

Dear Leads,

Autism and Culture in B&H

I write this as a parent of three neuro-divergent young adults and as a Director of mASCot. Thank you in advance for your time in reading and I hope it will shed some light on our joint endeavours to improve services for autistic people in our city.

There are many overlaps between groups in B&H, the neurodivergent community share much with the disability and LGBTQ+ communities - and with everyone who shares a desire to be treated fairly, with respect and to live well. mASCot has always striven to find solutions as we want this city to be the best it can be for everyone. That is the aim behind this letter.

During meetings I sit on as a Director of mASCot I have been reflecting on the positive number of autistic related conversations and themes currently happening in B&H; the need for commissioned services for autism without a learning disability; starting to openly question the lack of access to the mental health service for autistic people; the work being undertaken via the Autism Board; our Councillors interested in autism; an upcoming SEND case worker workshop and the promised re-establishment of the ASC Working Group so issues can be tackled on the ground. This is a really exciting time!

However, in a recent meeting between mASCot and BHCC there was mention that (some of the information collated by) the mASCot survey had 'defamed' SEND staff. mASCot's intention had been to find ways to move forward so Sam Bayley and I were shocked and disappointed, not that the term had been misappropriately used, but that it had been used in front of the representatives of an unpaid community group who are literally propping up statutory services. It sends a disquieting message about **culture** and raises a red flag - will communities who voice grievances and present evidence of poor working **culture** be discredited for doing so?

So I would like to provide a small thread through the current autism conversations and give context to some of the issues raised in the recent mASCot survey, as it feels timely to bring up **culture and work practices** and how we work together in addressing issues within this.

I understand the SEND team felt hurt by mASCot's survey and I appreciate it is difficult and uncomfortable to hear negative feedback. However, it is no less painful for parents to write about their experience than it is for services to read about them. Parents too feel hurt for their children and young people and for some of us, dismay that at a time of scant public sector resources, people are paid for poor work or for enabling a poor working culture (see mASCot Survey and attached case study).

The case study attached provides a clear example of a **negative work culture** that quietly permeates and is arguably behind so many of the problems experienced by families. It is one example that represents many, the culture behind it can be duplicated many times within the nearly 500 replies submitted to the mASCot survey and in the huge response to the 2021 mASCot CAMHS complaint. It is one example of the many reasons why we need to move to an **autism affirming culture in B&H**.

The case study, drafted for an upcoming SEND workshop, outlines one experience of obtaining an EHCP for a young autistic individual and demonstrates if simple things are not done well or are not joined up, how easily it can lead to poor life outcomes and associated costs for that individual and society.

The young person has an offer of university with a scholarship, but they are now too worn down and unwell to attend. Young people like this may not even be registered on anyone's statistics other than national unemployment figures. They are not contacted when their EHCPs expire, when they or their parents are sent around the houses in social care with no one following up. "They don't have a learning disability", "they don't need a ramp". Young people become statistics who are dropped off B&H books. One such young person described themselves as feeling "on the scrap heap". These young people with such huge potential are in their bedrooms, would anyone know if they are ok?

PUSHING FOR CHANGE

There will always be a need for specialist schools and provisions but if you refer to the case study, you will see why mASCot routinely say if resolvable issues are tackled **at source, within the schools and colleges or within social care or mental health services**, as an alternative to BHCC mitigating against the problems services create, we strongly feel costs will be reduced; less need for home to school transport, less demand for expensive out of area provisions and specialist units, less children being referred for mental health issues, less children falling out of education and families going under, less failed children becoming failed adults. It saves money.

The uptake of specialist units and provisions need to be reserve of those who most need them, not as the alternative for autistic children whose school or college is failing them. Pull the school up rather than adjust for poor practice; ensure care workers are as clued up about autism as the fabulous staff who win PaCC awards; respond quickly when parents need advice from CAMHS. All these things are being worked on, but the pace of change is slow not just because of resources and recruitment issues but because **culture** is lagging behind.

If schools fail to accommodate and adapt (and without the promised 2014 scrutiny recommendation of commissioned home support, with good autism strategies), desperate families turn to BHCC for EHCPs, then describe this experience as often feeling ignored, deflected, delayed, scuppered, tribunals used to grind families financially and emotionally to back down as the squeeze moves around the system (see mASCot's survey). No doubt caused by stretched resources but there is an accompanying sense that nothing can be done differently. 'Everything that can be done, is being done', as though we are all caught in some Kafkaesque cycle of moving ever reducing resources around a budget sheet. The black humour many parents develop stems from the miserable experience of being gaslit when negotiating for breadcrumbs.

Regardless of dropping school attendance figures post Covid, high levels of out of school SEND children and NEET figures in the city explains **why** parents express **how** worn out they are dealing with what **they experience** as an often obstructive and uncaring BHCC/school culture, and an often-reported parent blame culture in mental health and social care.

