

CYP Transforming Care: Autism Support

Proposal Paper (0.3)

August 2023

Executive Summary

The Learning Disability and Autism (LD/A) Health Equalities (HE) Team have received non-recurrent funding from NHS England (NHSE) for deployment against Autism Diagnostic Pathway Support and Autism in Schools, to the value of £60k and £70k respectively.

The LD/A HE Team are proposing to pool funds and offer additionality to the value of £50k, bringing the total financial envelope to £180k to deliver:

1. Expedited autism assessments for children and young people (CYP) who are known to SET CAMHS and who are at risk of educational placement breakdown.
2. Targeted support in schools for CYP who receive an autism diagnosis via employment of 3 FTE “Autism in Schools” Targeted Support Practitioners (i.e. post-diagnostic support)

Background Information

Across Southend, Essex and Thurrock (SET) Transforming Care Partnership (TCP) footprint, there has been a year-on-year increase in autistic CYP being admitted to a Tier 4 Mental Health hospital without a Learning Disability, and a year-on-year increase in the number of CYP receiving a post-admission diagnosis of autism (2022/23 = 24.6% regionally, increasing to 20% so far in 2023/24). Anecdotally, we now understand a correlation with admission and difficulties earlier within a CYP’s journey – namely disengagement and non-attendance at an educational provision – informed or compounded by a lack of (or misunderstood) diagnosis of autism.

Across the same footprint, Education Access Teams have seen a 44% increase in medical referrals in the 22/23 academic year; across all referrals, 25% of these are young people who have been diagnosed with ASD – this increases to 47% if extended to those waiting for an assessment. Medical referrals are defined as mental health or Emotionally Based School Absence (ESBA); the former is if the difficulty with engagement is pervasive, and the latter if attendance and engagement relates solely to the school setting.

In primary settings, 42% of referrals were for mental health. This jumps to 63% in secondary settings. Furthermore, a request for support from EAT spikes between KS2 and 3 (from 11%-40%), and again at KS4 (from 40%-46%) showing a developing trend of increasing difficulties for those experiencing transition which peaks in Year 10 (EAT Comparative Data, 2022/23).

Latterly, intentions to permanently exclude pupils with a primary SEND need (categorised by having an EHCP in place or receiving school support) reached 75% in primary provision and 27% in secondary provision. Trends locally in the Complex Case Forum show that requests for high-cost packages (often out of county) are for our autistic CYP.

Local Drivers and Data

“Over the last 5 years the number of children diagnosed with autism has increased by 10%” (Essex All Age Autism Strategy, 2022).

Across the TCP, there are 5 different assessment and treatment pathways. This means 5 different referral routes, 5 different providers, 5 different wait times, 5 different assessment pathways, and 5 different processes for continuity of care.

Current data sets for 2022/23* indicate that CYP are waiting up to 2 ½ years for a diagnostic assessment across Essex with a steady increase in referrals observed. As of March 2023, there are nearing 4,000 CYP waiting for an assessment. * Essex Data Only

The Essex Alliance (representing the 3 Parent/Carer Forums across the TCP) developed Advice, Support and Guidance for ASD/ADHD Pathways, based on Essex Outcomes and Effectiveness Measures (with the intention that learning be shared across the TCP). 85 families participated in the survey, with 84 of those families reporting that they would like information and support whilst on a diagnostic waiting list, as well as a more developed post-diagnostic support offer. A number of families shared concerns about the length of waiting times and lack of patient choice.

Voices of Children and Young People

During coproduction of the service specifications for the Keyworker Service and the first iteration of the Autism Outreach Service, feedback from CYP via the Multi-School's Council told us that:

- They have to wait too long for their appointments; timely assessments when the need is identified would be beneficial (high wait lists increase anxiety/acute of symptoms)
- Appointments are often inaccessible (environmentally/geographically)
- Healthcare staff often do not understand them, their needs, or dismiss them in their own appointments (prioritising conversation with parents)
- Their lack of understanding/psychoeducation about their own condition can lead to poor health outcomes
- Better linkage across health and education sectors would support reasonable adjustments and expectations around needs associated with neurodiversity
- Pressure to attend [a number of] appointments can be overwhelming and promote disengagement
- Diagnostic Pathway Support, post-diagnostic support and onward specialist interventions are all lacking/unclear; requires a needs-led/stage-led approach rather than being age-led

The Multi-Schools Council also produced a paper (2022) which speaks to the experience of CYP who struggle with school attendance. The findings from this report will be used to inform the Job Description and Person Specification of the "Autism in School" Targeted Support Practitioners, and the outcomes, outputs and inputs for the pathway as a whole.

National Context/Papers

The National Framework for Autism Assessment Pathways (NHSE, 2023) recognises that delayed diagnosis can lead to hospital admission or poorer health outcomes for CYP. There is a requirement for better management of assessment outcomes and experience for individuals and their families, regardless of diagnosis; an increase in packages of support available for those who have journeyed through the assessment pathways; maximisation of resource spent on well-evidenced interventions and a need for areas to develop pathways for expedited assessments.

