

Report to: Leeds City Council Scrutiny Board

Date of meeting: 28th March 2017

Report title: Child and Adolescent Mental Health Services – Autism Waits - Briefing Paper

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1 Introduction

Leeds Community Healthcare NHS Trust (LCH) is the provider of tier-3 Child and Adolescent Mental Health Services (CAMHS) in Leeds.

In early 2015 the CAMHS service faced a number of pressures which included a rise in demand for services, a national requirement to make efficiencies and a shortage of specialist staff. As a result, waiting times for non-urgent elements of the service increased.

A systematic review of capacity and demand in CAMHS has dramatically improved access for routine assessment (12 weeks or less) and urgent and emergency cases are prioritised and seen quickly. However, a particular concern has been the long waiting times to access a diagnostic assessment for autism, and a recovery plan was presented to the Scrutiny Board in March 2016. The initial forecast was to reduce waits for autism assessment to 12 weeks by the end of December 2016. Thea Stein, Chief Executive attended Scrutiny Board in July 2016 and explained that the forecast had been adjusted and confirmed the 12 week target could be achieved by 31st March 2017.

This paper provides an update on the progress to reduce waiting times, an explanation of the challenges faced and a revised forecast for achievement of a maximum waiting time of 12 weeks.

2 Background

2.1 A detailed description of the Child and Adolescent Mental Health Services (CAMHS) was provided to the Scrutiny Board in January 2016.

2.2 The specialist mental health element of the service has an annual budget of £5.4m and a staffing complement of 101.25 WTE. The workforce is multi-professional and includes clinical psychologists, nurses, psychiatrists, creative therapists, psychotherapists, family therapists, mental health practitioners (from a range of professional backgrounds including occupational therapy, social work), administration and clerical staff, team and service managers.

3 Access to CAMHS in Leeds

3.1 CAMHS responds quickly to the children and young people who present with the highest risk and most urgent need. All emergency and urgent referrals are

prioritised by clinicians and seen rapidly (e.g. within 4 hours for self-harm presentations in A&E, and between 1-5 days for urgent referrals).

- 3.2 Young people wait 12 weeks or less for a routine assessment. The national average in 2015-16 was 32 weeks.
- 3.3 The Local Transformation Plan for the city in respect of young people and their emotional and mental health has seen an investment in a specialist eating disorder service and the development of a single point of access for referrers (MindMate SPA) which is also set to expand and develop further.

4 Support for children and young people waiting for diagnostic assessment

4.1 An autism assessment is undertaken by a specialist multi-disciplinary team including Child Psychiatrist/Paediatrician, Speech and Language Therapist, a CAMHS practitioner and Clinical Psychologist. The assessment includes a detailed parental interview, assessment of the child or young person, a school observation followed by a further assessment by the team in a clinic setting. Demand for assessment has risen significantly (+35%) between March 2016 and February 2017. All the assessments are provided by Leeds CAMHS, in a variety of settings within the city.

4.2 It is important to recognise that the professional support available in school and healthcare settings for children with Special Educational Needs is not dependent on a formal diagnosis. The system that determines the support required is separate from any diagnostic testing and is based on an assessment of needs, individually tailored to each child. A shared Education, Health and Care Plan (EHC) will specify the treatment and support to be provided and this is regularly reviewed. Schools in Leeds are helped to support students with autism by a training programme offered by STARS (Specialist Training in Autism and Raising Standards). A description of the training programme offered to schools is here: <http://www.starsteam.org.uk/our-service>. It is also commonplace for children and young people waiting for a diagnosis to receive treatment and support in CAMHS. There is no autism specific "treatment" as such, so the therapy and help provided is based on the individual and their presenting difficulties.

5. The value of diagnosis

5.1 A confirmed diagnosis of autism will not necessarily alter an existing plan of care and support. Neither will diagnosis affect decisions about DLA support or other benefits. It does though provide an important opportunity to discuss long term implications and issues, and it can build on the capacity of the family and school to see and relate to the young person's difficulties in an effective way.

5.2 When a diagnosis is confirmed, parents can be referred to the Cygnet Group which offers a programme of education and support about autism. A link to the promotional information is here: <http://www.starsteam.org.uk/media/new-information-parents.pdf>.

