

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

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 incompleteness, 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