NICE Guidance (2021) for Local Pathways require areas to establish a multiagency autism strategy group, and an autism team whose responsibility it is to triage referrals, conduct assessments and manage outcomes, supported by a single point of access.

The Department for Education SEND Action Plan (February 2023) cites new national standards which are to include a focus on early identification of needs and intervention, with clear expectations for the types of support that should be ordinarily available in mainstream settings. There should also be provision of greater clarity to parents about timely and accurate identification of needs, and support for CYP to be able to access and regularly attend the most appropriate early years setting for their needs.

Target Cohort

This pathway proposal intends to target CYP who are on the edge of (or at risk of) an educational placement breakdown due to their autism (or lack of diagnosis) who require earlier identification of need and targeted support within that provision to meet the need.

For expedited diagnostic assessments, CYP eligible will be those in Years 6-8 with an educational risk of placement breakdown, where a referral to CAMHS is in progress or has been accepted and the CYP is already on a diagnostic pathway for ASD assessment. It is anticipated that identification of CYP within scope will be a manual process based on agreed criteria (to be developed) and supported by a Standard Operating Procedure; it is an intention to develop workstreams to inherit and oversee such requirements once the principles of this proposal are met with endorsement.

Future considerations include how educational colleagues identify need/pressure within their system, in order to establish risk and eligibility for inclusion in the pilot (i.e. CYP with late attendance/part time timetables/request made for a change of placement, etc.).

Positioning this resource in a more considered and upstream way will allow us to deliver additionality within existing diagnostic pathways to mitigate risks associated with the transitions from primary to secondary provision and maintain a focus of need on the CYP's autism.

The target cohort for the "Autism in School" Targeted Support Practitioners will remain the same (years 6-8 and known to SET CAMHS) but will be positioned as a post-diagnostic offer for those in receipt of a positive diagnosis. A third of this provision will be ring-fenced to meet the needs of those moving through the ADP pilot arm of this pathway (approximately 33 CYP) with two thirds of the resource remaining available for eligible CYP who will be identified by their schools via the Annual Review process. It is anticipated that the onward pathway for access to the offer will be via QRAP and presentation of the case by Send Operations.

Proposed Pathway of Identification/Access (Tentative)

- Autism Diagnostic Pathway
 - Education to identify CYP at risk of educational placement breakdown or where a request for an alternative provision has already been raised
 - Manual cross-referencing of identified cohort with CAMHS Locality Hubs to identify if and where the CYP exists on the CAMHS pathway (scope requires a referral to have been made and in progress – either accepted and waiting, or where the CYP is in treatment)
 - Further cross-referencing with Paediatric sector colleagues in relevant locality to identify if/where the CYP exists on the NDD pathway and awaiting ASD diagnostic assessment
 - CYP collated into a caseload across SET TCP; direct approach made to CYP/families based on MH need and risk of educational provision breakdown, and shared with provider

- “Autism in Schools” Targeted Support Practitioner
 - CYP identified by school via the Annual Review Process (i.e. change of provision/increase in funding to support existing provision, etc) where positive diagnosis of Autism is confirmed
 - Presented to QRAP via SEND Ops, and includes:
 - Nature of request
 - Length/Type of support/involvement required from the practitioners.
 - Review points – considered and agreed at the outset of the offer

Delivery

The additionality within the Autism Diagnostics Pathway Support will deliver approximately 33 assessments for CYP across the SET TCP footprint. An agreement in principle exists with PROVIDE Wellbeing who are an established provider with a track record of clearing long-standing waiting lists for ICBs across the region.

PROVIDE Wellbeing will offer a Standard Offer. This includes a pre-assessment triage/screening process and (typically) a 1 ½ – 2-hour assessment process in a clinic. It is anticipated that this will be scheduled delivery, with assessment time protected in advance and a pre-identified cohort “booked” into the available slots.

To support an expedited pathway, PROVIDE Wellbeing are able to offer assessment within a 2–3-week lead time, via a scheduled clinic arrangement. Venues include a number in Chelmsford, 1 in Colchester, 1 in Southend and with access to other paediatric units as required.

Autism in School’s funding will deliver resource for employment of 3x FTE Targeted Support Practitioners across SET TCP; 2 posts will be resource for CYP already diagnosed with autism, with the additional post ringfenced for support of the ADP Pilot cohort (additional 33 cases). It is envisaged that the caseload will be delegated evenly, with split coverage across the TCP based on capacity, need of the CYP being referred and location of the worker.

The role will deliver on site direct support to the CYP, their school team and the family (bridging the gap between home and school to ensure consistency in approach and support across settings) which will be targeted, bespoke and autism focused.

