

28th February 2019

Open Letter in response to RightPro

Brighton & Hove City Council (B&HCC), Sussex Partnership Foundation Trust (SPFT) & Brighton & Hove Clinical Commissioning Group (CCG) received the same open letter, dated 12th June 2018, from Dr Joshua Carrit-Baker on behalf of a local charity Right-Pro “reporting of multi-agency failures in Brighton & Hove relating to autism and other neurodevelopmental disorders”.

Following a discussion between the Council and CCG about the open letter and linked documents, it was considered that in order to provide a comprehensive response to the concerns that two meetings with representatives of Right-Pro would be held.

An initial meeting took place on Friday 21st September 2018 and was hosted by Georgina Clarke-Green, Assistant Director for Health, SEN & Disability (B&HCC) with Gill Brooks, Lead Manager for Children’s Mental Health & Wellbeing (CCG) and Kathy Felton, Commissioning Manager for Community & Paediatrics (CCG). It was chaired by Fiona England, Parent & Carer Council and attended by representatives from local organisations Amaze, PaCC, mASCot and Brighton and Hove Inclusion Support Service (BHISS).

At this meeting we addressed the broader issues raised such as multi-agency working at a strategic level, which included information on our diagnostic and assessment pathways and our approach to joint commissioning. We also briefly discussed the role of Brighton & Hove City Council’s Inclusion Support Service (BHISS) and Education Health & Care plans. It was acknowledged the open letter gave CCG and B&HCC an opportunity to look at what can be improved. We decided to open up the second meeting so that we could benefit from the expertise of other local NHS clinicians.

At the second meeting we had a more focused discussion on diagnostic approaches led by one of our Consultant Paediatricians and supported by professional colleagues in CAMHS and BHISS.

The sections below cover discussions and presentations at the meetings:

Current practice in Brighton and Hove

As a Local Authority and Clinical Commissioning Group for Brighton & Hove local area, we commission sometimes jointly, provision and professionals to meet educational, health and care needs informed by clear assessments of needs.

Our ambition for children and young people with neurodevelopmental conditions is the same as that for all our children and young people: we want them to access opportunities, participate in our communities, progress and achieve through education, skills and employment; so they are able to lead happy and fulfilled lives.

The Local Authority provides support and challenge to help schools to meet the needs of our children and young people. Local SEND guidance has been co-produced and sets out how we are focusing on schools to include and support children and young people with SEND. A local strategy for *Hidden Children*, which seeks to identify and support children who are at a higher risk of harm due to not being in receipt of full-time education, has also been produced. The Local Authority want all children and young people to receive their full entitlement to education and for that learning to be delivered in a way that is suited to their needs. Schools can act as a protective factor, as children who do not attend school can become *hidden*, where we are less able to help and protect them. The Hidden Children strategy seeks to ensure that the Council has an overview of all children and young people that are at potential risk of harm who are not in receipt of fulltime education, thereby providing challenge and support for arrangements that reduce the child's vulnerability. The council is committed to working with the whole family through the formulation of a relationship-based approach.

We are increasing our efforts to clarify responsibilities, process, criteria and thresholds for the identification and provision for special educational needs and disability. Our expectation is for an assess-plan-do-review framework to be used and children and young people's progress should be continuously monitored and reviewed. A formal education, health and care needs assessment with the local authority and key partners is made available when a child or young person fails to make the expected progress and additional provision might be needed. This threshold applies regardless of whether a child attends school or is receiving their education elsewhere. It is possible for children and young people with average intellectual or academic functioning to have an EHC plan if they have significant and complex special educational needs and disability including neurodevelopmental conditions. Although we are continuously embedding the principles of the SEND reforms in schools, and within the local authority and health partners, since our Local Area Ofsted and CQC Inspection in 2016 we know that some Brighton & Hove parents/carers feel that they have to *fight* to access services for their children. However, we know this is also a national issue.

Ofsted also hold individual schools to account - with an expectation that schools will identify special educational needs and support pupils to make progress. Schools must ensure that staff can meet the needs of children with SEND as part of their approach to

school improvement, professional development and performance management. This is also being supported through our children's workforce development programme, SEND specialists in Brighton & Hove Inclusion Support Services (BHISS) and SENDS Hubs / Area Special Schools. All commissioned providers and employed staff are expected to meet professional standards.

We continue to work locally with statutory, voluntary and community groups and organisations to improve the way education, health and social care services work together to provide and commission provision; as well as in our collective efforts to help young people with SEND access opportunities and employment to live fulfilled lives. This focus will benefit all children and young people with SEND and their families including those with neurodevelopmental conditions.

Children & Young People's Autism Diagnostic Assessment health services in Brighton & Hove

In our most recent meeting the Autism Lead for Sussex Community NHS Foundation Trust (SCFT), Consultant Community Paediatrician from our Child Development Centre provided an overview of the local Autism Diagnostic Assessment Services, currently shared between the Child Development Centre (from 2 to 11 year olds) provided by SCFT and Child & Adolescent Mental Health Services (from 11 to 18 year olds) provided by SPFT. B&H CCG have reviewed local diagnostic pathways in line with recommendations from a 2014 Scrutiny Committee review and subsequent scoping project that summarised the views of all stakeholders, particularly service users from which has been developed a draft proposal for a more integrated and streamlined neurodevelopmental pathway, which was shared during our first meeting with RightPro.

