NHSE Autism Team

All-age autism assessment pathway – update

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Session Outline

Key topics

1. Current Autism Assessment waiting times crisis
2. Current work of the National Autism Team
3. Current system and service landscape
4. Common regional queries & quandaries (Wicked Problems)
5. Supporting the adoption of evidence-based and best practice across the pathway
6. Example - An Integrated and Evidenced Early Care Pathway for Autism
7. Appendix A - An Integrated and Evidenced Early Care Pathway for Autism

Current waiting times crisis

There has been a 23% increase in all-age referrals for people waiting for an autism assessment between March 2024 and March 2025- Autism Statistics (Mental Health Services Data Set – MHSDS), May 2025 publication.

224,382 people are now waiting, and 137, 977 of these patients are aged 0 – 17 years old (MHSDS).

But the focus of the National Autism Team is not only on waiting times.
It is about quality, equity of access to assessment and post-diagnostic support and addressing transitions.

Current work to address autism assessment pathways

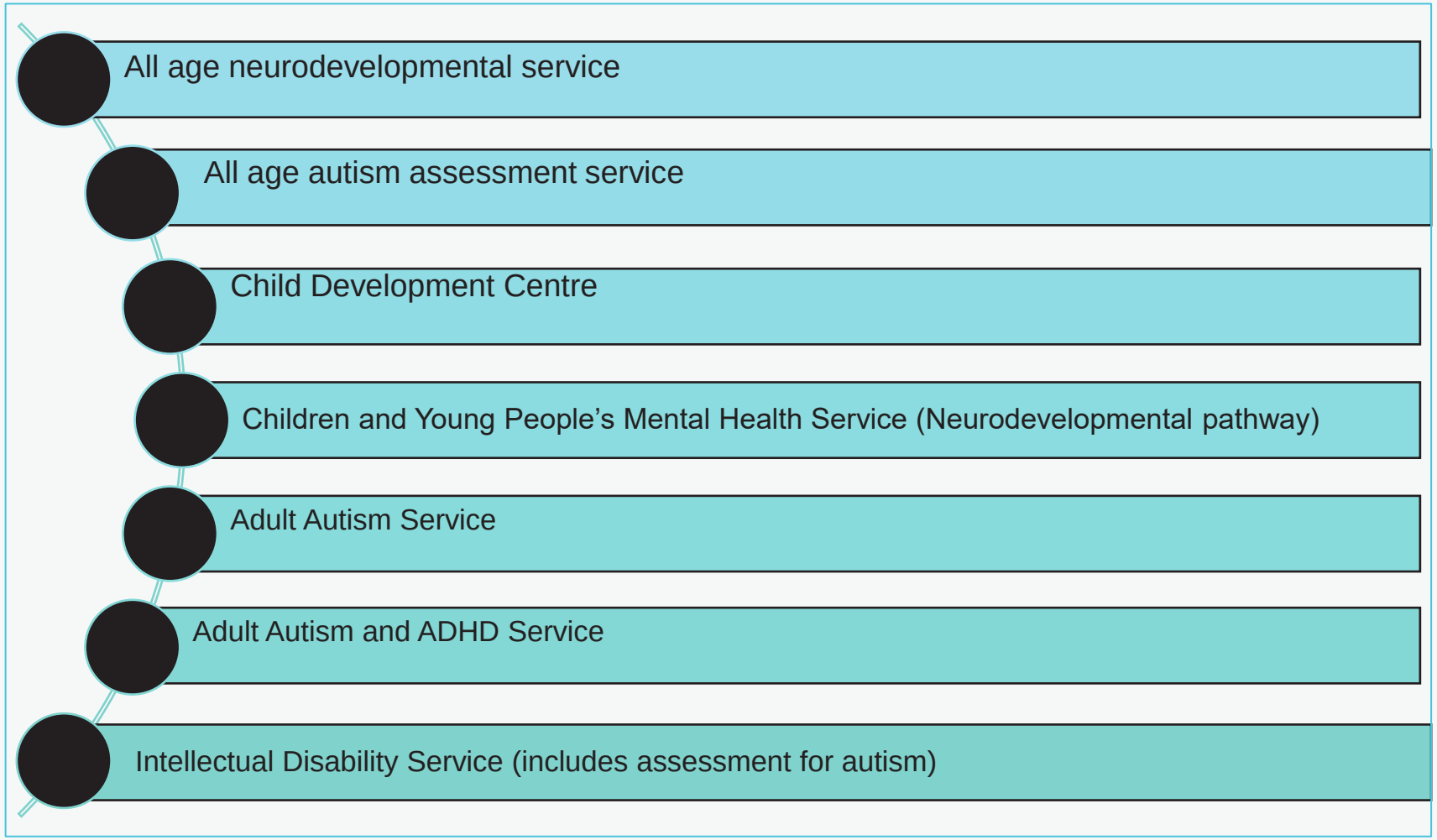
System development and support

Current commitments and ongoing plans						
A national framework to deliver improved outcomes in all-age autism assessment pathways **Operational guidance to deliver improved outcomes in all-age autism assessment pathways**	Capacity building within current system Workforce, Training and Education (NHSE) e.g., RCPsych / Training Consortium Exploring how different staff can become involved in the assessment pathway, including the pre- and post-assessment support Hosting annual webinars to support pathway improvement and innovation	Continuing to support the Autism Practitioner Network – national community of practice Working with the ADHD National Programme around joint areas of interest and possible solutions Providing an accessible version of the autism assessment pathway for adults	Identifying and sharing examples of good practice and tested innovation and research Establishing scalability, e.g., an integrated and evidenced early care pathway for autism Sharing research/innovation with wider systems Supporting systems and services to implement use of appropriate evidence-based tools	Identifying and signalling gaps for research with partner organisations and research-funding bodies Working with DHSC and CQC around regulation of all-age autism assessment services Working with NICE to strategically influence change in guidelines	Supporting and shaping evaluation of new ways of working, e.g., UCL university-based assessment service and training resource Developing and rolling out of practical resources to support ICBs and providers in managing the autism assessment pathway	Working closely with regions via a series of workshops to understand obstacles and opportunities for improved assessment pathways Considering how the MHSDS projections regarding workforce and investment required to meet autism assessment waiting time stands can be practically implemented

All based on current model of assessments predominantly within specialist autism services

Current (typical) routes to assessment

Service models



Some changes on the ground

Regional variation in seeking solutions and opportunities

Commissioners/ providers adopting needs-led approach

