



Lincolnshire Parent Carer Forum

Registered Charity No: 1141060

Feedback from The Designated Clinical Officer for SEND Parents Voice Report April 25 – June 25

Page 12– FND for more info please look at [FND Action - Home](#)

Page 12 -ADOS Waiting times

ADOS Assessment / Paediatrics

The waiting time for an ADOS (Autism Diagnostic Observation Schedule) assessment in Lincolnshire can be quite lengthy, with current estimates suggesting a minimum of 12 months for children. This is due to huge surge in demand nationally. After the ADOS is completed, the child is typically seen by a community paediatrician to discuss the outcome and determine whether the diagnostic criteria for autism are met.

For more support whilst waiting or after diagnosis please contact [Virtual Autism Hub :: Lincolnshire Partnership NHS Trust](#)

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The Virtual Autism Hub is an innovative source of all age autism support to empower autistic people and their parents/carers. We work closely with community groups and organisations to strengthen support for autistic children and young people and parent/carers, increasing the range, breadth and reach of these groups.

www.lpft.nhs.uk

- **Page 13 – Specialist Food therapy**

Children & Young People's Eating Disorder Service run by LPFT, this service supports younger individuals and offers tailored care for families navigating early signs of disordered eating [Eating concerns and/or disorders :: Lincolnshire Young Minds](#)

- **Page 14 – PDA**

You're absolutely right—**Pathological Demand Avoidance (PDA)** is *not* formally recognised as a standalone diagnosis in the NHS or in the major diagnostic manuals used in the UK, such as the **DSM-5** or **ICD-112**. This means clinicians cannot officially diagnose PDA as a separate condition.

Instead, PDA is often described as a **profile within the autism spectrum**, typically referred to as *“autism with a PDA profile”* or *“autism with demand avoidance”*

- **Page 15-16 – ADOS Process**

The current CYP diagnostic pathway for autism in Lincolnshire (also referred to as the CYP Social Communication Pathway) is for CYP up to their 16th birthday where parents or professionals have concerns about their social communication skills (particularly related to verbal and non-verbal skills), social interactions and concerning/unusual behaviours, such as associated with autism. If accepted onto the pathway, CYP will go through assessments with a multi-disciplinary team (MDT) of professionals to find out whether a diagnosis is applicable. They may also help identify appropriate support needed for the CYP and their parents/carers from other services including health and education Referral, screening and triage Referrals to the pathway are via professionals, mainly from schools/SENCOs, but also from Health Visitors, GPs, Children and Young People's Nurses and other professionals. Referrals for autism assessments are triaged by the MDT team weekly:

For children aged up to 5 years parents/carers should contact the Health Visiting service (or speak to their pre-school/nursery setting to discuss any concerns around social communication, social interaction or concerning/unusual behaviours). For school-age children (5-16), they should speak to the child's school about these concerns. Schools have access to a range of services and support that may be available regardless of diagnosis and they will be required to provide input before an assessment by a Community Paediatrician is considered. If the CYP does not attend school (e.g. home educated) parents/carers should contact the Children's 0-19 Health Service, who can offer advice and signposting or will support a referral to the Community Paediatric Service if they agree that this is what is needed.

Page 18 – Behavioural Ophthalmologist - this is not a service commissioned in Lincolnshire