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LEARNING DISABILITY – HOW CONFIDENT ARE WE TO MAKE THE DIAGNOSIS?

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Background There are an estimated 1.5 million people in the UK with a learning disability (LD), of which 351,000 are children (2.5% of total childhood population).¹ It is recognised that for people with LDs to have the best life chance, early diagnosis and appropriate intervention in childhood is key.² However, a formal diagnosis of LD may never be made despite a continuing acknowledgement of a child's global development delay as they progress towards adulthood.³ Of those that are diagnosed, many do not receive recommended interventions, with only 55% of those registered as having an LD receiving their annual health check in primary care.⁴

Objectives To survey practice regarding diagnosing LD within community paediatrics.

Methods A questionnaire was designed by the authors and distributed amongst community paediatric departments in the West Midlands via a lead trainee. Responses were requested from community paediatric consultants and speciality doctors. It was open for responses between 7th January and 25th February 2020. The questionnaire addressed areas such as confidence in diagnosing LD, methods used in clinical practice to diagnose LD, and other conditions where you would consider giving a diagnosis of LD.

All responses were voluntary and anonymous. Both quantitative and qualitative data were obtained from the responses.

Results 40 responses were obtained, of which 29 (72.5%) were from consultant community paediatricians. Only 2 (5%) were completely confident in diagnosing LD. 13 (32.5%) were fairly confident, 19 (47.5%) somewhat confident, 4 (10%) slightly confident and 2 (5%) lacked confidence in making the diagnosis. Clinicians used a range of tools and methods to assist with making a diagnosis including school reports, educational psychology reports, functional skills histories, IQ/WISC (The Wechsler Intelligence Scale for Children). A lack of access to educational psychology reports was felt to be a barrier to making a diagnosis with 17 clinicians (42.5%) stating access to their reports would help them make a diagnosis.

Conclusions Confidence in diagnosing LD varies amongst clinicians. We call for the development of standardised pathways in diagnosing LDs. We hope that this would empower community paediatricians to confidently diagnose LDs, enable children and young people to access the health care and support services available to them, and subsequently reduce their future physical and mental health complications.

An additional survey of practice following these results is currently being undertaken to explore the diagnosis of LD amongst Educational Psychologists within the region.

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FETAL ALCOHOL SYNDROME (FAS) IN THE U.K. AND IRELAND: A NEW STUDY

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Background FAS is a complex condition which occurs as a result of in utero alcohol exposure and is characterised by physical, behavioural and neurodevelopmental difficulties. The development of prevention strategies, referral pathways and support services for this vulnerable patient-group relies on understanding its epidemiology. There have been several international surveillance studies describing FAS epidemiology but no such UK studies.

Objectives To determine the epidemiology of FAS in the UK and Ireland in children aged 0–16 years.

This study does not include Fetal Alcohol Spectrum Disorder (FASD) or other paediatric disorders associated with alcohol exposure.

Methods Active surveillance was undertaken through the BPSU between October 2018 to October 2019 (inclusive). Data were collected from reporting clinicians using standardised questionnaires. A history of alcohol use during pregnancy was not required for reporting. The case definition matches the diagnostic criteria used by the Centers for Disease Control.

Case definitions:

Confirmed Case	Probable Case
3 facial features with centiles	3 facial features without centiles
Pre or postnatal growth failure (weight or length <10th percentile)	As confirmed case
Structural or functional brain abnormality (including microcephaly)	As confirmed case

Results There were a total of 148 notifications.

Exclusions

- 9 duplicates.
- 28 lost to follow-up.
- 10 data could no longer be provided.
- 34 notifying clinician felt case no longer met case definition.
- 19 excluded by authors (did not meet case definition)

Included 48 cases (38 probable, 10 confirmed.)

- Confirmed and probable cases were analysed together.

