Protocol

ADMINISTRATIVE INFORMATION

Title: A mapping review to identify and map UK examples of sustainable transformations or initiatives within speech and language therapy (SLT) and neurodevelopmental assessment under a community paediatrics service.

Identification

A mapping review to identify and map UK examples of sustainable transformations or initiatives within SLT and neurodevelopmental assessment under a community paediatrics service.

Registration

The protocol will be registered with the National Institute for Health and Care Research (NIHR) and available on their website.

Authors

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Contributions

Anna Cantrell will lead the review.

Dr Emma Simpson will work as a reviewer, inputting into all aspects of the review process.
Dr Lukasz Lagodja will work as a reviewer, inputting into all aspects of the review process.
Emily Pulsford will provide information specialist input, including developing the search approach, and will complete the searches for the review.
Dr Andrew Booth will provide methodological advice and will be the guarantor for the review.
Katie Lewis will provide administrative support.

Amendments

Any amendments would be agreed with NIHR and NHS England.

Sources

Funded under the NIHR Health and Social Care Delivery Research (HSDR) Sheffield Evidence Synthesis Centre from the The NIHR HSDR programme.

Sponsor

The NIHR HSDR programme

Role of sponsor or funder

The project idea was developed by NHS England and presented to NIHR. The protocol was developed by the NIHR HSDR Sheffield Evidence Synthesis Centre project team and will be agreed by NHS England and NIHR.

INTRODUCTION

Rationale

Community paediatric services have very long waiting lists. The highest number of waits are for SLT services and neurodevelopmental assessments within community paediatric services and the waiting lists are growing. The community network survey surveyed 65 community providers between 15th March and 21st April 2023 and estimated average waiting time for an initial assessment for speech and language therapy was 20.2 weeks and for neuro-developmental pathways was 40.3 weeks (1). The average waiting time is significantly longer than the NICE guidance on Autism spectrum disorder in under 19s: recognition, referral and diagnosis Clinical guideline [CG128], which recommends that "1.5.1 Start the autism diagnostic assessment within 3 months of the referral to the autism team. [2011]" (2). Waiting longer than clinically acceptable can lead to increased case complexity and prevent the achievement of educational and developmental milestones. This pertinent issue is highlighted in the 2024 Children's Commissioner's report (3) on Waiting times for assessment and support for autism, ADHD, and other neurodevelopmental conditions "Many children are unsupported during these waits, with little access to therapeutic interventions. This can mean children continue to miss key developmental milestones, with the gap between them and their neurotypical peers widening. Their behavioural and mental health needs can also become more severe and complex, with some children and families reaching crisis" (3):14. This impacts on downstream service utilisation for health and care needs and wider societal impact e.g. employment chances and interactions with the justice system.

These delays also place undue pressures on families, carers and educational settings which is highlighted in the quotes from the 2024 Children's Commissioner's report (3) on Waiting times for assessment and support for autism, ADHD, and other neurodevelopmental conditions. The challenges that families are facing are illustrated in the following quotes from the report:

- "Neurodivergent girls, especially, are often mistreated or misdiagnosed, which can lead to tragic outcomes. My sister was an example of this, and I feel the system failed her. Living with these disorders without a diagnosis is very difficult because I cannot receive support or guidance until I have 'proof' of my problems." – Neurodivergent girl, aged 16. (3):p104.
- "We would have loved the support to have been there earlier for him so that he could have gone to a mainstream school. We would have loved it. I never see him back in mainstream now" – Parent of a child, aged 5, with autism, ADHD, and epilepsy. (3):p126.

Waiting lists are lengthening due to the increase in demand for neurodevelopmental assessment without an increase in community capacity or resources. This mapping review aims to identify innovative solutions, with or without funding that reduce waiting times and improve the quality of care and outcomes for the children and young people and their families accessing the services. This includes innovative approaches to reduce waiting lists, the use of digital tools, earlier identification of needs and provision of support for those waiting for assessment.