Both SCFT and SPFT follow National Institute of Clinical Excellence (NICE) Guidelines when considering the possibility of Autism (2011 and 2017) in terms of best practice diagnostic process and procedures, and DSM V and ICD 10 criteria when considering the possibility of autism / making a differential diagnosis. Possible signs and symptoms need to be considered in the context of the child or young person's overall development. This includes the influence of the wider family system, that of possible negative experiences such as trauma and or deprivation, and other possible existing or comorbid physical, mental, cognitive and/or neurodevelopmental disorders or disabilities. Previous childhood trauma would not prevent a child from receiving a diagnosis of Autism, if the child meets the criteria for Autism.

Following receipt of the open letter from RightPro and through our recent meetings we have been open to looking at organisational issues; and from our dialogue and discussions we have highlighted issues requiring multi-faceted collaboration:

- Further work to ensure increased joint working where there is diagnostic complexity;
- Some training needs for non-specialist education and health professionals, including Special Educational Needs Co-ordinators;
- Some training needs for awareness around neurodevelopmental conditions within Social Care;

- There is a need for awareness and improvement of the effect of environmental factors on individuals with ASD;
Referrals onto the pathway require information from different contexts including school and parents/carers.

For children aged between 2 and 11 after being accepted at triage by the Child Development Centre, they receive an Initial Developmental Assessment (IDA) by a Paediatrician. If there are sufficient concerns at IDA that a child has social communication or interaction difficulties (with or without behavioural rigidities) they will refer to the ASC Panel requesting an Autism Diagnostic Assessment (Stage 2).

The Autism Diagnostic Assessment is undertaken by two clinicians, normally a Paediatrician and Speech & Language Therapist/Clinical Psychologist/Specialist Teacher trained in Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview (ADI). This is followed by discussion amongst professionals.

The Diagnostic & Statistical Manual – Fifth Edition (DSM-V) and International Statistical Classification of Diseases and Related Health Problems – 10th Edition (ICD-10) are used to assess if child meets criteria across all diagnostic domains. If there is diagnostic uncertainty they may arrange further school or home observations. Over 80% of those assessed will receive an Autism diagnosis.

For young people between 11 and 18 years, an initial screening assessment/stage 1 is conducted by a clinician at Child & Adolescent Mental Health Service (CAMHS) with ASD expertise. This also includes detailed information from school and completion of the Social Communication Questionnaire by parents/carers. If these together are indicative of a possible ASD, a diagnostic assessment is conducted by a Clinical Psychologist and a Psychiatrist, also using the ADOS and ADI, as for this age group differential diagnosis often includes consideration of a mental health problem. A combined report is then compiled and discussed with the parents/carers and young person (as appropriate) in a feedback appointment, which includes a follow up plan and information pack. If there is no comorbid mental health problem, the young person is then discharged from CAMHS.

Through our recent meetings we have together identified areas for quality and service user experience improvement to be addressed:

- Anyone meeting the criteria through the multi-disciplinary assessment receives a diagnosis. We accept private diagnosis when the assessment undertaken is consistent with the guidance and advice of the National Institute for Health and Care Excellence (NICE compliant);
- As part of the neurodevelopmental assessments we will be considering using Educational Psychologist involvement jointly commissioned between the BHCC and the B&H CCG to provide developmental neuropsychological assessments;
- Some cases have environmental factors affecting behaviour;
- When a diagnosis is not made, we need to make transparent the processes we have to review cases in light of any new information;

- We accept children and young people can still have neurodevelopmental type/ executive functioning problems, without a diagnosis; and may benefit from similar interventions. We will consider providing some helpful recommendations from the detailed multi-disciplinary assessment provided;
- Parents/carers require consistency of experience from our services. Currently formulation within diagnostic reports can be variable, including in the description of strengths and needs. To address this, we are considering undertaking a peer review of assessments and reports with an aim to provide a more consistent format.

Lastly, in response to the open letter received we wanted to clarify how local services and professionals are regulated in the section below:

Compliance with regulations

Our local health and social care services are regulated and inspected by the Care Quality Commission (CQC), an executive non-departmental public body of the Department of Health and Social Care of the United Kingdom. Our local education and social care services are regulated by the Office for Standards in Education, Children's Services and Skills (Ofsted).

All our local specialist practitioners employed or commissioned by the CCG, SPFT, SCFT or BHCC hold essential qualifications and practising certificates through the appropriate regulatory bodies (e.g. HCPC, NMC, and GMC).

For example, the **Health and Care Professions Council (HCPC)** is a statutory regulator for professionals from 16 health and care professions in the UK. The HCPC reports its main purpose is to protect the public. It does this by setting and maintaining standards of proficiency and conduct for the professions it regulates. Its key functions include approving education and training programmes which health and care professionals must complete before they can register with the HCPC; and maintaining and publishing a Register of health and care providers who meet pre-determined professional requirements and standards of practice.

We have worked together with openness and honesty to address the challenges and concerns raised by Dr Carritt-Baker, on behalf of RightPro.

Our meetings have been helpful and informative; and we hope now that we continue to work together in the best interests of children, young people and their families to ensure they get the best care and timely access to specialist support and services to help meet their needs.