May not be well-evidenced and may have unintended consequences on families seeking assessment later or via RtC

Commissioners and Providers seeking to adopt evidence-based pathway for early identification, support and assessment, where indicated

Testing and employing implementation science approach

Joint/integrated model

Commissioners & Providers seeking to adopt integrated model, e.g., ND pathway or Autism and ADHD

System change takes time; not clear how best to conduct multiple assessments efficiently

Hub and Spoke model

Specialist autism team conducts highly specialist assessments, trains, consults to and supports local mental health services in their assessments of patients already under their care

The case for change

System-based intelligence about alternative assessment provision models

Assessments are being conducted within specialist mental health teams:

- Early Intervention for Psychosis Services where there is concern about possible underlying autism
- Eating Disorder Services
- Personality Disorder Services
- Gender Dysphoria Clinic
- Perinatal Mental Health Service
- ADHD
- This **does not mean** all autism referrals would be made to mental health teams – only if already engaged in mental health assessments and intervention
- **Criteria** for referrals to Specialist Autism Teams?

Common regional queries & quandaries (Wicked Problems)

Common regional queries & quandaries (Wicked Problems)

- Managing demand that outstrips capacity
- Managing 2nd opinions & processes around Right to Choose or independent assessments
- Quality/legislation and alignment with NICE
- Models for pre-assessment support and by whom?
- Needs-led models

Regions seeking national steer on:

- External referrals/ transitions between areas/ across ages
- Addressing Right to Choose oversight, quality and impact
- Data quality, standards and completion
- Good enough diagnostic assessment reports

- **What are the quandaries in your region and how have you addressed them?**

Supporting the adoption of evidence-based and best practice across the pathway

Adopting evidence-based best practice (1 of 2)

Model	Description	Impact	Key takeaways
Ambitious about Autism – a peer support programme for autistic young adults aged 16 – 25.	A co-produced 6-week online course called "Understanding You, Discovering You" has been piloted. This is aimed at helping young people understand autism, explore their own experiences, strengths and challenges and learn self-advocacy skills	• The online course has been accessed by approximately 220 autistic young people • Initial findings and feedback very positive • Online tools and resources have also been co-produced and made freely available to young people and healthcare professionals	A feasibility study (randomised control trial) funded by NIHR and led by the University of Bath is due to be completed by end of June 2025
North East London Foundation Trust - an integrated Children's Autism Service	A coordinated and systematic approach to rebuilding and redesigning the CYP pathways	• Early intervention support for children and young people including pre-and post-diagnostic support • Improved timely access with 80% reduction in waiting times • Improved health and wellbeing outcomes for CYP	Integrated autism spectrum service Reduces waiting times

Adopting evidence-based best practice (1 of 2)

