

AGENDA ITEM

REPORT TO HEALTH AND WELLBEING BOARD

25 OCTOBER 2017

REPORT OF CLINICAL COMMISSIONING GROUP

ASD briefing paper for Stockton Health & Wellbeing Board

Purpose

To update Health & Wellbeing Board on progress to date with the development of the Autistic Spectrum Disorder Diagnostic pathway.

Background

1. Autism is a lifelong developmental condition affecting 1 in 100 people in the UK. It impacts on the way a person communicates and how they experience the world around them. Autism is described as a spectrum condition. This means that while people with autism, including Asperger's Syndrome, share certain characteristics, they will be highly individual in their needs and preferences. Some people with autism are able to live relatively independent lives but others face additional challenges, including learning disabilities, and need varying levels of support for the whole of their lives.
2. Nationally, it has been suggested, by the Autism Alliance that Autism affects 1.1% of the UK population. We do not yet know exact local numbers of children affected with Autism, but the following section begins to establish a local estimate (please see appendix 1 for further detail re: prevalence).
3. As a safe guide we could calculate prevalence at 1.1% of the population of children (probably with diagnoses) and then look at the weighting of 4 times as many boys to girls.

Population figures taken from ONS mid 2015 population estimates analysis tool (0-19)

Population CYP	1.1%
47,351	521

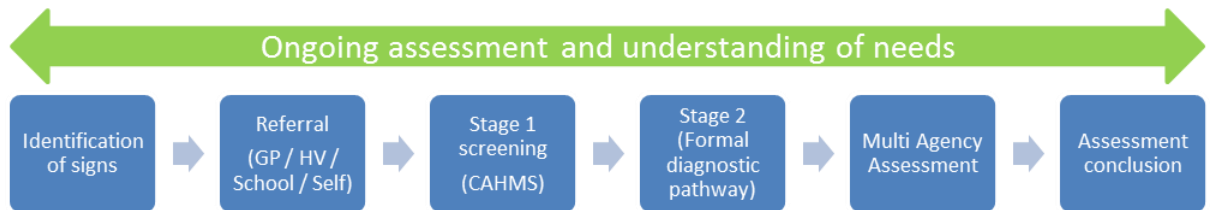
4. In terms of those being assessed/unmet need, good practice suggested prevalence can be multiplied by 3 or 4 which would increase the figures to between 1,563-2,084.
5. Nationally the time taken for diagnostic waits has received recent political attention, with direct links to Stockton. A call for a nationally mandated waiting time from referral to initial assessment of three months has been made, in line with NICE guidance, but no detail has been suggested for overall diagnostic times. The local pathway is NICE compliant. NICE standards are available in appendix 1.
6. NICE guidance states that Local Authorities 'should ensure that they have a diagnostic pathway for autism' but sets clear expectations about working jointly with CCGs. Currently, the specialist diagnostic pathway is commissioned directly by the CCG and provided by TEWV with Paediatrics leading on under 5s.
7. In 2013/14 the CCG funded Teesside for a Band 7 ASD Coordinator post in each Local Authority area. This equates to £45,317 per annum per Local Authority (please note this isn't the total amount for the ASD pathway). NICE Guidelines state the role of the ASD coordinator should be:
 - *Act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team*
 - *Keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments arrange the provision of information and support for parents, carers, children and young people as directed by the autism team*
 - *Gather information relevant to the autism diagnostic assessment*
 - *Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand.*
8. Additional investment that was made by the CCG in 13/14 into the pathway for a non-recurrent waiting list initiative funding that went in, and again in 15/16 in an attempt to impact waiting times.
9. Locally, issues have been identified with the existing ASD pathway and associated services and are summarised below:
 - Referral – pre-referral and also actually getting on the ASD pathway itself
 - Lack of comprehensive needs assessment
 - IM&T & Information sharing – linked to identification, needs assessment and case management
 - Workforce issues
 - Delays in diagnosis and concerns with needs being met whilst child is being diagnosed.
 - Over medicalisation of the pathway
 - Two step processes to approach ASD pathway - generic / universal and specialist

- Educational psychologists not played an active role in ASD management since 2014/15.
- Issues with communication across the pathway
- Diagnosis in itself does not appear to be critical to pathway in terms of what if any on-going support is provided (the exceptions being access to Daisy Chain and sensory OT)

10. The ultimate aim of this piece of work is to develop and implement a revised pathway

High level pathway

11. The front end of the pathway requires focused attention, along with inconsistencies to how it is coordinated. There are several stages which have been simplified and summarised below:



12. The pathway for Stockton appears linear in nature, with a focus on diagnosis. There appears to be a mis-conception that a diagnosis is required to access funding and services.