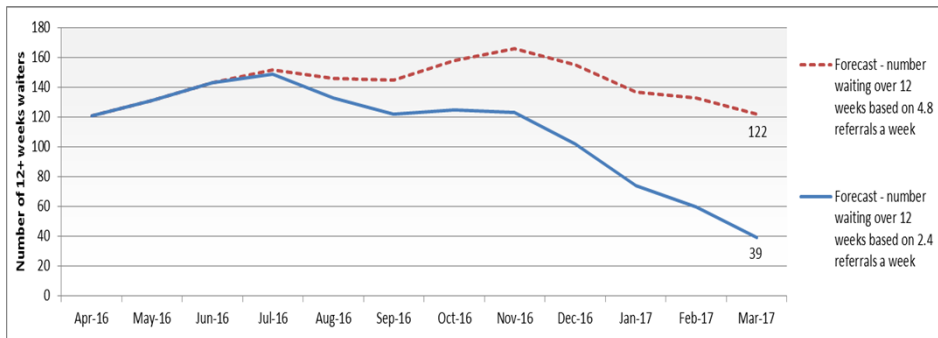
5.3 STARS also offer support to parents at a "drop-in" session <http://www.starsteam.org.uk/drop-in-advice-session-at-the-central-library>.

6. Current waiting times for diagnosis

6.1 The demand for assessment has changed significantly. There has been a 35.4% increase in referral rate between March 2016 and February 2017. The increase in referral is welcomed by the LA and CCGs as this increase better correlates with expected referral rates (incidence) expected for a population the size of Leeds. Partners have been concerned at under-identification of autism in the city.

Increased referral for assessment demonstrates better identification of children and young people with autism. However, this increase has impacted significantly on resource available to diagnose children and young people.

- 6.2 This increase in demand coupled with a limited access to the pool of specialist assessors has combined to slow down the expected rate of progress on the 12 week waiting target. The CAMHS service continually juggles priorities, and cannot safely stop responding to a wide range of needs to focus solely on one specific area of need. The specialist assessors in the service combine this work with other clinical responsibilities and it is not possible to relieve them of these other duties to work on autism assessment alone.
- 6.3 From CAMHS clinical staffing resource of 69.49 whole time equivalents (WTE), 13WTEe CAMHS staff are specialists in autism diagnosis. The service is developing a clinical competence framework around autism to facilitate development of additional clinical skill in autism.
- 6.4 NHS England monies were secured by South and East commissioners in late October 2016 to support increased capacity into CAMHS autism assessments. This funding was used to deliver an additional 49 assessment clinics between January and March. These additional clinics were delivered outside of normal working hours – primarily on Saturdays and also weekly evening clinics. This improved access for parents and young people is being audited by CAMHS to see if this is a model the service should pursue going forwards (in addition to access to other CAMHS services such as interventions). This approach would fit well with the Local Transformation Plan.
- 6.5 We have been able to offer these additional clinics because some colleagues in CAMHS have offered to work additional hours. This is not currently a sustainable position. We are actively looking to bring in additional locum staff to address the backlog but here too, there is a limited supply locally. We have so far ruled out using the funding to pay for assessments out of the Leeds area.
- 6.6 The total number of young people waiting for assessment has reduced from a peak of 233 to 193. Of the 193 waiting, 147 have waited more than 12 weeks. The average length of wait is currently 24.4 weeks. The longest wait is around 45 weeks
- 6.7 However two young people have waited more than 52 weeks; in both of these cases parents have declined earlier appointments offered by CAMHS and expressed a preference for an alternative time and therefore agreed to wait longer than necessary.
- 6.8 If the rate of referral remains at its current level, and the amount of clinic time dedicated to assessment remains the same, the earliest that the 12 week target can be achieved is by December 2017. We are now beginning to see some steady progress but given the possible fluctuations in both demand and clinical capacity, a more realistic target is between January and March 2018. This will not mean that families are left unsupported (see 4.2 above) while they wait for diagnosis, but it does enable the service to continue to see other young people with significant other needs, and is realistic about the supply of specialist clinicians needed for the work.
- 6.9 It is worth noting that if the referral rate had remained constant at 2.4 referrals per week since the start of the initiative to improve access to Autism diagnosis, there would now be less than forty children waiting over 12 weeks



7. Next Steps

As previously stated the 12-week target is likely to be achieved by December 2017 (subject to current assumptions). The service continues to address the shortfall in capacity and the following actions are in train:

- Weekly monitoring of performance
- Careful management of capacity within the service
- Consideration of stopping other elements of the service to focus on this pathway
- Optimisation of time available from existing clinicians as part of a waiting list initiative
- Exploration of capacity available in the wider private market within Leeds