

AGENDA ITEM

REPORT TO HEALTH AND WELLBEING BOARD

28 MARCH 2018

AUTISM SPECTRUM DISORDER PATHWAY

1. Purpose of the report

- 1.1 This report is to provide the Health & Wellbeing Board with an update as to the progress of the work outlined in a paper to the Board from October 2017 on the development of the Autistic Spectrum Disorder Pathway.

2. Background

- 2.1 The report from October focused on the vision for the new pathway following a multi-agency development week together with short term and medium term steps.
- 2.2 Since October, the ASD Reference Group has met twice and it is apparent that there is a need to separate the 2 main areas of work to enable the new model to move forward.
- 2.3 Meetings to progress the model have been, understandably, overshadowed by the need to improve the waiting list position, especially in Stockton.
- 2.4 It has therefore been determined that the CCG will work with partners to address the issue of the waiting list, whilst the Reference Group will meet to refine the model designed through the 3P.

3 Refining the 3P Model

- 3.1 In a meeting on the 25th January 2018, the 3P model was reviewed by the Reference Group and determined that it was still a model they felt was fit for purpose.
- 3.2 In its current form, there are unanswered questions as to how it will practically work.
- 3.3 A meeting to begin to work through the model in stages has been set for the 28th February 2018.
- 3.4 The new model focuses on the need of the individual child and their family, enabling support to be available to meet needs whilst or instead of pursuing a diagnosis.
- 3.5 Work has begun in Stockton to map out the current services available to meet the key needs of children with communication and interaction difficulties. The CCG attended this meeting with a number of other key agencies.
- 3.6 This work overlaps into the 'Waiting List' area of work, as we need to ensure that families and their children can access support whilst we reduce the waiting times.

4. Waiting List

- 4.1 In January 2018, the majority of children on the pathway aged under 5 received a diagnosis within 20 months, for the over 5's this wait stood at 21 months. Within both age groups there are a number of outliers; under 5's there is 1 who has waited 21 months, and for the over 5's there is one at 23, 25, 26 and 27 months.
- 4.2 None of these timescales are acceptable and as you will be aware the wait times are longer than the rest of the Tees teams. Stockton, as you are also aware, makes the highest number of referrals for suspected ASD than any other area, making the referrals close to prevalence levels. Due to these wait times, we continue to meet with Stockton Borough Council outside of the Reference Group meeting.
- 4.3 Since October, we have spent a lot of time with TEWV to understand the pathway in to the diagnostic pathway through core CAMHS, spoken with the ASD Co-ordinators in both Hartlepool and Stockton to understand how the pathways differ, looked through the chronological paperwork and met with the Therapies teams (OT and SALT) at North Tees & Hartlepool Foundation Trust.
- 4.4 The key issues which are being worked on are; 1) the ASD Co-ordinators are not carrying out their role as defined, as they are constantly chasing information and dealing with phone calls from parents and schools 2) the capacity of the MAAT's to diagnose an individual is not sufficient 3) the time it takes to be assessed through core CAMHS and access the specialist SALT worker are too long.

5. How we are looking to address these issues

- 5.1 TEWV have been tasked with a number of initial actions: 1) to increase the efficiency of the MAAT process e.g. the use of technology to enable the meetings to be held remotely and at more regular intervals 2) build in quality assurance processes to ensure that no cases are being passed to the ASD Co-ordinators without all the required information being present and in the correct format 3) looking at whether specific cohorts could be fast tracked if there is existing assessments in place such as those with an EHC plan.
- 5.2 We are looking at the provision of support available to both children and families whilst they are on the waiting list. Again we are working with TEWV to understand the frequency and availability of the courses and training programmes they run and to determine if these can be increased.
- 5.3 We have secured funding from NHS England, to enable us to roll out Early Bird training to allow more families to access this support and it would be our preference that this could be accessed by families waiting for a diagnosis as well as those who receive one.
- 5.4 We have provided Stockton Borough Council with a breakdown of the services with which the children on the waiting list are involved. Quite surprisingly there are lower numbers on both the over and under 5 waiting lists who are known to a local authority service than are not. The numbers of children with SEN or an EHCP were surprisingly low and we therefore feel more work needs to be done to understand this.

6. Moving forward

- 6.1 We are meeting with the Paediatricians at North Tees to look at their pathway, as although it is co-ordinated by TEWV, the Paediatricians are the key refers for the under 5's.
- 6.2 We would like to explore with the SEN team in Stockton whether there are any opportunities within their contract with Future Steps to help support the sensory needs of children on the waiting list.
- 6.3 We are compiling a questionnaire to go out across Hartlepool & Stockton into schools, to understand their processes once they receive notification from TEWV that a referral for ASD has been received. This will be done in consultation with both education teams and we hope for support in circulating the questionnaire.
- 6.4 We want to explore the pathway to Stockton's Early Help offer to ensure that TEWV are consistent with the referrals they make to ensure that all families who could access additional support are doing so, without overwhelming the Early help service. This is the same for Hartlepool.
- 6.5 We have worked with the Stockton Parent Carer Forum to develop a Survey Monkey to ask parents/carers about support offered along the diagnostic pathway, what worked well and what was missing. The parent carer forum have agreed to circulate this for us and will be sent out imminently.
- 6.6 The majority of the actions which we are proposing to do, will feed into the new model, as the new model is about meeting need and the investigations into various other services to see if we can support families on the waiting list is pre-empting the changes which are required for the new model.

7. Learning from other areas

- 7.1 We have already set out some of the areas which we would like to jointly explore with the Local Authority and in areas where the waits are not as extensive, such as Northumberland, the Local Authority has complementary services which support families through the process.
- 7.3 In Devon, referrals cannot be made into the diagnostic pathway, until initial assessments from educational psychology and paediatrics have been completed and the parents have answered questionnaires as to how their child behaves in the home. The onus is on the parents to provide this information and it is closely monitored to ensure that the 'co-ordinator' role is specifically co-ordinating onward referrals and supporting the family through the pathway. We would like to explore this with the Local Authority to understand if education teams and schools can support meeting needs and provide the relevant evidence to support a diagnosis.
- 7.4 Discussions with TEWV will be held to look to introduce a more defined referral route in an attempt to stem the flow whilst the waiting list is addressed. Initial discussions with Stockton Parent Carer Forum lead us to believe that there would not be too much resistance to this by parents, as they often have a lot of reports and assessments which they would readily share. However, we will do further consultation on this proposal.

8. Recommendations

8.1 The Board is asked to:

- Acknowledge the report and the complexities of the work
- Support the decision to separate the work into the 2 workstreams
- Support the future actions outlined in the report

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