Model	Description	Impact	Key takeaways
An integrated and evidenced early care pathway for autism - early identification and support of young children	Evidenced based early years pathway consisting of SACs-R detection tool and iBASIS intervention	• Many of the children were on multiple waiting lists – e.g., SALT and CAPS – working together led to a reduction in duplication and better use of resources • In Manchester, reduced wait time for referral to assessment and reduced numbers on waiting list • If/when child progressed to autism assessment, flexible approach to more or less intensive process, hence managing resources	Evidence based tool and model Reduces waiting times Economic evaluation from clinical trials suggests that this pre-emptive pathway approach will be cost-effective in the medium and longer term
PACT – Paediatric Autism Communication Therapy	Evidence based family-focused intervention to optimise child development and build caregiver skills	• Improves parent/child play & communication, social interaction, repetitive restricted behaviour (after both 13m & 6 yrs) • PACT not cost-effective at 13m but cost-saving at 6 yrs	Compelling economic argument for widespread adoption of PACT – Knapp et al (2024)

Example - An Integrated and Evidenced Early Care Pathway for Autism

Opportunities for wider implementation

Adopting evidence-based practice during the early years

Model	Impact	Key takeaways
An integrated and evidenced early care pathway for autism - **early identification and support** of young children **Evidence-based** early years pathway consisting of SACs-R detection tool and iBASIS targeted intervention Model can be used **flexibly across local situations**	Many of the children were on multiple waiting lists – e.g., SALT and CAPS – working together led to **a reduction in duplication and better use of resources** In Manchester, the **wait time** for referral to assessment decreased from 65.5 weeks to 34.4 weeks; the numbers on the **waiting list** also decreased by 50% If/when child progressed to autism assessment, less intensive assessment needed, **building on information** already gathered over the months of intervention May **reduce the need for other assessments** early on, e.g., SLT.	Uses **evidence-based** tool and model Identifies the developmental differences/needs of **all children,** not just those who are likely to be autistic Supports families **to be involved** in actively managing their child's care, and decisions about assessment pathway **Benefits** persist over time Reduces **waiting times** Opportunity to agree **system-wide change** to benefit all stakeholders **Economic evaluation** from clinical trials suggests that this pre-emptive pathway approach will be **cost-effective in the medium and longer term.**

Considerations

- **Financial** – currently no additional funding, hence repurposing financing and resources
- System **readiness**
- **Operational factors** and **logistics**
- **Implementation of a change programm**e – systematic approach to influence and buy-in
- **Leadership** – Clinical leads / ICB executive SRO
- **Linking to levers** within 10-year plan/national policies
- **Workforce** – optimising workforce across sectors; using new or existing staff; consider backfill capacity for training
- **Training and support** – as offered by Manchester and Stockport teams
- **Level of support** needed to implement change

Offer from Manchester & Stockport colleagues

To provide to a limited number of regions:

- A costed workforce plan blueprint for **pathway implementation**
- A **readiness tracker** to help services assess readiness for implementation
- **Training** of MDT and a **support programme**

Appendix

APPENDIX

APPENDIX A

Supplementary information regarding the pathway

Evidence-based early years pathway

- **Australia**: Early identification tool for infants and toddlers – Social Attention and Communication Surveillance (SACS)
- Identifies infants 11+ months at high likelihood of autism (score of 3+)
- These infants/toddlers would be offered targeted intervention
- **UK& Australia:** iBASIS – evidence-based programme supporting infants and toddlers showing early differences in social interaction and communication development
- Randomised Controlled Trials:

- Babies more interactive and socially engaged
- Parents more connected to children
- Benefits persisted over time
- Not instead of other support and may still require other support or assessment after iBASIS
- Model can be used flexibly across local situations
- SACS-R can be incorporated at standard targeted assessment visits, e.g., 18 months

Characteristics of Early Care Pathway for autism

- **Proactive as opposed to reactive** identification of developmental differences
- Identifies the **developmental needs** of all children, not just those who are autistic
- Provides **well-evidenced** and appropriate and targeted **support**, as early as possible for children and their families, prior to diagnosis
- May **reduce the need for other assessments** early on, e.g., SLT
- Provides support and step-up care that is developmentally phased, lifelong and **flexible,** for children and their families
- Supports families **to be involved** in actively managing their child's care, including making informed decisions about whether to continue on an assessment pathway

Local Implementation

- Early interventions using SACS-R, iBASIS (Stockport) and SACS-R , PACT (Manchester, early years)
- Staff education and training included additional iBASIS therapists, health visitors, early years workers and health visitors
- New roles of Specialist Health Visitors and Autism Play Specialists were created
- For families who do go on to have an assessment, it is conducted by the MDT in line with current requirements
- Working with private nurseries
- Local commissioner supported