Short Report: Undiagnosed Exploring the extent to which Intellectual Disability is undiagnosed within children attending developmental paediatric clinics

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Dedication: This paper is dedicated to Professor Anne O'Hare, a kind and generous mentor, colleague and paediatrician, who dedicated her life to improving diagnosis and support for children with neurodevelopmental disorders and their families.

ABSTRACT

Intellectual Disability is under-ascertained worldwide and is associated with greater physical and mental health difficulties. This research aimed to identify clinical features and characteristics of children with Intellectual Disability in a population of 126 6-18 year olds in mainstream school, attending paediatric developmental clinics

Intellectual Disability was defined according to the DSM-5 (deficits in intellectual *and* adaptive functioning, present during childhood). Measures used to assess this were WISC-IV IQ (score <70) and ABAS adaptive behaviour (score =<70). Clinical features were compared from a structured clinical records investigation and logistic regression explored which factors were associated with Intellectual Disability.

Twenty-eight children (22%) met the criteria for Intellectual Disability. Five variables were associated with higher odds of having Intellectual Disability: no other neurodevelopmental diagnosis, multiple other health problems, prior genetic testing, maternal smoking during pregnancy, and parental unemployment.

Routinely-collected paediatric data only predicted Intellectual Disability correctly in two out of five cases. Further research is needed to verify these findings and improve identification.

What this paper adds?

Many children with Intellectual Disability, particularly a milder version, still reach adulthood without a diagnosis, despite evidence indicating that diagnosis is generally well received by children and families, and that early intervention leads to improvements in outcomes. This short report, based on a small sample of 126 children aged 6-18 in mainstream school who attended a paediatric development clinic in South East Scotland, provides tentative data on

the clinical features and characteristics which are associated with Intellectual Disability. This tentative evidence suggests that the combination of a) having multiple concerns and investigations, alongside b) one or both parents being out of work (which may be related to familial undiagnosed Intellectual Disability), should raise a flag for paediatricians to further investigate the possibility of an Intellectual Disability diagnosis among these children and young people. Further research with larger samples is needed to explore this more robustly, with the potential to create an algorithm to highlight to paediatricians cases requiring formal screening for Intellectual Disability.

1.1 INTRODUCTION

Intellectual Disability is characterized by impairment in intellectual functioning (including reasoning, problem solving, planning, abstract thinking, judgement, academic learning and/or experiential learning) and adaptive functioning (including communication, social skills, personal independence and/or school functioning) that occur during the developmental period of childhood or adolescence (American Psychiatric Association, 2013). It is a stigmatized and common disability, with an estimated prevalence of 1-2% (Maulik et al., 2011). This prevalence is thought to be globally under-ascertained for a number of reasons: diagnosis is complex, time-intensive and requires input from appropriately qualified professionals who are not always readily available; professionals who may be well-placed to identify children who potentially have an intellectual disability (e.g. teachers), often lack knowledge about the condition, so miss relevant signs; and finally, while evidence-based screening tools exist, these are not yet used in systematic ways (McKenzie et al., 2019b). There is emerging evidence that early identification and intervention may improve cognitive and social outcomes (Guralnick, 2017). Previous studies suggest that screening high risk groups, such as those attending paediatric developmental clinics, who have had developmental concerns already raised about them, is effective in identifying those who may need further assessment of their intellectual and adaptive functioning (McKenzie et al., 2019b), however in reality this rarely happens, and patients often reach adulthood without a diagnosis.

At the time that this study was carried out in Scotland, all children were routinely assessed for developmental delay by Health Visitors at 27-30 months (this has since been extended to include additional assessments at 13-15 months and 4-5 years). For those with a concern raised about their development, paediatricians will usually carry out further investigations. Paediatricians are well placed to contribute to formal diagnosis of Intellectual Disability in developmental clinics (Lindsay, 2018), although formal diagnosis requires input from

appropriately qualified applied psychologists who conduct assessments of intellectual and adaptive functioning (British Psychological Society, 2001). Severe and profound Intellectual Disability is usually diagnosed in early life. Diagnosis of the milder forms, affecting c.85% of Children and Young People (CYP) with an Intellectual Disability, can be more difficult to diagnose. CYP often present with later difficulties due to academic and social demands of school (Voigt and Accardo, 2016). The complexity of the environmental, genetic, and psycho-social determinants of academic attainment make the diagnosis of Intellectual Disability challenging (Hair et al., 2015).

