

Working Paper on a New Autism Care Pathway

Audience

The working paper was commissioned by NHS England and NHS Improvement's National Autism Team. It is being shared through NHSE/I regional teams to help local services consider possible ways of innovating on local autism pathways as part of the Expression of Interest (EOI) process.

Purpose

This paper is not national guidance. Its purpose is to propose an evidence-led pathway model for identifying and supporting young autistic children and their families and sets out potential delivery models that the NHS could use to introduce it. In particular, the paper focuses on how services could be re-imagined to move from reactive care to delivering proactive, scalable support that varies depending on the stage of a child's development.

This paper is being shared with local services who are interested in changing elements of the proposed pathway as part of the Expression of Interest (EOI) process for improving autism diagnostic and support pathways for Children and Young People.

Scope

The pathway described in this document has been designed for young autistic children and their families; approximately those aged 0 to 10 years. Many elements of this pathway may be appropriate for older age groups, although changes would likely be needed to the content of the support proposed around diagnosis (section 2B) and post-diagnostic support (section 2C).

The paper outlines the short- and medium- term steps the NHS could take to introduce the new autism pathway model. Some of these can be made locally, while other steps are more relevant at a national level.

Methodology

The Working Paper is not a formal review but collates extensive evidence from autism research with insights on evidenced models for managing long term conditions in other areas of health care.



Its authors are an internationally renowned clinical research team, with an excellent track record of designing and testing effective interventions to support autistic children and families.

Primary Content

The Working Paper is split into two main sections:

- 1) *A new autism early care pathway* – the first section describes elements that could be aligned to deliver a pro-active, developmentally-phased pathway for pre-, post- and long-term support to young autistic people and families. The pathway combines scientific evidence about what supports are effective in improving autistic children's/ families' outcomes, with theory and practice from other long-term conditions.
- 2) *Potential new health system delivery models* – The second section (from page 22 onwards) describes system delivery models that could optimally support this pathway. In particular, the paper scopes out the role that new digital technologies could play in enabling parts of the pathway in the medium-term.

Key recommendations

The Working Paper identifies pathway elements that could be implemented immediately:

- Before diagnosis: Introducing tools to help parents and local health systems monitor
- Before diagnosis: Increasing access to a pre-emptive family-focused intervention with evidence for effectiveness in improving early social interaction skills.
- After diagnosis: Widespread roll out of a family-focused intervention with proven long-term effectiveness in improving social communication skills, addressing restricted/sensory behaviours, and improving parental wellbeing.
- Long term support: Delivering evidenced care solutions for co-occurring conditions in autism such as anxiety, depression, OCD and behavioural challenges, potentially as part of a stepped approach

The paper also identifies pathway elements that could be tested in the medium term:

- Around diagnosis: Family psychological support and psychoeducation (trial underway).
- Before diagnosis: Digital health technologies to help track a child's early development.
- Long term support: Health system developments including digital shared care records to help symptom tracking and need for step up care with autism specialist teams
- Long term support: Digital 'care navigators' making key worker case management to good standard a realistic possibility.

EOIs could consider testing out any of these immediate and medium term elements.