- Only 4 of the 48 children were living with their birth mother at diagnosis.
- The mean age at diagnosis was 60 months.
- In all but 1 of the (probable) cases, the palpebral fissure measurement was either not recorded or inconsistent with FAS; philtrum and lip assessment were more accurately recorded.
- 80% (where data was available) had a birth weight <10th percentile, 54% had a weight <10th percentile at notification.
- 65% of babies were microcephalic at birth and 83% were microcephalic at notification.
- Neuro-cognitive diagnoses were extremely common with over 70% reported to have 1 or more diagnoses.
- 19 cases had seen a geneticist and 38 had genetic investigations, of which all had an array CGH. Results showed 1 micro deletion and 3 VOUS.

Conclusions

- The formal diagnosis of FAS is rarely made by UK paediatricians.
- This in part reflects that FAS, as defined by strict internationally agreed criteria, is a rare disease.
- The results also reflect a lack of education and confidence in making the diagnosis of FAS as demonstrated by the number of initial notifications withdrawn and challenges in obtaining accurate information regarding facial features.
- There is a high level of microcephaly and neuro-behavioural diagnoses in this group.
- Diagnostic yield from genetics investigations is low.
- Early diagnosis is important so that children with FAS can benefit from more targeted cognitive and behavioural interventions.
- FAS is the tip of the iceberg, however, FASD surveillance presents challenges due to the current lack of agreed diagnostic criteria. Establishing the incidence of FASD would help health and social care develop appropriate services for these patients.

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IMPROVING REFERRAL PATHWAYS IN COMMUNITY PAEDIATRICS – FORMING THE SOLUTION

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Background Good quality referrals containing the correct information are a crucial first step in the patient journey. Our Community Paediatric Service receives over one hundred external referrals a month from many different sources. With no standardized process currently in place, the referrals come in various forms and are of varying quality. This can result in inappropriate or poor quality referrals being rejected, which can lead to overall delays in the child's care.

The British Association for Community Child Health and British Association for Child and Adolescent Public Health (BACCH-BACPAH) 2014 recognise the importance of good quality referrals in their Family Friendly Framework standards.

These state, in order to streamline a child's care effectively, thorough recognition of a child's main issues and provision of such information to referring services is required. In addition, the 2017 Royal College of Paediatrics and Child Health (RCPCH) Community workforce guide advocates clear community service referral pathways to enable effective patient care.

Objectives We aimed to review our current referral practice, and to identify improvements required, to ensure compliance with the above national standards.

Methods A month period was chosen at random, whereby 119 external referrals were received. Each referral was accessed on EMIS, and rated as poor, sufficient or good according to pre-determined criteria. The reasons for referral rejections were explored.

Results Of the 119 referrals, 103 (87%) of them were accepted. 10 (8.4%) were classified as poor quality, 61 (51.3%) as satisfactory quality and only 48 (40.3%) were deemed good quality. Of the 16 referrals that were rejected, 3 were already known to the service, 1 required advice only and 13 were deemed more suitable to another service. The majority of rejections were for children with a suspected social communication disorder who were over 5 years old, where the local agreement is for this age group to be reviewed by Child and Adolescent Mental Health Services (CAMHS).

Conclusions Our findings highlighted the need for improvement in our referral pathway. As well as enhancing the quality of referrals, it showed a need for improved communication regarding the correct local referral pathways. In response to these problems, we designed a new bespoke standardised referral document that will be distributed to all local health and education services.

The form includes mandatory sub-sections that will help facilitate clinic allocation (*main concerns, reason for referral, salient background information including safeguarding assessments, overview of development and professionals involved*). To minimise inappropriate referrals, the form provides an overview of up-to-date referral criteria with pathways for all possible community presentations. Lastly, it incorporates an appendix signposting parents and carers to useful local services available to them.

Going forward, we plan to review the impact of the new referral form in 6 months time, reassessing referral quality and rejection rates. Based on its success, this form could be implemented more widely to streamline the referral pathway for all community paediatric patients.

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OPTIMAL MANAGEMENT OF MINOR AILMENTS IN CHILDREN: HEALTHCARE PROFESSIONALS' VIEWS

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Background Minor ailments are self-limiting conditions often managed without medical intervention. Children are particularly susceptible due to immature immune systems however, there are currently no gold-standard references for managing minor ailments in children, and pharmacological and non-pharmacological interventions differ both culturally and globally. There are concerns regarding carer health literacy and how this influences management decisions. Health literacy is