The aim of the present study was to identify clinical features and characteristics of children with Intellectual Disability in a population of 6-18 year-old CYP in mainstream school, attending paediatric developmental clinics. Children attending schools for additional support needs (schools specializing in education of children with particular needs e.g. children with relatively severe disabilities) were excluded from the study: these children were more likely to have other complex needs (Rae et al., 2011) and be already receiving support. Rather than identifying a sample representative of all children with an intellectual disability, our focus was therefore on those who had not yet received a diagnosis, were attending a school for additional support needs, and were therefore not deemed to be in need of substantial levels of support, and were therefore *more likely* to have had their diagnosis missed or delayed. Identifying the clinical features that best predict Intellectual Disability in CYP attending mainstream school might improve opportunities to advocate for onward referral for formal screening and assessment for Intellectual Disability, thereby improving the identification and related support of CYP with this condition. As factors investigated were part of a structured clinical assessment for developmental concerns in paediatric clinics, we anticipate that findings have potential to be translated into everyday clinical practice, improving identification and diagnosis of Intellectual Disability.

1.2 METHODS

1.2.1 Design

An observational study comparing clinical features between those with and without Intellectual Disability was conducted.

1.2.2 Participants and recruitment

Participants were 126 CYP aged 6 to 18 years without a known diagnosis of Intellectual Disability at the time of attending paediatric developmental clinics in South East Scotland (area population of 850,000, representing 16% of the Scottish population) as part of a larger study which ran between 2013 and 2015. The particular NHS region was chosen because it contained both urban and rural areas and included different socio-economic bandings. The clinic paediatrician had introduced families to the larger study to evaluate a screening tool for Intellectual Disability (McKenzie, 2019a). In the original study, parents of children who were attending neurodevelopmental paediatric clinics in the south-east of Scotland were provided with information about the study by their paediatrician and with contact details of the research team should they have any questions. Those who wished to participate signed and returned a consent form. They were then contacted by a member of the research team to arrange a suitable time to complete assessments. Exclusion criteria for the original study were any severe sensory, physical or cognitive impairment that would preclude a formal cognitive assessment. Children were referred to the paediatric developmental clinics for a variety of developmental concerns. As recruitment was via paediatricians, the number and characteristics of those who were invited to participate, but chose not to, is unknown.

For the current study, the research team were then permitted to approach the original participating families for permission to link their child's health records to the Intellectual Disability screening tool for the purposes of the current study (East Midlands Research Ethics

Committee ref: 14/EM/1024). Out of the 181 children in the original screening study, 126 (69.6%) agreed to have the screening data linked with their medical records. Eighty-five children (67.5%) were male, and the mean age of children attending the clinics was 115 months (range 72 - 188 months; standard deviation 29.6).

1.2.3 Instruments

Intellectual ability was measured using the Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV)(Wechsler, 2003), which produces 4 composite scores which altogether make a full scale IQ (FSIQ). Adaptive functioning was assessed using the Adaptive Behaviour Assessment System (26 using ABAS-II and 174 using ABAS-III, as it was updated during the study) (Harrison, 2015), which generates a score across 3 domains, forming an overall general adaptive composite score (GAC). For the purpose of this study, the criteria for Intellectual Disability refers to an IQ of less than 70, and GAC of 70 or less.

With the exception of 'age at study' which was the age of the child recorded at attendance at the screening clinic, all other data (i.e. sample characteristics and clinical features) were analysed from a clinical case note review conducted retrospectively. These were collected in a systematic way using a data gathering tool developed from consensus between expert practitioners and the evidence-based literature (Sup Table 1). Data were collected by NK and LD. A small, random sample was simultaneously collected by AOH. Data on the main sample were compared with the random sample of children to confirm the same information had been identified within the records and to ensure a consistent approach to data collection. Any disagreements were discussed and a final decision agreed by consensus. This was not captured quantitatively.

A clinical feature was designated present if it was recorded in the records; missing data and not recorded were combined. 'Clinical features' included previous health services utilised and

investigations conducted, as well as previous concerns raised, diagnoses, and prior health risk factors e.g. parental smoking in pregnancy/low birth weight. Sample characteristics included child and family socio-demographic factors, such as parental employment status and deprivation level.

Two age variables were available: 'age at referral', which was the age at which the child was initially referred to the paediatric clinic with concerns relating to their health/development; and 'age at study', the age of the child at the time of taking part in the original study. In some cases a substantial period of time had passed between these two timepoints.

1.2.4 Analyses

Data were analysed using SPSS24. Data were described with proportions given for the Intellectual Disability and non-Intellectual Disability groups, respectively, and univariable logistic regression models were fitted to investigate which features were associated at a binary level with meeting criteria for Intellectual Disability. Variables with a p-value <0.25 (Zhang, 2016) at the univariable level were entered into the multivariable model. The multivariable model was then fitted for a second and then third time using only those variables with a p value of <0.05. Model fit was assessed using the Hosmer-Lemeshow test.