13. The overall time from end to end is unclear, but we know that a referral into CAHMS is seen within four weeks, and the first stage of the assessment may take up to 6 months as it involves observations in 3 settings, details developmental history. Current maximum wait for diagnosis for under 5s is 17 months and over 5s is 25 months. Stockton waits from referral to assessment are in line with the national median – see appendix 2 for more information.

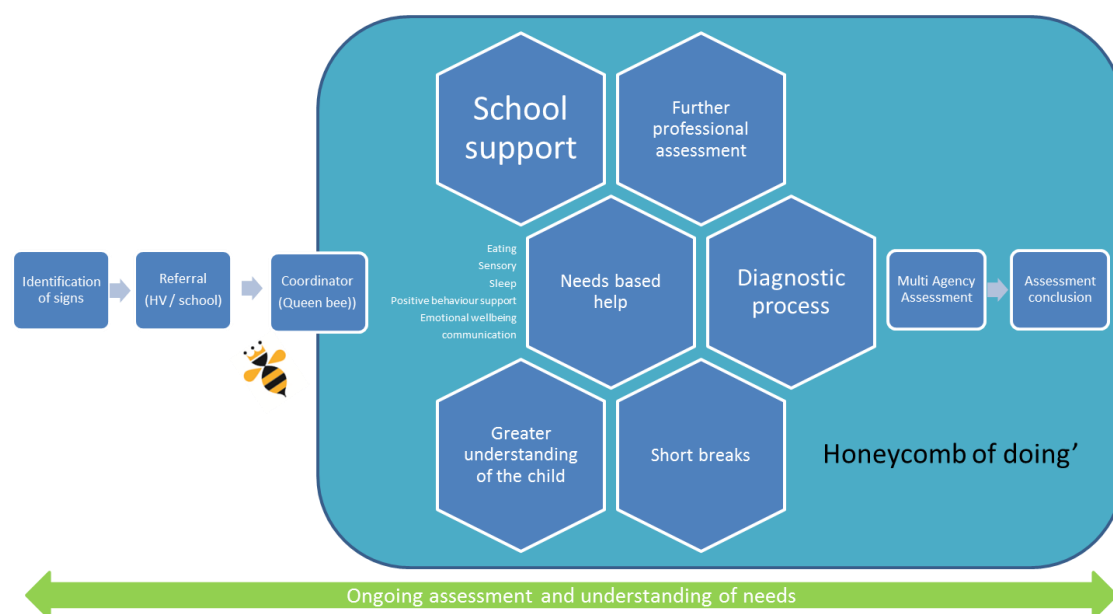
14. A multi-agency approach is taken to deliver the pathway as follows: TEVV - stage 1 screening and coordination, Psychology & OT; NT&HFT - SALT, Physio, OT, Paediatrics.

15. Demand also appears to be high in Stockton and has been increasing over the past few years, and reasons again are not clearly understood. One hypothesis is that in Stockton there is a single flow in, which appears to inflate the demand. In other areas children may be directed to other alternative services where their needs are met and information is collated, which can then be passed on if the child progresses through to the formal diagnostic pathway. It is also felt that the referral rates in Stockton may be closest to the expected prevalence of 1.1%.

16. This demand does make delivery of waiting times difficult with the fixed amount of capacity available. Previous waiting list initiatives reduced the waits, but they have returned to an unacceptable level.

Vision for new pathway

17. Earlier this year an event was held by NHS Hartlepool & Stockton CCG, Stockton Borough Council, and Hartlepool Borough Council, to look at the way children with suspected Autism are cared for locally. Further information, including the full pathway can be found in Appendix 3.
18. Following the event an expert reference group has been established to help make positive changes to the way we care for children with Autism.
19. A key focus for the group was looking at the length of time it takes to diagnose a child with Autism and the impact this has on the child and their family. What was also recognised as being crucial was the need to focus on the individual needs of the child and their families, as everyone's needs are different and ensure these are met as quickly as possible.
20. The group also recognise that some families want a formal diagnosis of autism and have clear expectations about access to support and intervention. However, we recognise that other families might prefer not to pursue a formal diagnosis for their child, perhaps knowing their child's strengths and needs is enough, along with having been assured that their additional needs are being met. The group feel that there should be informed choice right at the beginning of the process.
21. The emphasis of the new pathway is early identification of need, and supporting these needs, whilst offering choice whether to pursue a formal diagnosis.



