lengthy diagnosis process are often left with little information, or understanding of ‘what next?’. Having a diagnosis can also help the families understand limitations but also celebrate the strengths and additional support that this brings to their lives.

Families that use the community paediatric service across Bedfordshire and Luton have participated in many service improvement projects and contributed via feedback channels such as focus groups, parent panels and family and friends test surveys. A key theme highlighted by these families was a need for information, resources and support post diagnosis of a neurodevelopmental disorder.

Objectives We have taken up an educational and service improvement project to:

1. co-produce an all-encompassing ‘Post Diagnosis Resource Pack’ for NDD.
2. host online the resource pack which will include printable resources and multi-media information and support to children, young people and families.

Methods We have set up a series of online meetings involving professionals from our community paediatric services, CAMHS, three local authorities, Parent Carer Forums and third sector stakeholders such as Autism Bedfordshire and FACES (Family and Children’s Early-help Services) spectrum support.

We also involved parents/carers, children and young people for their advice and feedback. Parent Carer Forums have ‘Frequently Asked Questions’ which formed the basis of some of the resources. In addition, many professionals and parents contributed to brief educational videos; technical expertise was enlisted to produce infographics and animations as part of the resource pack.

Results The outcome of the initial discussions was to initiate 14 different work streams within the resource pack project, each with a ‘task-and-finish group’ with both parental and multiprofessional involvement, ensuring that the project is truly co-produced.

Examples of the topics that have emerged include the following:

- What should I expect at my appointment?
- What do I need to know about medications?
- How can I speak to my child and family about a diagnosis

The project has also addressed the issues of how to develop a holistic approach, discussing strengths and ‘positives of neurodiversity’, the need for a ‘jargon buster’, and the provision of information on sensory sensitivities and sleep problems.

Some of the material produced is already available and can be downloaded free from the Trust website – https://www.cambscommunityservices.nhs.uk/docs/default-source/bedfordshire-childrens-services/Beds—ADHD—Comm-Paeds/how-do-adhd-medications-work—an-interactive-guide.pdf?sfvrsn=0

Conclusions Psychoeducation involves provision of easy-to-understand and evidence-based information. A user-friendly multimedia resource pack co-produced with user groups aims not only to empower patients and families but also to improve the quality of both service delivery and outcome.

British Society for the History of Paediatrics and Child Health (ePoster presentations only)


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Background Neonatal tetanus has killed many infants. Its impact on human history is difficult to estimate. Even in 2019 fewer than 5% of deaths from this preventable illness were reported to the WHO maternal and neonatal tetanus elimination program. Of the many reasons for under-reporting, variation in its nomenclature within communities remains a challenge.

Objectives To identify names employed to describe infant tetanus in an extensive set of historical documents from Scotland.

Methods The First (Old) Statistical Account of Scotland included population records collected by 900 parish ministers between 1790 and 1799. We carefully examined these to identify information relating to infant deaths. Comparisons have been made with accounts of neonatal deaths in that period from Europe, the Caribbean, southern states of America and Brazil.

Results Records from 1791 described Scottish infants dying of an ‘eight-day sickness’ in Kilbride, Arran, and a ‘fifth-night’s sickness’ in Stornoway. A visiting surgeon referred to these conditions as infant lockjaw or trismus infantum. In Barvas an illness called five or seven night’s sickness was described, in Uig an epilepsy among very young infants. Accounts from Skye recorded infants dying in the first and second weeks of life of ‘pleurisy’. No ministers compared cases of this condition with those in neighbouring areas or other countries. The problem was described as having disappeared in Arran by the 1840s, although at this time it became a growing problem on St Kilda.

Joseph Clarke documented clusters of cases of trismus nascentium in the Dublin Lying In Hospital in the 1780s. In 1791 a gold medal was offered in Madrid to find a treatment for the scourge of ‘mal de barretas’ or ‘trisme del nado’. In St Dominique where infant deaths compromised the growth of the enslaved workforce, the Cercle des Philadelphes published a report on trismus nascentium in 1786. European records included the terms ginklofi or jaw-falling (Iceland), gichteren (Germany), klamper (Norway), mal de sete dias (Portugal and Brazil), mal a machior, pasmo or spasmo (Spain and Puerto Rico). Many sources recorded seizures as a cause of neonatal deaths. Descriptive terminologies focused on the fearsome impacts of tetanus: initially on feeding, then the infant’s face or jaw, followed by muscular spasms with gasping. These infants became ill and perished in the first weeks of life. Scottish nomenclature noted more gently the timings of commencement of symptoms.
Conclusions The early weeks of infant existence were poorly documented prior to the nineteenth century. Neonatal tetanus was described earlier in urban and rural settings, temperate or tropical communities, Hospitals and homes. Variation in nosology was one of several factors limiting communications about this fatal illness. This deprived parents of an explanation or causation. Crucially it delayed the sharing of preventive best practices among birth assistants.