Objectives

We aim to identify and map examples of sustainable transformations or initiatives within SLT and neurodevelopmental assessment service provision under a community paediatrics service in the UK, both with and without additional funding, to provide guidance for commissioners and providers.

What pathways and transformational approaches have been used to:

1. Reduce waiting times.
2. Support children and young people awaiting assessment to prevent deterioration and wider impact of unmet needs.
3. Improve earlier identification of needs, including in early years and educational settings.

The focus will be on the following community services for children and young people aged 0–19:

- Speech and Language Therapy (SLT).
- Neurodevelopmental Assessments-delivered under a community paediatrics service.

METHODS

We will undertake a systematic mapping review in order to map examples of sustainable transformations or initiatives within SLT and neurodevelopmental assessment service provision under a community paediatrics service in the UK, both with and without additional funding, to provide guidance for commissioners and providers. The mapping review will aim to explore the quality and quantity of the available evidence.

The systematic mapping review will closely adhere to published methods for a mapping review. The methodology described by James and colleagues (4) will be used to guide the five stages of the review; setting the scope and inclusion criteria; searching for evidence; screening evidence; coding and database production; describing and visualising the findings.

Eligibility criteria

Population:
For Objectives 1 (Reduce waiting times) and 2 (Support during waiting time)
Children and young people aged 0–19 on a waiting list for Speech and Language Therapy or neurodevelopmental assessment services in the UK. Variations in service provision for different age brackets within this range will be considered.

For Objective 3 (Identifying those who need services)
Children and young people aged 0-19

Intervention:
UK pathways to care, community service delivery models:

- Approaches to reduce waiting times e.g. different approaches to early intervention, referrals, prioritisation, triage and assessment; digital tools; alternative workforce models; integrated working across services and agencies including education.
- Measures to support children and young people, families and carers during waiting periods to prevent clinical deterioration and reduce impact on wider determinants of health, e.g. digital tools or workforce solutions.
- Measures to support earlier identification of needs, to include interventions by clinicians, educational staff, parents or guardians.

Comparator:
None

Publication types: Published literature (articles, reports, guidelines) and examples of good practice/initiatives in English language

Outcome:
Objective 1 (Reduce waiting times)

waiting times (time from referral to first appointment) as reported (e.g. mean SD, range), including by subgroup (e.g. sex, ethnicity) if reported;

factors that aid implementation;

barriers to implementation;

costs, and sources of funding - to include staffing resources and digital tools as applicable

Objective 2 (Support during waiting time)

impact on patient during waiting time - harms e.g. neurodevelopmental delay;

impact on patient during waiting time - increased need for services, e.g. extra time from educational staff.

impact on parents/carers during waiting time;

factors that aid implementation;

barriers to implementation;

costs, and sources of funding - to include staffing resources and digital tools as applicable.

Objective 3 (Identifying those who need services)

Age at referral to services, as reported (e.g. mean SD, range), including by subgroup (e.g. sex, ethnicity) if reported

impact on patient during waiting time - harms e.g. neurodevelopmental delay;

impact on patient during waiting time - increased need for services, e.g. extra time from educational staff.

factors that aid implementation;

barriers to implementation;

costs, and sources of funding - to include staffing resources and digital tools as applicable.

Searching for evidence

Information sources

The search will incorporate a focused database search for recent published research and an extensive search for examples of good practice.The literature search will cover the period 2020-2025 and will be restricted to English only. This search cut-off date has been determined by the need to optimise the relevance to the current context and ways of working. Databases to be searched include MEDLINE, PsycINFO, HMIC (to retrieve organisational reports), CINAHL and ASSIA to cover allied health and social science literature. Searching of internet websites of relevant organisations (see list of sources below) will focus on .org; .nhs.uk and .gov domains, also limited to the years 2020-2025. Details of searches of organisational websites, specific search terms or strings, filtering or limitations will be provided as Supplementary material. Supplementary searching will include grey literature searching of the websites of key UK research organisations and professional associations to identify reports about service transformation or initiatives within community services. We will carry out snowballing by citation searching key studies in Google Scholar™ and will scrutinise reference lists of included papers for relevant research.

