

An integrated early care pathway for autism

Green, J., Leadbitter, K., Ainsworth, J., & Bucci, S. (2022). An integrated early care pathway for autism. *The Lancet Child and Adolescent Health*. Available from: [https://doi.org/10.1016/S2352-4642\(22\)00037-2](https://doi.org/10.1016/S2352-4642(22)00037-2)

Now is the right time to innovate the diagnosis-care pathway for young autistic children, according to a recent Viewpoint published by a Manchester-based clinical-academic partnership.

According to the Viewpoint, we now have a rich mix of clinical evidence, taken from several disciplines, that when considered together support the development of a comprehensive diagnosis-care pathway for young autistic children. The distinct evidence sources referred to in the Lancet Viewpoint are:

1. effective interventions and support for young children waiting for an autism assessment
2. effective supports for children once they are diagnosed as autistic
3. the management of other long-term conditions.

Current service issues

Currently autism-specific services are largely reactive – they are typically only involved when a diagnostic assessment or crisis care is required. Services are rarely proactive – they tend not to routinely identify developmental differences or offer low intensity support before somebody hits crisis.

This presents several challenges:

- autism cannot be reliably diagnosed before about 2 years of age and may go undetected for many more years, but developmental differences can emerge early and remain unsupported when a diagnosis is not available
- focusing on assessment ahead of providing support risks an assessment bottleneck and a disproportionate allocation of limited resource toward assessment over support
- insufficient or unevidenced post-diagnostic support is commonly offered which may undermine the value of a diagnosis
- lifelong autism-specific services may help autistic people to thrive and reduce reliance on crisis but support like this is rare.

The pathway advocated for by Professor Green and colleagues, based on work funded by the National Autism Team at NHS England and NHS Improvement, propose a new model for early-years autism services, one that emphasises the following components:

1. Proactive identification of developmental differences

Developmental differences converge into a pattern reliably diagnosable as autism later in some children than others. These differences may also go overlooked because of an atypical or nuanced presentation or because of cultural or societal biases.

Considerations for practice

- Developmental detection and monitoring tools need to be more widely used to support parents to:
 - understand if their child's social and cognitive development is typical
 - make informed decisions about seeking further assessment.
- There are two opportunities for the deployment of these tools:
 - by early years services, such as community health visitors, child development and child mental health services, working together to proactively identify and monitor children in whom developmental difference appears to be emerging
 - by parents, such as evidence-based apps they can use to monitor their child's development and to prompt when they should seek expert advice. These may serve to streamline onward referrals or offer reassurance that assessment is unlikely to be needed.

2. Providing well-evidenced support, as early as possible

A common justification for predicating intervention on a formal diagnosis is that autism interventions have been shown to be effective in those who meet the clinically determined diagnosis of autism but not in children awaiting assessment.

This justification no longer holds. For instance, we now have replicated evidence that pre- and post-diagnostic delivery of the Paediatric Autism Communication Therapy (PACT) or a conceptually similar therapy called iBASIS-VIPP (video-aided parent-mediated interventions) improves communication skills and reduces sensory sensitivities.

Considerations for practice

An early autism pathway should provide:

- evidence-based pre-assessment interventions and support (eg iBASIS-VIPP) as soon as possible after developmental differences indicative of autism are identified
- evidence-based post-assessment interventions and support for those children who go on to receive an autism diagnosis (eg PACT).

3. Providing support that is developmentally phased, lifelong and flexible

The most effective support for autistic children will change as they develop – through childhood and into adulthood. We must therefore create a system where developmentally appropriate support is always available. Critically, each developmentally phased support offer must be backed by evidence for its effectiveness.

Considerations for practice

An early autism pathway should provide:

- a pre-assessment information and support offer for parents of children who are undergoing assessment; this should be tailored for parents of children at different developmental stages
- a post-diagnosis information and support offer for parents whose children have been diagnosed as autistic

- a suite of developmentally appropriate interventions to meet the needs of children, irrespective of their developmental stage at diagnosis.

4. Lessons from care models for other enduring conditions

Autism is a lifelong diagnosis. Yet, autism services have tended to be organised around diagnosis provision and points of crises. Autism care pathways should be re-organised similarly to those for long-term health conditions such as, for example, diabetes and depression. The evidence for the management of these long-term conditions underscores three important components:

1. **Providing foundational treatment shortly after diagnosis** – for example, for any acute issues that lead someone to seek a diagnostic assessment. This could include psychoeducation providing high-quality information, a peer support programme, support with accepting a new diagnosis or nurturing a positive autistic identity.
2. **The active involvement of the individual in managing their own condition.** The initial treatment should seek to set a solid foundation for actively involving the autistic child and their family in the management of their condition; for example, by having shared access to their patient data and supporting joint clinical care decision-making.
3. **Ongoing, sustained and adaptable case management.** After diagnosis, it should be possible for an autistic child's ongoing care to remain under a specialist autism team, facilitating step-up and step-down in care as needed through the child's development.

Autistic people are much more likely to experience mental and physical ill-health than their non-autistic peers and services should anticipate the future health needs of a newly diagnosed autistic person. A system of stepped care allows the specialist team and parents to collectively decide when the team should increase support and when they should step back and allow the family to take ownership of case management, but remain available to increase supports if needed.

Considerations for practice

- Ensure support is available in the post-diagnostic period.
- Design a service that helps the autistic child and their family understand and take ownership of the management of their condition, where possible.
- Be innovative in designing services to allow for ongoing stepped care after the diagnostic period.

5. Emphasises scalability

New digital health technologies can help scale a redesigned pathway.

Considerations for practice

- Consider evidence-based digital tools can support the early identification, monitoring and referral of children for assessment.
- Is there an opportunity to improve the sharing of healthcare records with families, to help them be actively involved in managing their child's care?
- Consider if evidence-based technologies could be used for therapeutic self-management or psychoeducation?

If you would like help accessing the paper and cannot access it at this link, please email england.autismteam@nhs.net.