Practitioners will provide an intensive support offer to CYP and their network to:

- Support home and school to work together
- Work with the CYP to uncover issues and resolve them (amplify reasonable adjustments)
- Walk through the day of the life of the child, with a focus on environment
- Support schools with adopting and embedding evidence-based interventions (e.g. Progression Framework)

Access is anticipated to be via Quadrant Resource Allocation Panel (QRAP) once Inclusion Partners and Educational Facilitators have been exhausted. CYP will be identified by SEND Ops when there is risk of educational placement breakdown (including exclusion), an open referral to SET CAMHS and when the CYP has received a diagnosis of autism.

It is anticipated that Targeted Practitioners will hold/deliver:

- Autism specificity

- 1:1 support
- Targeted interventions over a period of time
- Working across home and school settings to embed approaches and improve consistency.
- SI knowledge/experience
- Ability to bring adaptations in for the child for a realistic/pragmatic way.

Existing Offer and Differentiation

In recognition of existing offers available within the educational sector, further detail is provided on scope below:

- Inclusion Partners – Support for schools to identify needs and enable schools to meet this need. May include delivery of Autism in Schools Training but would be school wide. Offer does not include targeted or individualised support, or bespoke/specialist intervention. Not autism-specific
 - Engagement Facilitators – Deployed to support a relationship breakdown between a family and the school setting, at the request of an Inclusion Partner. Not autism-specific, nor targeted/specialist work around a named area of need.
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- “Autism in School” Targeted Support Practitioner - Will deliver targeted, bespoke provision for specialist advice and support, after being discussed at QRAP. Support will be delivered on an individual basis with the CYP, their school support and the home setting for autism-related needs, bridging the gap between home and school to ensure consistency.

Funding

The LD/A HE Team will retain responsibility for the deployment of NHSE funding against Autism Diagnostics and will organise spend via MSE ICB and a Contract Variation with PROVIDE Wellbeing. The CV will allow delivery of approximately 33 additional assessments (at a value of £1,775) during the contract life.

Delivery of “Autism in School” Targeted Support Practitioners will sit with ECC as the hosting authority but deployed across the SET TCP footprint via a Memorandum of Understanding (MoU). Approximate costs per worker are £28,432 (less non-staffing/on-costs); NHSE funding (of £70k) has been bolstered by the LD/A HE Team (via SDF) for an additional £50k, bringing the financial envelope to £110k to deliver 3x FTE workers.

This will allow for financial resource to be deployed directly to a provider to deliver diagnostic additionality, and to workers delivering “boots on the ground” resource for individual targeted support (also bridging the gap between home and school settings).

Impact

We already know that families wish to experience a positive referral into community paediatrics that is clear and accessible, made by the appropriate professional (*ASD ADHD Outcomes and Effectiveness Measures, Essex Family Forum, September, 2022*), and that children and young people wish for schools to be safe, fun and supportive based on established relationships with staff (*Essex Young People: School Attendance 2022*).

Families also wish to have a clearer understanding of their journey, timescales, the information gathering process and the assessment process itself, have access to the right support at the right time and, along with their children and young people, feel listened to (*Family Impact Survey, 2023*).

Families have also provided tangible feedback on improvements required within existing pathways, such as an improvement in wait times, improvement in school's awareness of the assessment process, school acceptance and support after diagnosis, and communication and joint working based on engagement between health and education (NDD Survey, 2021) which this proposal will help to deliver.

Specific outcomes, outputs and inputs for this proposal will be authentically coproduced with our key stakeholders including those with lived experience. Essentially, we are aiming to appropriately identify CYP early enough in their journey to ensure their needs are understood and met (by way of reasonable adjustments or otherwise), ensuring they gain access to appropriately tailored support (via Targeted Support Practitioners) in order to sustain their educational placement and remain healthy and well within their local communities.

Next Steps

- To socialise the paper with key stakeholders for comment/endorsement
- To take the paper through SEND/Transforming Care governance routes for comment/endorsement
- To develop and agree key workstreams to support the design and delivery of the pathway
- To agree the Contract Variation for the Diagnostic Pathway and Memorandum of Understanding for Autism in Schools funding

References:

1. NHSE Regional Post-Admission Diagnostic Data Report



3.1 RLDA Board CYP
discussion point_Post

2. Essex and National ASD Wait Times



Diagnostic Waiting
Times Essex and Natic

3. Advice, Support and Guidance (EFF)



Advice and Support
Guidance Feedback. E

4. Essex Outcome and Effectiveness Measures (EFF)



ASD ADHD
Outcomes Measures I

5. School Attendance Report (MSC)



School attendance
report 2022 VERSION

6. National Frameworks and Papers

- a. National Framework for Autism Pathways (2023): <https://www.england.nhs.uk/long-read/a-national-framework-to-deliver-improved-outcomes-in-all-age-autism-assessment-pathways-guidance-for-integrated-care-boards/>
- b. NICE Guidance (2017): <https://www.nice.org.uk/guidance/cg128>
- c. SEND Alternative Provision Improvement Plan (2023): https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1139561/SEND_and_alternative_provision_improvement_plan.pdf

7. NDD Survey (2021), EFF



NDD-Survey-2021-Fi
nal-Version.pdf