22. This is a suite of needs based options for families to select in any configuration that best suits them. So, for example, they may wish to access some specific therapeutic work addressing their child's sensory needs that are impacting upon function, along with some respite via the short breaks.
23. Another family may only want to pursue formal diagnosis of ASD

24. Another may want to explore what additional support is required in the local school setting along with some help with sleep and a Speech and Language Therapy assessment
25. It is a 'honeycomb' of 'doing' that is designed by and for the family to meet their perceived needs in an optimistic and hopeful way
26. None of the choices are mutually exclusive, it is tailored to individual need with the Queen Bee having oversight in order to help the family feel confident in getting their needs met in a timely way.
27. It is also important to understand that there is no limit to how many times families dip into the honeycomb, they can return to the same or new sections as required.

Next steps

Short term:

- Hold a half day development session in November to drive actions and improvements
- Validate current waiting list within three months to ensure children are on the correct pathway, along with an understanding of their needs
- Agree communications plan in November to ensure mis-conceptions and myths are dispelled, to include parents and families; Schools and referrers into the service
- Streamline the referral process and assign the 'queen bee' coordinator role to smooth journey through the pathway by November
- Test out an approach to working with Daisy Chain which is based on cases being worked by agencies where there is a need for additional guidance on issues and potential solutions. (by November)
- Look for improvements within individual services to maximise capacity by November
- Consider moving to weekly multi agency assessment team meetings
- Consider improvements in flow via Paediatrics for both under 5s and over 5s (meeting due in October)
- Develop improvement trajectories to ensure impact is understood and delivered (by end October)

Medium term (timescales to be agreed at half day development

session):

- Agree virtual team approach to support the new model
- Agree standard work and processes, including joint policies and procedures
- Agree compact between members of the team to ensure behaviours and 'gives' and 'gets' are understood
- Understand capacity and demand for each element of the new service to ensure acceptable times are met
- Continue to monitor waiting times, including referral to start of assessment and overall diagnostic wait

Appendix 1 – NICE standards

Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Statement 2. People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3. People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement 4. People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5. People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

Statement 6. People with autism are not prescribed medication to address the core features of autism.

Statement 7. People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8. People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Quality statement 1: Diagnostic assessment by an autism team

Quality statement

People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Rationale

There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.

Quality measures

Structure

Evidence of local arrangements to ensure that people with possible autism referred for a diagnostic assessment by an autism team have the assessment started within 3 months of their referral.

Data source: Local data collection.

Process

Proportion of people with possible autism referred to an autism team for a diagnostic assessment who have the assessment started within 3 months of their referral.

Numerator – the number of people in the denominator who have a diagnostic assessment started within 3 months of referral to the autism team.

Denominator – the number of people with possible autism referred to an autism team for a diagnostic assessment.

Data source: Local data collection. NICE clinical audit support tool: Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, criterion 1 states that autism diagnostic assessments should start within 3 months of the referral to the autism team.

What the quality statement means for service providers, health and social care practitioners, and commissioners

Service providers ensure that they are part of a transparent diagnostic pathway for autism, and that people with possible autism who are referred to an autism team for a diagnostic assessment have the assessment started within 3 months of their referral.

Health and social care practitioners working within an autism team ensure that people with possible autism who are referred for a diagnostic assessment have the assessment started within 3 months of their referral.

Commissioners should work with local health, social care and education partners to commission an autism diagnostic pathway that includes provisions for people referred for a diagnostic assessment by an autism team to have the assessment started within 3 months of their referral.

What the quality statement means for service users and carers

People who are referred for an assessment because they may have autism are seen by a specialist autism team and have their assessment started within 3 months.

Source guidance

- Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128), recommendation 1.5.1
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (NICE clinical guideline 142), recommendation 1.2.5

Definitions of terms used in this quality statement

Autism team

The team conducting the assessment for children, young people or adults should be a specialist integrated autism team with age-appropriate expertise, and should be part of the local autism diagnostic pathway (as required by the Autism Act 2009).

Children and young people

The core staff of the autism team for children and young people should include:

- paediatricians and/or child and adolescent psychiatrists
- speech and language therapists
- clinical and/or educational psychologists.