Grey literature searching will include, but is not limited to, the following sources:

- Royal College of Paediatrics and Child Health (RCPCH)
- Trip Database - use “Guidelines” filter
- British Medical Association (BMA)
- Guidelines search - search a curated list of websites to find guidelines from the UK
- National Institute for Health and Care Excellence (NICE)
- BMJ Best Practice
- UHCW LKS Programmable Search Engine
- Department of Health and Social Care https://www.gov.uk/government/organisations/department-of-health-and-social-care
- Nuffield Trust https://www.nuffieldtrust.org.uk/
- The King’s Fund https://www.kingsfund.org.uk/
- Health Foundation https://www.health.org.uk/
- National Institute for Health and Care Research (NIHR) https://www.nihr.ac.uk/
- Office for Health Improvement and Disparities https://fingertips.phe.org.uk/profiles

- Royal College of Speech and Language Therapy https://www.rcslt.org/

- Department for Education https://www.gov.uk/government/organisations/department-for-education

- Education Endowment Foundation https://educationendowmentfoundation.org.uk/

Search strategy

Database searches will be conducted iteratively, including search terms for the major concepts outlisted in the table below. An example search strategy designed in Ovid MEDLINE is also provided below, which would then be translated for other platforms and databases. Where appropriate, a published and validated search filter will be used to limit UK results. All searches will be limited to the date range 2020-2025.

Concept	**Search terms**
Services	speech and language therapy services; SaLT services; neurodevelopmental assessment services;
Population: Children, young adults, aged 0-19 years	child*, infant*, pre-school*, school-age*, toddler, adolescent*, teen*, young adult*, 0-19, paediatric*
Evaluation/outcomes: Reduction in waiting lists/waiting time	time to treat*, TTT, referral to treatment RTT, time to referral, TTR, waiting time, waiting list*, waitlist*, awaiting
Context: within community/primary care	community health; community health service*; primary care; primary health; primary care service*; primary health service*

Sample database search (for Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions):

1 exp child/ or exp infant/ 2902547
2 (child* or infan* or toddler* or pre-school* or school-age* or "young adult*" or teen* or adolescen* or "0-19" or p?ediatric*).mp. 5372822
3 1 or 2 5372822

4 ("speech and language therap*" or "salt service*" or ((neurodevelopment* or neurodivers*) adj3 (assess* or diagnos* or access*)) or "neurodevelopmental assessment service*").mp. 5626
5 (community adj3 ("p?ediatric service*" or "health service")).mp. 1946
6 Language Therapy/ 2307
7 Speech Therapy/ 7142
8 4 or 5 or 6 or 7 15070
9 Waiting Lists/ 14564
10 ("time to treat*" or ttt or "referral to treat*" or rtt or "time to referral*" or ttr or "wait* time*" or "waiting list*" or waitlist* or await*).mp. 115903
11 9 or 10 115903
12 3 and 8 and 11 96

Screening evidence

Study records

The search results will be managed in Endnote 21 (https://endnote.co.uk/) and imported into Rayyan (https://new.rayyan.ai/) for study selection.

Data management

As this is an evidence synthesis project, no confidential patient information will be used. Any case studies provided will be anonymised.

Evidence selection process

A team of three reviewers will independently screen the titles and abstracts of a test set of 100 references in Rayyan. We will pre-specify classifications of study design types and content descriptors and use these to code items on the basis of abstracts, where relevant. Screening decisions will be compared and the acceptability of inter-reviewer reliability assessed. We will review these eligibility criteria and revise them where necessary. We will divide the remaining references amongst the review team members for screening by a single reviewer and record an initial assessment based on the information in each title and abstract. A second reviewer will examine 10% of excluded abstracts to explore the likelihood of false negatives due to inconsistent application of title/abstract criteria.