It is difficult for us in mASCot to understand why planning and funding is allocated to mitigating around issues created by schools, colleges, mental health, and social care services instead of the same tenacity and ingenuity being put into developing a more constructive **culture** within these services, which could start with the particularly arrogant attitude in some providers that "the Local Authority have no authority here" ¹.

Whilst the case study details the struggle of one mASCot family to secure a 'level playing field' education for an academically able young autistic adult, it is not clear cut. Even with an EHCP, the young person's educational and mental health needs may not have been resolved, but a timely Plan would have formally recorded adjustments and adaptations needed and helped in identifying next steps for mental health support.

Mental health support itself is an ongoing challenge as there is no mental health provision commissioned and tailored for autistic children and adults, who are routinely rejected from accessing mental health services or if accepted, face a lack of awareness or adaption (e.g. issue of 'safe cutting' and suicide risk)² This is reflected in the consultation work currently being undertaken in adult services and mASCot has fought for years to highlight the lack of commissioning, the tacit acceptance and discrimination of this is almost impossible to fathom.

I write from the perspective of a parent with neurodiverse children, but the issues overlap into adults. So it is important to say and have it acknowledged, that a **closed communication culture** is contributing to the exhaustion autistic families face and is hindering how children, young people and adults are supported.

All this can be clearly seen in the responses within the recent mASCot survey, which mASCot directors and leads will continue to meet to discuss. Prior to this survey mASCot highlighted **culture** in the 2021 CAMHS complaint and received four lines in the response. Before that we highlighted **culture** as a major issue in the 2014 Autism Scrutiny review. Prior to even that, I drew attention to culture in a formal complaint I made to CAMHS in 2010 regarding staff to client hostility; a SPFT staff survey in 2014 reported a widescale culture of staff bullying and fear. ³

PUSHING FOR CHANGE

The issue of **culture** is not being resolved because it is not being openly addressed. If poor culture or bad working practices are now being called out within BHCC and NHS Sussex, please let parents know because four lines in a reply would indicate organisational **culture** is the last taboo, still the elephant in the room.

I am not referring to the wonderful workers and teachers who go above and beyond for families and who are appreciated and need to be celebrated ⁴, and the new autism provisions are hugely welcomed, but everyone needs to be concerned about a **culture** that turns a blind eye and allows substandard practices, or inherent bias about autistic people to go unchallenged or which manifests as parent or client blame. To deny access to mental health support, to diminish or ignore a young person's educational needs or to intimidate parents is gaslighting of the highest order.

As we go forward, aligning autism policies and practices, mASCot ask that there be an honest review of where things go wrong and an agreement to work towards a **culture that 'joins the dots,' sends a message of zero tolerance of poor practice and promotes a problem-solving approach.** A **culture** that roots out and calls out parent blame and any lazy complacency silo thinking, it's not my responsibility'. Safeguarding autistic children, adults and families is everyone's responsibility.

Whilst mASCot want to work with providers to develop and improve services, we would prefer to focus on what we do best, providing clubs, activities and a community of mutual support that helps build families up. We do not want to use the little energy we have left, after looking after our own families and holding up our fellow exhausted families, writing letters and running surveys hoping to draw attention to the despair many families experience when unsupported by the very people paid to do so.

We do this to bring about improvements, we saw the benefit when issues got tackled on the ground, the Autism Working Group now having fallen to the wayside as no one will take ownership of it. It is not efficient to work in isolated sectors or to leave the small problems, they become the big ones. Yes, there are lots of strategy and working groups in the city and we still have huge problems because **culture and working practices** are not being addressed. mASCot called for an Autism Champion in 2014, a role to take ownership of developing cohesive policies and procedures that affirmed autism. We are still only moving towards it.

If you would like mASCot to expand on any of the issues raised in this letter we will of course, but while we continue to work with you to see the previously promised recommendations be set up, we ask that **culture and working practice** is made a central focus in autism provision across the board. We hope the upcoming SEND workshop will be part of this ongoing process with a commitment to looking at how **culture in B&H** is as important as the city's strategies, if not more so.

Best wishes,

Paula Donovan

Parent and mASCot Director

1. B&H 6th form college with regard to one young adult when asked if a meeting with the BHCC could be set up.
2. 'Safe cutting' - [Creating Autistic suffering: CAMHS advise "safe cutting" for Autistic children - Emergent Divergence](#)
3. Culture of bullying - [Sussex mental health boss sorry for 'blame, fear and bullying' highlighted in staff survey | The Argus](#)
4. BHISS going over and above in offering practical and direct advice when outside their remit as there was no provision for post 16 at that time. Human kindness goes a long way.