

AGENDA ITEM

**REPORT TO HEALTH AND
WELLBEING BOARD**

26 JUNE 2019

**JOINT REPORT OF CCG,
TEWV AND SBC**

AUTISTIC DISORDER PATHWAY UPDATE

SUMMARY

This report is to provide the Health & Wellbeing Board with an update as to the work being undertaken:

- to address the number of children and young people waiting for a clinical assessment for autism
- To progress the development of a new needs led neurodevelopmental pathway.

DETAIL

Background

1. The CCG's last presentation to the Health & Wellbeing Board on Autism was in June 2018. At that time we provided an update to inform the Board of the CCG's and Stockton Borough Council's investment into both Tees, Esk & Wear Valley (TEWV) and North Tees & Hartlepool Foundation Trust (NTHFT) to enable a 12 month waiting list initiative to be undertaken.
2. We also advised the Board of the collective intention between the CCG and Stockton on Tees Borough Council to move to a need led Neurodevelopmental Pathway based on the model in St Helen's. This model would be mobilised during the 12 month waiting list
3. This paper is to update the Board as to the progress of this work

Actions to date - Waiting list

4. All children who had joined the waiting list prior to May 2018 were to be part of the waiting list initiative. In total this equated 517 children across Hartlepool & Stockton, 297 were over 5 and 220 were under 5.
5. Paediatricians are the lead clinicians for the under 5's and TEWV clinicians lead on the over 5's. Both pathways are co-ordinated by TEWV.
6. There was a slippage in time lines for the start of the waiting list initiative due to recruitment difficulties.

7. The over 5's work commenced in November 2018, with the under 5's starting later in February 2019.
8. Work was undertaken with Stockton Parent Carer Forum, CCG and TEWV to review existing letters and create new ones. The purpose of this was to make the letters less clinical and to ensure parents knew they could access a general Autism awareness course through Daisy Chain, support and advice from the Parent Carer Forum and access resources through the Local Offer.
9. Part of the work undertaken by TEWV was to review their internal systems and streamline and refine processes to make best use of resources for this initiative and going forward into a new model. This would look to improve the experience for the family through better communications, signposting to resources and shorter waiting times.
10. To provide clarity, the waiting list initiative has purely focused on the diagnostic element of the pathway. As a further explanation, to be assessed for autism, a child has to undergo a number of assessments carried out by various clinicians. These clinicians all then come together in a Multi-Agency Assessment Team or a MAAT, discuss the outcomes of the assessments and make a collective determination as to whether the child should receive a diagnosis of Autism.
11. As of June 2019 the following number of children have received an Autism assessment:

Pathway	Waiting initiative start date	Number of CYP in initiative	Number assessment to date	Outstanding
Over 5's	November 2018	297	164	133
Under 5's	February 2019	220	71	149

12. Trajectory's indicate that the required number of children within the waiting list initiative will have received an assessment within the 12 month window. The effectiveness of changes to the MAAT process has had a significant effect on the predicted waiting times for referrals received since May 2018 with revised MAAT dates being set for approx.. 17 month earlier than initially set for. These predictions are given with a degree of caution as to sustain these time scales we have to ensure there is the correct level of staffing retained within the assessment team once the waiting list initiative resources come to an end. The CCG are currently working with TEWV and NTHFT to determine the required composition of the diagnostic team and the frequency of MAAT's which would enable the current timescales to be sustained.
13. From May 2018, Children have continued to join the waiting list. Although their predicted MAAT date has moved forward, these families have received correspondence to make them aware of the services which they can access for support. They have been offered the same services as the families whose child is part of the waiting list initiative; awareness raising

courses through Daisy Chain signposting to the Local Offer and to the Stockton Parent Carer Forum for peer support and advice.

14. More recently the names have been shared into the Local Authority for them to determine if they are already known to any support services such as Early Help and SEN. This will enable the local authority to start to triangulate information between health, social care and education which will create the mechanisms to build a joint approach to support.
15. Writing to all families on the waiting list, both pre and post May 2018, to advise them of the support available has been done to start to build the change in culture which is needed and described throughout this report. This change encourages families to access support which will support them to meet their needs of their child.

