

RESPONSE TO AUTISM REPORT (HEALTHWATCH CHESHIRE EAST, OCTOBER 2015)-

LIVING WITH AUTISM IN CHESHIRE EAST

The report has highlighted:

1. Different waiting times for Autistic Spectrum Disorder (ASD) diagnostic assessments for children and young people (YP) in Cheshire East CCG and South Cheshire/Vale Royal CCGs
2. The lack of post ASD diagnostic support
3. The number of appointments that a child or YP has to attend because of the child /YP's co morbidities associated with ASD
4. The lack of adult ASD services
5. The lack of information given to parents

Different waiting times for ASD diagnostic assessments for children and YP in Cheshire East CCG and South Cheshire/Vale Royal CCGs

The services provided by the community paediatric team from MCHFT are commissioned by the Vale Royal and South Cheshire CCGs. Our waiting time from a school doctor's referral to an ASD diagnostic assessment currently stands at 20 weeks. A year ago, the waiting time for this assessment had been closer to 18 months.

The team looked at the ASD Pathway and assessed what work was time effective (e.g. taking the decision that a multidisciplinary assessment could be done on a virtual basis i.e. not having all professionals involved sitting together in a meeting); reviewed clinic templates; employed locums; revisited the referrals criteria to the team; reviewed individual doctors' job plans and enhanced training for locums.

Some issues highlighted by some of the carers are acknowledged as, when a department is short staffed, continuity is lost for the child and the family. The shortage in staffing levels is a national problem for community paediatric teams. Our staffing levels have improved since September with 2.5 vacant Consultant posts now being filled.

ASD assessments are multidisciplinary assessments and completion of the assessments will also depend on assessments by other agencies (e.g. education, allied health professionals, CAMHS) involved with the child. As other organisations become increasingly financially stretched, the multidisciplinary assessments also become increasingly difficult to achieve.

NICE CG 170(Autism: The Management and Support of Children and Young People on the Autism Spectrum) clearly states that the assessment and management and coordination of care for children and YP with autism should be provided through a local specialist community based multidisciplinary team. This cannot be provided by just one team or organisation

The lack of post ASD diagnostic support

This is fully acknowledged. Our team currently only provide 3 Cygnet parenting groups(Tier 1), with a CAMHS professional per year. Our team is currently not funded for this provision and there is a waiting list for accessing this parenting group.

There are other issues (like anxiety) that the children/ YP feel are not well addressed.. This provision cannot be provided by the community paediatric team and will need to be addressed by other teams(Tier 2). The doctors and nurses in our team do not have a mental health training background.

South Cheshire CCG has already started discussions with CAMHS in South Cheshire and the community paediatric team with regards to post ASD diagnostic service and most of this support will probably be provided by CAMHS and other agencies. Provision at Tier 2 level is being looked at by Vale Royal CAMHS and other agencies(not community paediatrics).

The number of appointments that a child or YP has to attend because of the child/YP's co morbidities associated with ASD

ASD can be associated with other comorbidities. The number of appointments attended is sometimes unavoidable for the following reasons:

- Not all professionals are trained to assess all the conditions. For example, to assess dyspraxia would involve an Occupational Therapy (OT) assessment. Dyspraxia is also a neurodevelopmental condition and most neurodevelopmental assessments involve multidisciplinary input. Not all our doctors are trained to assess both ASD and Attention Deficit Hyperactivity Disorder (ADHD). Training requires time and supervision
- Sometimes symptoms and signs of another Neurodevelopmental condition (NDC) are not recognised until the other has been managed appropriately.
- Sometimes the child/YP has complex needs and the assessments are just more difficult

The lack of adult ASD SERVICES

This is true and is being addressed by some CCGs. However, the childhood services still need to be addressed.

The lack of information given to parents

For children/YP diagnosed with ASD by our team, an ASD Pack is given to them which we feel contains a lot of information.

Parents are also offered the Cygnet Parenting Group

As a professional involved in children with ASD, I believe that the following needs to be addressed:

- A ASD post diagnostic services needs to be commissioned.
- Other agencies(who know about ASD) need to be able to feed back good quality information into the multidisciplinary process involved in an ASD diagnostic assessment. This is required because, very often, the paediatrician finds that she/he may be the only professional involved. This also holds up assessments or may result in an inconclusive assessment.
- The time of the professionals also needs to be used effectively so that the numbers seen in a timely manner can be managed
- Resources in the community like parenting groups etc needs to be available for parents to access

Dr. Evelyn Loke
Consultant Community Paediatrician
Clinical Lead

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