The autism team should either include or have regular access to:

- paediatricians or paediatric neurologists
- child and adolescent psychiatrists
- clinical and educational psychologists
- occupational therapists
- other professionals who may assist with the assessment, for example specialist health visitors or nurses, specialist teachers or social workers.

[Adapted from Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128), recommendations 1.1.3 and 1.1.4]

Diagnostic assessment

This definition describes the autism diagnostic assessment for people who the autism team decide need an assessment. Some people who are referred for assessment will not receive a diagnostic assessment if the team's initial review of the referral suggests that the person does not have autism. For these people the autism team will either refer the person to another service and/or inform the practitioner who made the initial referral.

Children and young people

The following should be included in every autism diagnostic assessment for children and young people:

- Detailed questions about parents or carers' concerns and, if appropriate, the child or young person's concerns.
- Details of the child or young person's experiences of home life, education and social care.
- A developmental history, focusing on developmental and behavioural features consistent with the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the

Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) criteria (consider using an autism-specific tool to gather this information).

- Assessment (by interacting with and observing the child or young person) of social and communication skills and repetitive and stereotyped behaviours, including sensory sensitivities, focusing on features consistent with the ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information).

- A medical history, including prenatal, perinatal and family history, and past and current health conditions.

- A physical examination.

- Consideration of the differential diagnoses (see NICE clinical guideline 128, recommendation 1.5.7).

- Systematic assessment for conditions that may coexist with autism (see NICE clinical guideline 128, recommendation 1.5.15).

- Developing a profile of the child or young person's strengths, skills, impairments and needs, including: intellectual ability and learning style, academic skills, speech, language and communication, fine and gross motor skills, adaptive behaviour (including self-help skills), mental and emotional health (including self-esteem), physical health and nutrition, sensory sensitivities, and behaviour likely to affect day-to-day functioning and social participation. This profile can be used to create a personalised plan, taking into account family and educational context. The assessment findings should be communicated to the parent or carer and, if appropriate, the child or young person.

[Adapted from Autism: recognition, referral and diagnosis of children and young people on the autism spectrum (NICE clinical guideline 128), recommendations 1.4.1–8, 1.5.5 and 1.5.8]

Equality and diversity considerations

If the local autism team does not have the expertise to carry out an assessment, or in complex situations, a person may need to be referred to the regional (national specialist) team.

If a person does not have access to a specialist autism team near their homes, and has difficulty travelling long distances (because of the financial cost or other reasons), support may be needed to help them access the service.

Appendix 2 – Local waiting times information & Average wait between referral to assessment from Autism self-assessment (includes adults)