Actions to date - Development of the Future Model

16. As highlighted in our previous paper, we are keen to learn from other areas, especially those who have been highlighted as best practice through their SEND inspections. We therefore presented the St Helen's model to the ASD Steering Group and it was well received.
17. Their model focuses on meeting the needs of the child and their family as soon as a need is identified. This does not prevent the child from accessing the diagnostic pathway but it means that their needs are being met whilst this process is undertaken.
18. We recognise that there is a great belief held by parents that a diagnosis is like a 'golden ticket' and will unlock a whole realm of support for the child. This is not the case and we need to work collectively as a system to dispel this myth and to encourage parents to access support at the earliest opportunity.
19. To oversee the transformation work required, a project group with membership from; Early Help, Public Health, 0-19 service, Education, Stockton Parent Carer Forum, TEWV, NTHFT and the CCG has been formed. This group has met monthly since September 2018.
20. The commitment to changing the way children and their families with neurodevelopmental needs are supported, which has come from this group cannot be under represented. Service leads have looked internally to see how services can be changed, promoted and staff released to receive training to be able to support these families more effectively.
21. Having the Parent Carer rep attend these meetings has enabled us to ensure we keep the focus of having the child at the centre of the decisions we are making.

Joint commissioning to meet needs

22. It was identified through parent consultation and work with schools that there were 3 gaps/issues which needed to be addressed in terms of support:
 - Lack of family support

- Inability to access sensory support
- Inconsistent approach across schools

23. To begin to mobilise to a needs led approach, the CCG worked with Stockton Borough Council to develop 2 service specifications to address these gaps in provision. The services have been built on outcomes and focus on upskilling parents and other professionals to meet the needs children are presenting with. A diagnosis is not required to access these services. The services have been jointly commissioned in ‘pilot’ form as we need to be assured that they meet the needs of families and help support and are an enhanced service, above and beyond what is provided by the local authority or health.

24. The services are:

Family Support Service – Daisy Chain

There are a number of elements to this service; For families - 1:1 support, drop in sessions based in the Children’s Hubs, training programmes for families, siblings and young people. For professionals – training around neurodevelopmental conditions, how to support a CYP with additional needs, practical advice and guidance. For Schools – whole school training on general awareness and more focused courses available as to how to support a CYP with a neurodevelopmental condition. Support is also available for CYP in schools. The service is also providing training and support to the Early Help teams to enable families to be co-worked where appropriate at the earliest opportunity to prevent escalation of need.

25. The Family Support service has been slowly rolled out since February 2019, with momentum and promotion starting to build more recently now that the staff team is in place. The table below is an illustration of the number of interventions given to Stockton families to date:

1:1 consultations	63 parents attended a total of 78 1:1 consultations
Drop in sessions	9 sessions delivered
Training	<ul style="list-style-type: none"> • 10 parents have attended introduction to neurodevelopmental disorders training • 100% reported the training increased their confidence in supporting their child • Currently advertising parent training sessions and so far 30/72 spaces are booked
Other services delivered by the family support team	<ul style="list-style-type: none"> • 180 phone calls taken with advice given <p>Other resources given to families to help manage behaviours and support emotional regulation have been:</p> <ul style="list-style-type: none"> • 21 social stories created • 2 5-point scale resources created • 112 email enquiries answered • 16 visual timetables created for morning routine, sleep and eating

Sunflower Sensory Training Programme – NTHFT

26. This is a 3 session training programme for families to identify and support their child's needs through advice and guidance from trained Occupational Therapists. The service is aimed at families whose child is aged between 4-11. To triangulate the learning, a teaching assistant or other teaching professional is encouraged to attend the sessions along with the family to enable the learning for that child to be taken into the school environment. Through this service, training is made available to schools to make them more aware of the environment and provide general strategies for supporting children with sensory needs.
27. The service commenced in May 2019 and for Stockton, the 3rd group of families are commencing the training programme this week. Referrals have been tightly managed due to it being a finite resource but now that the service has had a bedding in period, the provider is attending the Stockton SENCO forum to provide further detail on the service and to open up the referral route to them. This should increase the take up from Stockton families.
28. Both of the services have been commissioned as 'pilots' to enable us to work collectively with the Parent Carer Forum to ensure that the services meet the needs identified and if they don't, then we are able to flex the service to address the issue. The services will be monitored collectively between CCG, Stockton Borough Council and Parent Carer Forum.

