

BRIGHTON & HOVE CITY COUNCIL
SCRUTINY PANEL ON SERVICES FOR CHILDREN WITH AUTISM

12.30pm 9 JULY 2013

COMMITTEE ROOM 1, BRIGHTON TOWN HALL

DRAFT MINUTES

Present: Councillor Jarrett, Pissaridou, and Wealls

Also in attendance: Rosie Moore, co-opted Member

Others present: Alison Nuttall, Commissioner, CAHMS, Julia Riches, Scrutiny Officer

PART ONE

5. PROCEDURAL BUSINESS

No substitutes are allowed on Scrutiny Panels.

There were no declarations of interest?

There were no declarations of party whip?

6. CHAIR'S COMMUNICATIONS

Welcome to everyone to this first public meeting of the Scrutiny Panel looking at services for children with ASC.

The Panel have set their terms of reference as:

““To consider what services are currently in place to help children with ASC and their families including: issues around diagnosis, health, education, social care, and home support; to look at areas of best practice; and to make recommendations for action.”

This meeting is intended to give the Panel up-to-date information on the national and local pathways for assessment, diagnosis and support for children with autistic spectrum conditions and their parents and carers. I will be asking everyone to introduce themselves then speak for 10-15 minutes and then take questions.

7. NATIONAL PATHWAY

Dr Vicky Slonims, Consultant Speech and Language Therapist, Honorary Senior Lecturer (Kings College London), Children's Neurosciences Centre, Newcomen Centre at St Thomas' Hospital, London.

Studies estimate that around 1% of the population have ASC so it is no longer a rare condition. This has been a significant change in the last decade. There are high levels of additional need and 70% of individuals with ASC having one other behavioural or mental health issue and 40% have at least two. Challenging behaviours are very common.

Outcomes for adult life for those with ASC tend to be poor in comparison with others, including those with good intellectual skills – only 25-30% find employment as adults. Having a child with ASC can have a significant – and sometimes negative – impact on family life.

The annual cost of supporting children with ASC is estimated at £2.7b which means the total annual cost per child reaches £25,400 (over and above the cost of a neuro-typical child). A study in 2012 found that over 6 months the cost of parents seeking additional services was on average £2,581 with almost half of the costs for education and childcare and only 12% for hospital services.

There is no screening program for ASC or other neuro-developmental disorders: the approach is of universal surveillance by Health Visitors and other primary health professionals. The National Health service does not recommend screening for neuro-developmental disorders such as autism. There are 4 levels of health provision in the UK from primary care, district and regional services with some specialist national centres and there is guidance on triggers for referral onto the next level. Care pathways across age ranges permit smooth transition across levels.

The National Autism Plan for Children (NAP-C) published in 2003 was influential. There are now more local assessment teams although only 54% have a formal assessment protocol. More services are using multiagency teams and more teams have multi-disciplinary assessment clinics – 57% in 2007 although there is evidence that this is decreasing due to cutbacks. There is still a wide variation on access to, and quality of, diagnostic and intervention services, but there is good awareness and better training in many areas. Nationally, the prevalence of ASC has put huge pressure on services with long waiting lists. In one or two areas, some diagnostic services are being provided by educational professionals and private sector teams not NHS.

Initial provision may be through community health services, e.g. occupational therapy, or speech and language therapy (SLT). Education services are more involved and at an earlier stage from 2-3yrs old. Some services offer home based interventions and placements in mainstream or specialist nursery provision. The Children and Families Bill is extending education to 25yrs old and this will have an interesting effect. In the past, there has been a form of 'postcode lottery' as there has been differing levels of provision hence the drive towards a single package of care. Traditionally, education has tended to fall outside of the care package due to the infrastructure and there is a

hope that there will now be one single package of support with all services working together.

70% of children with ASC attend mainstream schools and legislation states that schools must make 'reasonable adjustments'. In 2009 the government set up a resource called the Inclusion Development Programme (IDS) to help teachers address the needs of ASC children. The programme has stopped under this government, although is still available on-line. Vicky was part of developing the IDS and a key aim was to help teachers to understand that children may come in to school with a style of behaviour, not necessarily a label of an autism spectrum disorder.

When children with recognised Special Educational Needs reach 14yrs old there should be a transition plan meeting to provide a benchmark when or current skills and plans for future needs. This has not routinely included Health and Social Services and some professionals feel this may be too early, however the new NICE guidelines have recognised the value of early evaluation of future needs. .