George Still Forum: ADHD Disorders (ePoster presentations only)

1804 AUTISM DIAGNOSTIC ASSESSMENT OF PRESCHOOL CHILDREN IN AN INTEGRATED MULTIDISCIPLINARY CHILD DEVELOPMENT TEAM: A QUALITY IMPROVEMENT PROJECT

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Background The ASD diagnostic process can be a source of stress for parents due to the long waits for assessment and poor understanding of the diagnostic process. The pathway should adhere to NICE guidelines. Gaining information about parent's experience of the assessment process can be used to inform adjustments to the current diagnostic pathway.

Objectives

1. To evaluate the current diagnostic pathway for preschool children in a Child Development Centre in South East Essex.
2. To gain understanding of parent's experience of the current ASD diagnostic process

Methods Eighty-four children were assessed by the integrated Child Development Multidisciplinary Team between April 2019 and March 2020. A random sample of 24 children from the cohort of 84 children was used to examine adherence to the National NICE Autism Spectrum Disorder clinical guidance. The information was obtained through clinical records from two electronic record systems used by the MSE Hospital Trust and Essex Partnership University Trust.

All families were sent questionnaires to obtain anonymised qualitative and quantitative data about their experience of assessment. Questions referred to parental understanding of the assessment process, the quality of communication and interactions between the service providers and users, information and knowledge gained through the assessment process. Parents were invited to complete and return the questionnaires by post or electronically. Ethical approval through the Trust’s Quality Improvement Department was obtained. The results of the audit and parent's responses on the questionnaire were collated and reviewed.

Results Eighty-three percent of the children received a diagnosis of Autism Spectrum Disorder following assessment. The mean age at the time of diagnosis was 4 years. The mean length of time from referral to completed assessment was 20 months. Children were investigated and treated accordingly for co-morbid conditions.

Speech and language assessments were recorded on 22 of the children. Information used to complete the assessment is stored on two different electronic systems as two NHS providers are involved in the assessment of children with ASD. School information was recorded for the majority of the assessments. It is not clear whether assessment results were always shared with GP.

The response rate for the parent questionnaires was low with 9 parents out of 84 (11% of parents) returning questionnaires.

Conclusions The project revealed compliance with ASD assessment NICE guidelines in relation to collection of medical and neurodevelopmental history, direct observation and involvement of members of the Multidisciplinary team. Parents report overarching positive themes about the entire assessment and the interaction of parents with the Multidisciplinary Team clinicians.

However, areas in need of improvement such as poor recording keeping, information sharing with primary care and lack of post diagnosis training were highlighted. The results of the project has been discussed within our MDT team and resulted in establishment of adjustments to the existing evidence based autism pathway where regular monthly MDA team meetings have been initiated. Protocols for communicating with parents, health and education professionals have been established.

1805 CLINICAL RATIONALE AND EVIDENCE FOR EFFECTIVENESS OF NON-PHARMACOLOGICAL AND BEHAVIOURAL MANAGEMENT OF ADHD IN CHILDREN AND ADOLESCENTS

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Background Children and young people (CYP) with Attention deficit Hyperactivity Disorder (ADHD) often experience a wide range of multi-modal impairments often persisting into adulthood, affecting the patients, their carers and wider society. In addition to the core symptoms of age-inappropriate, persistent, and pervasive inattention and/or hyperactivity/impulsiveness that impairs daily functioning, 65–80% of patients with ADHD have conduct problems and other neurodevelopmental comorbidities, as well as poor social and organizational skills with low academic achievement. 10–30% of CYP with ADHD do not respond to psychostimulants while other children experience significant side effects that prohibit continued use. Some parents may have reservations about psychostimulant use due to concerns about potential side-effects and preference for alternative treatments.

Several national and international professional bodies have recommended that Pharmacological treatment should not be offered as the sole therapeutic intervention, especially for the preschool children.

Objectives We reviewed the extant literature to explore the rationale, principles and effectiveness of different modalities of non-pharmacological interventions for CYP with ADHD.

Methods We conducted a search of electronic database including the OVID, EMBASE, CINHAL and Cochrane’s Databases for publications regarding the principles and effectiveness of