Articles meeting the inclusion criteria for titles and abstracts (see above) or items with insufficient detail on content relating to SLT or neurodevelopmental assessment in community services will be reviewed at full-text. Similarly, there will be independent screening for a sample of full-texts with screening decisions compared and the acceptability of inter-reviewer reliability assessed. Once consensus is reached the remaining references will be shared between the three reviewers for full-text screening.

Coding and database production

Meta-data extraction and coding for studies will be undertaken using Microsoft Excel (https://www.microsoft.com/en-gb/microsoft-365/excel). For mapping purposes, references will be categorised at title and abstract stage according to study design, characteristics and broad thematic content. Screening of a sample of included full texts will be used to agree on how to code the data. A standardised data extraction form will be constructed in Microsoft Excel and piloted, with amendments if necessary. The data coding spreadsheet which may be adapted according to the publication type will be used to code data for study type, population, intervention (if present), outcomes or findings and conclusion. The includes will then be shared between the three reviewers with data extracted by one reviewer. Following granular coding we will classify related studies within broader thematic categories that will be used to present study characteristics and to structure an accompanying narrative. Due to the time and resource constraints of the proposed work, missing or unclear information will not be requested from authors. We will assess a sample of items (no more than 20%) for consistency of coding using multiple reviewers.

Data items

Data to extracted will include:
Population - reason for referral, age, sex, ethnicity, socioeconomic status (if reported)
Setting - geographical location, service setting
Intervention - approach, staff needed, digital tools needed, source of additional funding if any, region/commissioning body

Outcomes

time on waiting list (mean, range, as reported);
impact on patients during waiting time - to include harms such as neurodevelopmental delay / educational milestone, need for additional services;
age at referral
factors that enabled implementation;
barriers to implementation;
costs (e.g. staffing, digital tools).

Quality Assessment

The primary purpose of the mapping review is to create a profile of the available evidence base. Individual studies to be assessed at a study design level and not through individual critical appraisal.

Data synthesis

Data will be mapped. Aspects of successful pathways/service models will be identified and organised in a narrative discussion with information about the quality and quantity of the evidence categorised into research, quality improvement andinitiatives.

Stakeholder involvement

During the review process, we will consult with stakeholders at NHS England and the National Institute for Health and Care Research. This will ensure that this review is informed by the views and experiences of stakeholders. The aim of this consultation is to:

- illuminate the practical and personal challenges experienced by those planning community paediatric services.

The Transforming Children and Young People's Community Services programme has held sessions with parents and carers to learn about their experiences, concerns, and recommendations. Additional engagement is planned, including sessions with children and young people, to gather more evidence and provide feedback on the research findings. These additional sessions would be arranged by the Transforming Children and Young People's Community Services programme as needed.

Deliverables and timescales

Deliverable 1 – "Map" of the UK evidence – **23/04/2025.**

Potential additional work

In the mapping review report the Sheffield review team will identify potential further exploration of the topic depending on NHS England's requirements. The scope of any further work will be agreed between NIHR HSDR, NHS England and the Sheffield review team.

References

1. NHS Providers and NHS Confederation. 2023. Waiting times in children and young people's services: community network survey. https://nhsproviders.org/media/695836/cyp_survey_briefing-may-2023.pdf
2. National Institute for Health and Clinical Excellence. 2011. Updated 2017. Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. (Clinical guideline 128.). http://guidance.nice.org.uk/CG128.
3. Children's Commissioner. Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions. (2024). https://assets.childrenscommissioner.gov.uk/wpuploads/2024/10/CCo-report-on-ND-waiting-times_final.pdf
4. James, K.L., Randall, N.P. & Haddaway, N.R. A methodology for systematic mapping in environmental sciences. Environmental Evidence 5, 7 (2016). https://doi.org/10.1186/s13750-016-0059-6