Post 16yrs old, most children are expected to go to college or post 16 provision, There is a broad range of provision on offer ranging from university degrees to vocational training. In spite of this only a very low percentage of individuals with ASC and a typical IQ have a full time job -12%. Across the whole spectrum, this falls even further to 6%. This is lower than for those with other disabilities. There are some examples of success e.g. the NAS Prospectus Employment Consultancy assisted 67% of their clients to find work but this has funding problems at the moment.

The 2010 'Getting it right for children' review of services made key recommendations for the NHS around shared decision making. The Children's National Service Framework states care will be provided in an 'appropriate environment': this is key for people with ASC. For example, bringing ASC people into hospitals and dentists to see what their experience is like would enhance services.

The 2012 report of the Children and Young Peoples Health Outcomes Forum for children and young people included a subgroup for children with disability, SEN and long term conditions such as such as ASC. Some of the main recommendations were: a reduction in time from first presentation to diagnosis/start of treatment; a quality assessment; and a key working approach (families say there is a myriad of people and they would prefer to have one contact person). As soon as an individual that has been identified as having ASD comes in to the services there should be a rapid response time but this has not been done well in the past.

The NICE guidance covers three key areas: ASC diagnosis in children and young people (published Sept 2011), recognition, referral, diagnosis and management of adults with ASC (June 2012), and management of ASC in children and young people to be published September 2013.

One of the recommendations around diagnosis from NICE is the creation of a local autism strategy and management group. Aims of this include to improve early recognition and make sure professionals are aware of the care pathways.

The core of the diagnostic team will include a paediatrician and/or child psychiatrist; SLT; clinical and/or educational psychologist, and others as required (eg gastro, OT etc). There should be a single point of referral and a care case co-ordinator for every child or young person who is to have an ASC diagnostic assessment.

NICE recommend that there should be a local autism strategy group with responsibility to deliver and co-ordinate interventions across the age range (ie into adulthood). There was a lot of discussion on this but NICE were clear that the autism strategy group doesn't have to *deliver* the intervention but *ensure* the service is delivered and be there as a resource for parents to go back to – a central and single place to go.

Unrestricted access to CAMHS is a big issue.

NICE are aware that implementation could be problematic and are taking a lead on identifying barriers to implementation

A survey by the British Academy for Childhood Disability (BACD) due to be published soon shows a significant decline in services since 2007. It looks across 2 time points. Community Development Teams working together are less and less common.

8. LOCAL PATHWAY - CAHMS

Brenda Davis, Consultant Clinical Psychologist and Lead for Psychology for Brighton & Hove CAHMS, Sussex Partnership NHS Foundation Trust

Ms Davis is responsible for developing ASC pathways across Sussex (including CAMHS). The care pathway relates to the whole of Sussex (despite differences in commissioning).

The post-diagnostic pathway is Brighton & Hove specific. The Sussex Partnership Trust follows the Map of Medicine pathway. The Map of Medicine is a national pathway initially devised for members of the public to use and follow for physical health problems. The SPT took the national pathway and changed the information boxes.

Children over 9-11 years old.

CAHMS service covers 0-18years and offers intervention to any child. If a child has ASC and mental health issues then the service will go right across the age group. Diagnosis is divided so children aged 9-11 yrs are seen by child health colleagues. CAHMS see children above 9-11 yrs for diagnosis whether they have mental health problems or not. If someone does not get a diagnosis, that can be problematic.

Stage 1 assessments gather information so they have as much information as possible to decide whether or not to go onto Stage 2. Stage 2 is a more time-consuming multi-agency diagnostic assessment using NICE assessment tools and takes a whole morning. As the years go on, the number of children going to Stage 2 has reduced because they are better at doing Stage 1.

All children (even if they come in with a specific request for ASC diagnosis) will get screening in a diagnostic clinic prior to a Stage 1 assessment. The care co-ordinator will be a physician who will get all the information – including a detailed questionnaire for schools, and will talk to tutors and subject heads to get a flavour of how a child behaves in different environments. BRIEF (Behaviour Rating Inventory of Executive Functioning) is used as a screening tool. Clinical interviews take place that follow strict guidelines and provide information over and above the mental health assessment that all Tier 3 children go through. This leads to a detailed Stage 1 report in a standardised format. This report goes to the monthly referral meeting and all those in Stage 1 attend and decide how likely it is this is a child with ASC who needs to go to Stage 2.