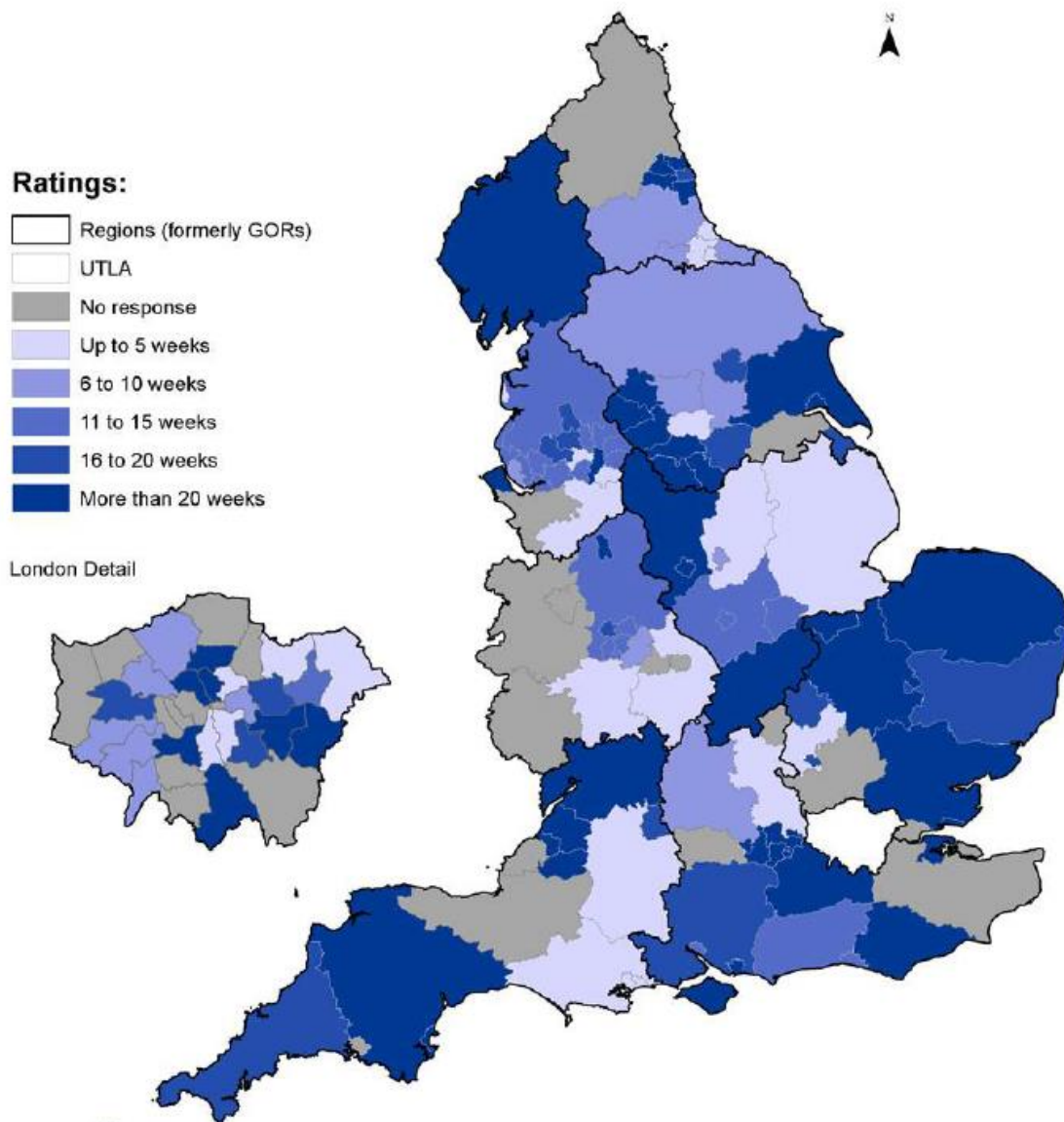
Month: September 2017	Hartlepool		Stockton		Middlesbrough		Redcar	
	Under 5	Over 5	Under 5	Over 5	Under 5	Over 5	Under 5	Over 5
Number on Waiting List	32	60	193	267	25	26	27	32
Period of Wait (months)	11	15	47	44	6	6	6	8
0	4	2	6	2	4	9	3	2
1	6	2	14	22	8	5	1	2
2	1	5	6	25	6	8	3	6
3	3	4	4	14	1	3	3	1
4	1	15	16	16	2	1	2	2
5	1	4	12	16	3		4	3
6	1	9	8	31	1		3	6
7	0	6	15	11	0		2	6
8	6	4	20	6	0		2	4
9	6	5	1	25	0		0	
10	0	2	30	10	0		0	
11	2	2	9	14	0		2	
12	1		2	3	0		1	
13	0		12	14	0		0	
14	0		12	10	0		0	
15	0		5	14	0		0	
16	0		9	12	0		0	
17	0		9	5	0		0	
18	0		0	9	0		0	
19	0		0	4	0		0	
20	0		0	0	0		0	
21	0		0	1	0		0	
22	0		0	0	0		0	
23	0		0	0	0		0	
24	0		0	1	0		0	
25	0		0	1	0		0	

	Waited – CYP discussed/formulation in next MAAT	Will wait – if referred into specialist ASD assessment today
Stockton Under 5	Longest wait is 17 months	If referred today will be 47 months
Hartlepool Under 5	Longest wait is 12 months	If referred today will be 11 months
Redcar Under 5	Longest wait is 12 months	If referred today will wait 9 months
Middlesbrough Under 5	Longest wait is 6 months	If referred today will wait 6 months
Stockton Over 5	Longest wait is 19 months	If referred today will be 44 months
Hartlepool Over 5	Longest wait is 11 months	If referred today will be 15 months
Redcar Over 5	Longest wait is 8 months	If referred today will wait 8 months
Middlesbrough Over 5	Longest wait is 4 months	If referred today will wait 6 months

Median number of weeks reported were 16 weeks

South East reported highest median weeks: 27

West Midlands reported the lowest median weeks: 9



Appendix 3: High level pathway from 3P event

