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OPEN LETTER: REPORTING OF MULTI-AGENCY FAILURES IN BRIGHTON AND HOVE

RELATING TO AUTISM AND OTHER NEURODEVELOPMENTAL DISORDERS

This letter should be read in conjunction with the [multi-agency reporting documents](#) – in particular, the [Draft Multi-Agency Notification Summary](#) available on www.AutismEquality.org.uk – where your responses to the general issues raised in those documents [will be detailed](#) for dissemination.

We have just started issuing notices of professional practice and general agency failures in relation to children with developmental disorders in Brighton and Hove. It is clear from the information now available, having assessed numerous children as well as attending meetings involving multiple agencies, that there is ongoing multi-agency failure in relation to the assessment and diagnosis of, and support for, neurodevelopmental disorders in Brighton and Hove.

Overall, the issues include:

1. Failure to properly assess for neurodevelopmental disorders
2. Failure to diagnose quite evident Autism Spectrum Disorder (ASD) and ADHD
3. Failure to abide by the duties of the Equality Act 2010 in terms of
 - a. Making a determination in relation to disability
 - b. Determining what adjustments are required
 - c. Determining what are reasonable
4. Failure to understand the difference between a diagnosis and having a condition that results in impairments that constitute a disability
5. Making inappropriate environmental-related pseudo-diagnoses
6. Providing inappropriate support and interventions related to parenting rather than neurodevelopment
7. Failure to understand that a diagnosis is something given by any appropriately qualified or experienced professional and is not restricted to statutory services
8. Failure to understand that ASD is not wholly or solely a disorder of social and communication development but that it comprises an entirely distinct component (i.e. DSM-5 Criterion B) that relates to restricted and repetitive behaviours and interests - and that it is this which often presents the greatest challenges in terms of engaging in education
9. Failure to understand that intellectual impairment is not a key factor in whether a child with ASD would be eligible for an EHCP
10. Failure to consider children with neurodevelopmental disorders for EHCPs at an appropriate time
11. Inappropriate reliance on screening measures over proper diagnostic assessment and failure to understand the difference between screening and diagnostic assessments
12. Inappropriate reliance on single-session, single-context assessments
13. Failure to take a necessary developmental and general history
14. Inappropriate formulation based around emotional and family rather than neurodevelopmental issues

15. Indication that an ASD assessment would not be completed until other things are completed (e.g. treatment for anxiety)
16. Inappropriate referral for psychological treatments in the absence of a proper assessment of the underlying issues
17. Failure to refer on to a relevant diagnostic service
18. Failure to understand the core role of cognitive stress and related demand avoidance within ASD, and how this then results in school refusal

Where Practitioner Psychologists or Social Workers have engaged in inadequate assessments, repeated misdiagnosis, incorrect treatment and/or serial instances of inadequate care, these would constitute [HCPC yellow or red flags](#) for competency to practice. That is, the HCPC would be expected to take some action. There are similar fitness to practice processes in relation to nurses through the NMC and doctors through the GMC. Accordingly, in a situation such as this, it is necessary to report those professionals so that the HCPC can make a determination in the individual case as well as connect them with other similar concerns.

It is of some particular concern that it has been conveyed to us that even children who are refusing to attend school will not be considered for an EHCP by the Local Authority if they have average intellectual or academic functioning. This would evidently seem to be incompatible with the EHCP framework and the specific place of ASD as the most complex neurodevelopmental disorder, and one that can often result in educational failure.

There is evidently something of a wider context to these issues. This wider context involves:

1. The current [Parliamentary Inquiry into Special Educational Needs and Disability](#), to which we are submitting written evidence
2. The [EHRC Discrimination in Education Legal Funding Project](#), for which we are collating cluster cases to submit to involved legal teams
3. The widespread failure to appropriately assess for and diagnose neurodevelopmental disorders

4. The widespread misattribution of neurodevelopmental symptoms to deprivation-related issues
5. The illogical separation of services that assess for different neurodevelopmental disorders
6. Failures to train relevant clinicians, social workers and other professionals in neurodevelopmental disorder presentations and differential diagnostic markers

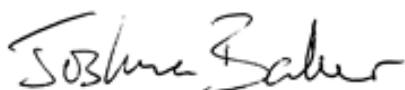
Whether or not there is a particular problem in Brighton and Hove is difficult to say. We certainly see lots of children from other Local Authorities and these are known to be national problems. However, we have seen numerous Brighton and Hove children over several years where there has been evident or highly likely disability discrimination, inappropriate allegations (e.g. of what amounts to Factitious Disorder Imposed on Another), or simple professional incompetence.

One issue of particular note is the simple failure to conduct or obtain routine developmental neuropsychological assessments using standard metrics. Team membership of, or 'regular access' to, an Educational Psychologist is a specific requirement for autism services under the NICE guidelines but is not currently not in place. The result of this failure is that children with autism who have often been seen by both CAMHS and the CDC - and have received an appropriate ASD diagnosis - are left without the necessary information for their educational programme to be appropriately tailored or adjustments made. This is usually the very reason we are then assessing them, often after considerable decline in education – or simple disengagement. Variations in cognitive and information processing are a fundamental feature of autism-type disorders (as well as ADHD), and this issue features prominently in the NICE guidelines. Conversely, parents are often told that an assessment 'is not valid' because it does not follow the NICE guideline to use the ADOS - but there is no such guideline and this represents a simple failure to understand the diagnostic process.

The systemic failings locally are now so evident that they mandate formal reporting to the relevant regulatory authorities, both in relation to individual practitioners as well as the services, schools and Local Authority itself - as well as forming case examples for the Parliamentary Inquiry. Clearly, these are all just means to an end – which is reform of the

systems, working practices and provision. **Whilst Brighton and Hove is just one area within a national project, it is now our test authority/district for examining if and how change can occur.** What is going on is just too often discriminatory, unlawful, contrary to fitness to practice or likely to have human rights implications (e.g. where a child with autism is wrongly thought to be displaying deprivation-related symptoms and child protection procedures are implemented or where there is a failure to identify autism in an adopted child and inappropriate treatments for e.g. 'developmental trauma' are provided). Clearly, an urgent multi-agency conference is likely to be needed as the alternative would seem to be a large number of individual regulatory fitness to practice reports and discrimination cases.

Yours sincerely



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