By secondary school age, the service is much better than it was at recognising ASC as more people are diagnosed earlier and better. By the age of 9,10,11 CAMHS are getting the most complex children with lots of co-morbidity problems. It is about determining whether ASC is part of a more co-morbid problem in complex children.

At Stage 2 the psychiatrist will use standardised NICE recognised Autism Diagnostic Interview that will be scored at the end with the parent/carer. The Psychologist will use a standardised set of activities and a diagnostic observations schedule which is also scored. The meeting will take a morning. They will meet the parent and child to explain, then the psychologist will meet the child. Following this, they will look at the assessments to see if they can be sure they are talking about ASC as one of the problems. They can call a SLT to explore further or ask for a cognitive assessment from other colleagues. If the assessment is that ASC is possible, there will be a detailed report in a standardised form over the next 4-6 weeks then they will meet with the parent/carer and young person to discuss the report and the action plan.

Some children may have learning difficulties (LD) as well as ASC. It is important to use the same tools so they try and use the same process as much as possible. If LD and ASC are present, the child will automatically fall to the LD team in CAHMS.

Q – What about children with ASC but no LD?

If there is LD and ASC present there is a team for this. If there is a mental health issue and ASC there is another team. If ASC is diagnosed but not LD or mental health issues there can be a lack of clarity. There are services but it is not as clear cut (Alison Nuttall).

If a child has LD then they will see the LD multi-agency team. If they have no LD but a co-morbid mental health issue, they will see that team.

In Tier 4 children need even more specialised intervention and they are at a high level of risk. The assessment may be done in an in-patient setting: there is a process by which these children aren't forgotten and can be part of the pathway.

A well-child with ASC may not need health provision but they are more at risk when a certain point might occur, for example transition (Vicky Slonims).

As the bulk of children are seen early, CAMHS do not have a waiting list. People wait no more than 2 months for an assessment (2nd line) and 4 weeks for a first assessment.

Q – If a child has only ASC with no interventions, can we prevent future problems?

There is no evidence on this. Nationally, we are not good at responding to need early so when a child is referred in mid childhood, problems arise, eg anxiety may be a core part of ASC but it may not meet the criteria for CAMHS referrals. We are not good at preventing acceleration. There are problems around CAMHS accepting children then. A key question is what is the definition of co-morbid presentations with ASC? (Vicky Slonims).

The pathway for post-diagnostic care at secondary age mirrors the primary pathway. CAHMS routinely offer to all parents whose child has been newly diagnosed a group to inform them of the sort of problems/anxieties that may not meet the criteria for anxiety disorder but can typically be expected of child of that age. There will also be planning meetings at the school and they will offer relevant interventions. There can feel like there is a gap, eg my child is anxious but it doesn't meet the criteria of a disorder – it is part of ASC. CAMHS try to cover this in educational psychology groups. A new neuro-disability post (psychologist) to work in Seaside View across the age group to try has just been appointed to try and fill this gap. It is recognition that there is a gap here.

Q – The initial CAMHS survey only went to new parents - this is an issue. How does the caseload information relate to access to services?

**It was agreed to explore the issue of the survey, past users of CAMHS as well as current users and the process around feedback at a future Panel meeting.*

CAHMS now is very different to 10 years ago and parents who used CAHMS then would have a very different experience to parents today.

9. LOCAL PATHWAYS - SEASIDE VIEW CHILD DEVELOPMENT CENTRE

Dr Katharine Anderson, Consultant Community Paediatrician, Seaside View Child Development Centre

This meeting note should be read alongside the powerpoint presentation given.