Mobilising the new model

29. Mobilising the new model needs to be done systematically and as a whole system approach. To move to a needs led approach requires true buy in from all partners and the work we have already done through the Stockton project group is paving the way as described in section 4.
30. The vision for the new model can be found at Appendix 1. The group of services which are illustrated within the circle, are what we call, the 'bubble of support'. These are universal and targeted services which exist in Stockton and can provide guidance, training and support to families whose children are displaying needs associated with a neurodevelopmental condition.
31. The identification of need ideally starts with the 0-19 service through their health visitors and statutory checks. Daisy Chain are working with the 0-19 service to upskill their workforce to provide training around identification of need and how to support the family to meet the needs of their child without immediately seeking a diagnosis. This training is also being rolled out to Early Help, social work and other front line teams. This will ensure Stockton has a more informed workforce who can offer support and guidance to families.
32. Whilst work is ongoing to upskill the workforce, the CCG, reps from Stockton Borough Council, Daisy Chain, NTHFT and TEWV have attended SENCO and Head teachers forums within the last month to make schools aware of the new needs led pathway and to promote the Daisy Chain Family support service and the Sunflower Service. We have asked schools to

start signposting families to the services when they have their early and sometimes tentative discussions with families as and when they identify that the child had additional needs. This will help to support the change in culture which is required whereby families access the support available to help meet their child's need rather than pursuing a diagnosis straight away.

33. For schools, Daisy Chain are in the process of arranging training dates for generic training to be rolled out across all Stockton schools which will ensure there is a base line of knowledge in each education establishment to be built upon.
34. The co-ordination of the diagnostic element of the pathway has been reviewed and it has been determined that the route into the pathway should not sit in core CAMHS as a neurodevelopmental issue is not necessarily a mental health need. Therefore the CCG are in the process of working with TEWV as to how the co-ordination team can be removed and sit as a standalone team.
35. With this change, we have worked collectively to determine how referrals will be received. Learning from St Helen's we are looking to remove self or parent referrals.
36. Aware that this might cause unease from parents we have discussed the proposal with the Stockton Parent Carer Forum and will build and deliver a communication plan to ensure all concerns from parents are addressed. Referrals will come from a professional who has knowledge of that child. For the Under 5's this will remain with the Paediatricians and Speech & Language service and therefore the parents will see no change. For the Over 5's who traditionally entered the pathway following a CAMHS assessment, they will access the service predominately, but not exclusively, via a referral from their school SENCO.
37. We have met with several of the Stockton SENCO's to consult on this proposal and to gather their views on the proposed referral form and all feedback received was positive. We have 5 SENCO's who have agreed to pilot the referral form for us during the remainder of this school term.
38. Alternative referral routes to the over 5 pathway will be: CAMHS, Daisy Chain, 0-19 service, GP's and any other professional who has knowledge of the child. The parents view, that of the professional and of the child are captured within the referral form. Consent is received at this point to enable referrals to be made to support services to ensure the needs of the child are met.
39. Discussions are being held with the paediatricians to review their paperwork and processes. They are also aware of the new services available and will be signposting children and their parents to access the support available within Stockton ensuring need is met at the earliest opportunity while the medical assessments are undertaken. Resources written by the NTHFT paediatricians will be made available on the local offer as part of a website review over the summer.

40. The referrals received on the new referral form will be screened by a triage panel. This will be piloted in line with the pilot of the form. This triage panel will be made up of professionals from TEWV, Speech & Language and from the local authority. Their role will be to review the information which has been received and determine what further assessment and/or support the child and their family needs. It will enable the connectivity to occur between health, social care and education to remove doubt and duplication.
41. There is a considerable amount of work already undertaken and ongoing to mobilise the Neurodevelopmental Pathway. The volume of joint meetings and presentations has enabled us to begin to move as a system to better support the needs of children and their families. What has been achieved to date is testament to partnership working and trusting relationships. We acknowledge that communicating the changes to the pathway to parents and getting them to think differently will take a whole system consistent approach..

Next steps

- 42 The review of the pilot processes will be undertaken through the summer period. This review will be carried out by CCG, Stockton Borough Council and Parent carer representatives with feedback from schools.
43. During this time, the discussions will continue as to the makeup and location of the Neurodevelopmental Co-ordination team.
44. During the summer period a communication plan will be developed to mitigate concerns from parents and/or professionals as to the new process.

Recommendations

The Board is asked to:

- Acknowledge the report and the complexities of the work
- Support the future actions outlined in the report
- Note the partnership working

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