and schools and psycho-education
- Clinical services: Speech and Language Therapist, Occupational Therapy, Dietetics, sleep, medicine reviews, mental health therapies as required.

The expected benefits of the new pathway include the following for the child or young person, their parents, family and carers:

- Clarity about the referral route and pre-referral help
- Support at the right time – rather than waiting for a diagnosis
- Able to gain some support earlier through appropriately adapted universal services
- Approach will build on individual aspiration and strengths
- Additional support to help individuals work with their employer/ understand employment and their condition

- Schools and early years workers are equipped to provide appropriate environments and techniques
- Early conversations about why an individual may not receive a diagnosis and where there are other sources of support.

The development of the neurodevelopmental pathway continues and we would be happy to share further as we agree implementation to support us in getting this right.

We recognise the need to work with families, children and young people - as well as organisations such as yours - to improve the experience of care that people receive. We do not agree with the view that there have been breaches of the statutory duty for children and young people in Sussex but I hope you can see we have taken the issues you have raised very seriously.

We would like to thank you again for approaching our organisations to highlight the concerns identified. We appreciate your candour and the constructive conversations you have had with us during the period of time we have taken to provide our response. We hope this formal response fully addresses the areas of concern that were identified both in your original letter and at the meeting with colleagues on 29 October 2021.

At the meeting in October, there was a shared commitment to meet collectively with representatives from all our respective organisations once you have received this formal written response to agree how we can collectively take forward working more closely in partnership and co-design to next steps. We stand by this commitment and by our desire to continue working with you to address the issues of concern you have raised with us. We will always seek to do so in the spirit of openness and responsiveness.

We recognise this response is very long. To aid those reading it we have attached the following: -

1. A list of all appended documents attached in the response.
2. A summary of all actions included in the response with a named lead, organisation and timescale for completion.

The formal point of contact regarding your letter of complaint is our Patient Advice and Liaison Service (PALS) via 0300 304 2198 or pals@spft.nhs.uk. That said, if you would like an informed discussion regarding the contents of this response - as part of the ongoing process of dialogue that is now in place - please do not hesitate to contact either John Child at SPFT, Georgina Clarke-Green at BHCC or Jessica Britton at CCG.

Yours sincerely



Samantha Allen
Chief Executive Officer



Deb Austin
Executive Director

SPFT

**Families Children and
Learning**



**Adam Doyle
Chief Executive Officer
Sussex NHS Commissioners**

**ICS Leader
Sussex Health and Care Partnership**

**Chief Executive Officer Designate
Sussex Integrated Care Board**