The Seaside View ASC assessment service works with children up to the end of primary school. The service is still a 2 stage process, but is broadly compliant with NICE. Seaside View accepts referrals from all professionals but no self-referrals. The first stage is a general developmental assessment and the second stage more ASC specific. The general policy at Seaside View is multi-disciplinary assessment from the start for many children, in the form of the Integrated Care Pathway (ICP). ASC is a bit different because we had a pre-existing pathway and also there is limited access to specialist SLT. If the question is 'has this child got ASC' then the ASC pathway is used. If there are wider concerns around the child's development, there will be a wider range of professionals engaged at the start ie the ICP. At the minimum there will be a paediatrician who will take a paediatric/developmental and family history. The majority of children with possible ASC are not already in the ICP, so they will see a paediatrician (only) for a general developmental assessment (stage 1) and if there are still concerns about ASC they will then be referred for a more detailed multidisciplinary ASC-specific clinic (stage 2). Between Stages 1 and 2, they may request a lot of information – particularly from the educational setting to see how children behave in the socially demanding environment of school, and in particular how they interact with their age peers.

Stage 2 lasts around 3 hours. They don't use ADI but a questionnaire based on it. The aim of the assessment is to either make a diagnosis or to reassure, if appropriate, that there is no diagnosis of ASC. They will identify the strengths and difficulties of the child and any possible co-existent or alternative diagnoses.

If there is a diagnosis of ASC they will discuss the needs of the child and support and advice. A focus group found that what parents wanted as they left Stage 2 was support. There is not an ASC key worker although it would be great to have one. They ask the family if they would like us to call anyone specific to support them eg health visitor.

Q – Do you recommend schools?

Not specific schools but may suggest that a child needs a special school or a mainstream school. Age 3-5 will have a planning meeting with the pre-SENs team.

Q - Is there support at that stage?

There should be that support there but can't say categorically that it is always there. (Regan Delf)

The Panel could discuss the issue of advice and where parents get it.

Seaside View is short on SLT time. They follow up all pre-school children but not all older children are followed up – they often aren't ill and therefore do not require routine medical follow-up. There is a need for there to be one person who says this person is struggling and they can be signposted to different services.

They have carried out an ASC peer review service for many years. This involves operational assessment and intervention planning but there is also the opportunity to present (anonymous) information on a child where arriving at the correct diagnosis is difficult for discussion. Seaside View can also refer people on to tertiary services – usually the Newcomen centre in London.

There is a Disability Partnership Board with Jenny Brickell, Head of the Integrated Child Development & Disability Service and Amaze as joint Chair. It is a wide ranging board and includes representatives from SEN, a parent carer (through PaCC), adult commissioning services, schools, educational psychologist and Pre-SEN amongst others. This Board has agreed to take on strategic level planning for services with ASC (as NICE recommends). There is also an ASC group that links in to this – the terms of reference will be circulated.

After the appointment, typed reports are sent to the family, the referrer, and the health, educational and social care professionals involved (with consent). People are referred as appropriate to the ASC Support Service, to a Time Out Course (which is a psycho-educational course that supplies more information about ASC and behaviours).

Q – Is access to services wrapped up with diagnosis?

It shouldn't be but realistically it probably is.

The complaints the Newcomen Centre receives are around indecision and the length of time taken. Waiting for services is a big issue and a 2 tier service can feel like a long time and they may be some issues arising from this but also from shortcutting the process and a diagnosis being made by a paediatrician alone (Vicky Slonim).

There is a care co-ordinator so people do not get left behind and there is not a long waiting list for secondary school age children in CAHMS (Brenda Davis).

An estimated 86 children were seen in the last calendar year through the standard Seaside View pathway (July 2012-June 2013); these numbers have increased to try to minimise the waiting time between Stage 1 and Stage 2. Around 64% receive a diagnosis of ASC through the standard pathway. This is an underestimate of total numbers as some (a minority) are seen through the ICP and special schools systems which involves a similar process but sometimes different professionals. More accurate figures could be provided.

10. SPECIAL EDUCATIONAL NEEDS PROVISION IN BRIGHTON & HOVE

Regan Delf, Head of Special Educational Needs (SEN), Brighton & Hove City Council.

ASC diagnosis has risen quite steeply over recent years and now ASC makes up the biggest category of statements of SEN (January 2013) at 19%. ASC statements are

eligible for 'top-up' funding as they have always been categorised as 'low incidence' and the LA provides additional funding in addition to funding delegated to schools for low incidence categories of need. However as ASC is now the highest incidence category of need for statements, this needs to be re-thought. There are 79 children with ASC in mainstream schools, 7 in academy schools, 12 in mainstream units, 66 in special schools, 11 in agencies (ie independent and non-maintained special schools) and 1 other. (for obvious reasons, numbers vary continuously as pupils move in and out of schools)

Where we need to make provision for pupils with ASC in agency schools, costs can be high – in one case currently heading for the SEN Tribunal, placement cost would be £320,000 per year. These can offer fantastic facilities but the cost is enormous. There is a need to make sure that all our maintained provision is really good so people don't need to seek provision in agency. However all our provision locally is rated good or outstanding by Ofsted and the number of children using agency schools (all categories) is declining.

