

12 January 2024

# Physiotherapy Input to Pathways in Delivery of NICE Guidelines for Children with ASD, ADHD and those Born Pre Term

Can you please tell me what is the physiotherapy input for the pathways in delivery of NICE guidelines with children with ASD, ADHD and children born preterm?

# There are 2 Guidelines for children with Autism Spectrum Disorder (ASD):

https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253

This guideline covers recognising and diagnosing Autism Spectrum Disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them. Physiotherapy in Belfast Trust are not involved in the referral or diagnostic process, so there is no local physiotherapy pathway pertaining to this guideline.

#### https://www.nice.org.uk/guidance/cg170

This guideline covers children and young people with Autism Spectrum Disorder (across the full range of intellectual ability) from birth until their 19<sup>th</sup> birthday. It covers the different ways that health and social care professionals can provide support, treatment and help for children and young people with autism, and their families and carers, from the early years through to their transition into young adult life.

There is no reference to physiotherapy within the guideline and there is no formal physiotherapy input to the pathway for care within the Trust.

#### For children with ADHD:

#### http://www.nice.org.uk/guidance/ng87

Again there is no specific reference to physiotherapy within the guideline. The guideline covers the diagnosis, management and support of children, young people and their families. Physiotherapy is not involved formally in this pathway in Belfast Trust.

The guidelines for children and young people with ADHD and those born preterm are linked to each other in that people born preterm may have increased prevalence of ADHD compared with the general population.

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# Developmental Follow up of Children and young people born preterm:

http://www.nice.org.uk/guidance/ng72

### Summary:

 Nice Guidelines (NG72) recommend enhanced surveillance for all babies born under 30 weeks. However, we are unable to meet demand for 28 - 30 weeks, as there is insufficient clinic capacity available.

This cohort of the caseload is triaged to identify infants who are at higher risk of developmental problems and then directed to the Neuro Developmental (ND) Clinic.

- Current consultant funding allows a specialist High Risk Neuro Developmental Follow up Clinic (ND Clinic) to run approximately 40 weeks per year to enable early identification of those preterm infants at high risk of ND disorder and allow onward referral for early intervention. These children are followed up until the age of 2 years approximately or transferred to community services.
- Current ND Clinic capacity enables enhanced surveillance for high risk babies:
  - o Born before 28+0 weeks' gestation or
  - Born between 28+0 and 36+6 weeks' gestation and has or had 1 or more of the following risk factors:
    - A brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
    - Grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period ◊ neonatal bacterial meningitis
    - Herpes simplex encephalitis in the neonatal period
  - Babies who undergo therapeutic cooling.
- The clinic is provided by a Multi-Disciplinary Team (MDT) with Consultant Neonatologist, Physiotherapist and Occupational Therapist.

While Physiotherapy has historically provided some input at the MDT Clinic, there has never been any specifically commissioned funding for physiotherapy. Participation from Physiotherapy in the clinic is dependent on other clinical priorities and factors, such as annual leave and study leave etc. The Advanced Practitioner Physiotherapist involved is a single post holder for Regional Neonatal Physiotherapy services based within Royal Jubilee Maternity Hospital. The post is commissioned for the delivery of Inpatient Physiotherapy.

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 Children who are identified as requiring ongoing Neurodevelopmental follow up are referred onwards to the Child Development Service, where their care will be continued by the MDT based in community.

Children may also be referred directly to the Physiotherapy service in advance of attendance at the Child Development Clinic to continue their physiotherapy intervention.

Please note that the information provided applies to Belfast Trust patients only and there are variations in follow up across the region.

## Can you also tell me what the waiting lists are for these services?

The Community Paediatrics waiting list is currently sitting at 12 weeks. This is our main waiting list.

It is longer for our Joint Assessment Clinic for Developmental Co-Ordination Disorder, which sits at around 30 weeks. This is a diagnostic clinic with Occupational Therapy and, although the children may have ASD, ADHD or have been born preterm they are not referred to the clinic as part of the diagnosis pathway or management.

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