The Swan Centre at BACA and now Hove Park Special Facility offer specialist facilities within a mainstream school,. These are not specialist ASC units but speech and language as well. Around half of a child's time is spent in the unit and the rest in mainstream classes. The model has been very successful.

All special schools with the exception of ACE offer places to pupils with ASC who need special school provision.

Outreach services from special schools also may offer support to some pupils with ASC and severe learning difficulties.

The Autistic Spectrum Support Service (ASCSS) offers outreach support to mainstream schools but it requires a diagnosis of ASC before you can access the service. There are 3 FT staff.

Q – Does this put pressure on people to provide a diagnosis?

Yes it can do –and it puts pressure on schools as well. There is also the issue that allowances (eg DLA) become accessible with a diagnosis. The team receive a lot of requests for statements – some parents may put pressure for a diagnosis because they see it as a 'passport' to services. This is a change from the past when a diagnosis was seen often seem as more devastating in terms of consequences for a young person. The question is always whether the higher prevalence of ASC diagnosis is about higher prevalence of ASC or a change in classification to include a wider spectrum of need or both.

Speech and language issues are difficult to diagnosis separately to ASC sometimes and sometimes a firm diagnosis means people lose out. It is a very complex area (Vicky Slonims).

Currently there are 250 pupils with a diagnosis of ASC in mainstream schools which represents 0.85% of the mainstream maintained school population. Only 39% of this 250 have statements of SEN so the ASCS service is supporting a lot of children with ASC but no statement.

ASCSS supports schools to understand ASC and supports teachers. There is a need to support families too. The ASCSS has 176 pupils on its active caseload.

In terms of specialist provision, Jeanne Saunders pre-school assessment centre works with children with complex needs, not just ASC. 5 of the 6 special schools offer places to pupils with ASC alongside a range of other complex needs. Downs Park make specific arrangements for pupils with ASC but in Cedar Park pupils are all in the same class. The West Blatchington ASC Facility (primary) only takes children with a diagnosis of ASC. The Hove Park Facility (secondary) is opening in September 2013 – this used to focus on children with dyslexia but that is not such a pressing need so the provision has changed.

There is a big overlap between BESD and deprivation but a very small one with ASC. The overlap between free school meals and ASC is 7%. The overlap with BESD is over 50%.

The ASCSS service is very well received by schools but is aware they need to extend their service to include families more hence recruiting to a vacant family support worker post. The LA is aware of the need to make signposting in education services clearer .

Q – Do you have any influence over independent schools?

It depends if the service are paying the school fees! Generally experience is good – although independent schools are not able to access ASCSS.

There is parent representation on the SEN strategy priority groups and they are currently looking to get better representation of young people.

Young users have been engaged (Aha! Group) via the SE7 pathfinder group (Alison Nuttall).

Q – Why is there not a systematic service user engagement as with adult services?

The focus has been on parents as service users but they need to think more about young people's views. Clearly with children there are issues to consider in terms of age, parental consent for involvement etc . The voice of the young person is a priority

area of development for us in our strategy. A lot of work done, but more needs to be done around mapping and collating activity.

Q – Is the ASCSS an advocate for schools rather than parents?

The service has grown hugely and there used to be a bigger focus on children and parents when the service had a family support worker. They still do a lot directly with parents and try to form a 'bridging' role between parents and schools – this will be easier with the agreement to recruit a new family support worker after a period of the post being vacant. (Mary Macphail).

Some parents want private consultants in schools working with their children and this can cause tensions.

Parents can be worried about how disinterested advice on educational provision is when it is provided by the LA. This is an important issue – if you want to make a difference then make this advice independent from the provider concerns (Vicky Slonims).

11. DATE OF NEXT MEETING

The Chair thanked everyone for a very useful and informative session.

The date of the next meeting is 17 September 2013 from 2.00pm in the Council Chamber, Hove Town Hall

The meeting concluded at Time Not Specified

Signed

Chair

Dated this

day of