1.3 RESULTS

1.3.1 Characteristics and clinical features of children with and without Intellectual Disability

Of the 126 children examined in the clinics, 28 (22.2%) met the criteria for Intellectual Disability based on significant deficits in intellectual and adaptive functioning. The majority of children meeting the criteria for Intellectual Disability were male (64.3%), compared with 68.4% of those who did not meet the criteria.

Table 1 describes the characteristics and clinical features of the children by whether they met the criteria for Intellectual Disability or not. Children in the Intellectual Disability group were more likely to have had contact with all services explored, particularly attending a Child Planning meeting (71.4% of the Intellectual Disability group vs. 41.8%), Speech and Language therapy (96.4% vs. 69.4%), and Occupational Therapy (71.4% vs. 48.0%). They were substantially more likely to have had concerns raised about their development in the early years, particularly around learning (28.6% vs. 12.2%), and developmental delay (39.3% vs. 19.4%). Differences could be seen between the Intellectual Disability and non-Intellectual Disability groups in terms of having had multiple health problems in the past (78.6 vs. 48.0%), having undergone testing for genetic abnormalities (71.4% vs. 46.9%), and maternal tobacco use during pregnancy (42.9% vs. 13.3%). In addition, children in the non-Intellectual Disability group were more likely to have a Neurodevelopmental diagnosis, e.g. dyslexia (37.5% in the Intellectual Disability group, vs 60.2% in the non-Intellectual Disability group). Children in the Intellectual Disability group were less likely to live in a household with one or both parents in employment (39.3% vs. 65.3%), although there were no differences between the area-levels of deprivation in which households were situated.

[TABLE 1 ABOUT HERE]

1.3.2 Predicting which children are more likely to receive a diagnosis of Intellectual Disability when screened

Logistic Regression models were fitted to ascertain whether a number of clinical factors were independently associated with meeting the criteria for Intellectual Disability. Contact with Speech and Language Therapy, Occupational Therapy and Child Protection services were not assessed in the models due to concerns around the diversity of experience in contact with these teams (from one mention in the clinical records to substantial service input), limiting

their usability in clinics. In addition, maternal infection during pregnancy was not explored in the models due to cell sizes being too small. Univariable models were firstly fitted for all other clinical and family factors. Eight factors measured in the developmental clinic or obtained from medical records appeared to be significantly associated with meeting the criteria for Intellectual Disability at a univariable level: having attended a child planning meeting, having had learning or developmental concerns noted in the early years, respectively, having experienced multiple other health problems, having had genetic tests conducted, and having a mother who smoked during pregnancy. Meeting the criteria for Intellectual Disability was also associated with having *lower odds* of having a neurodevelopmental diagnosis and having one or both parents in employment. In addition, a further four variables reached a level of significance which meant that they would be included in the multivariable model ($p<0.25$): these were having concerns noted about Speech and Language in the early years; having a family history of confirmed or suspected Learning Difficulties; having a history of health problems likely to impact on development; and having a lower height centile.

Model 1 explained c.58% of the variance in meeting criteria for Intellectual Disability, and correctly identified 74% of cases. Six factors remained statistically significant within the multivariable model. These were having multiple health problems recorded; having undertaken genetic testing; maternal smoking during pregnancy; *not* having one or both parents in work, *not* having a physical health problem likely to impact on developmental, and *not* having any other neurodevelopmental diagnoses (Table 2: Model 1). In model 2 all variables retained significance except having a physical health problem likely to impact on development. All variables entered into model 3 retained significance at the $p<0.05$ level. The final model explained c.35% of the variance in meeting criteria for Intellectual Disability, and

correctly identified 39% of cases. The Hosmer-Lemeshow Goodness of Fit test gave a p value of 0.04.

[TABLE 2 ABOUT HERE]

1.4 DISCUSSION

This paper indicates that 22% of 6-18 year olds attending mainstream school referred from typical paediatric developmental clinics to the screening study, met the criteria for Intellectual Disability. This significant under-ascertainment is in keeping with findings from an international metanalysis of estimated prevalence of Intellectual Disability (Maulik, 2011). Despite similar high rates of preschool developmental concerns and longstanding involvement with health and education services, individuals who met the criteria for Intellectual Disability were far less likely to have a previous neurodevelopmental diagnosis that might have explained their developmental difficulties. It was notable, however, that paediatricians had recognised children's developmental delay and had investigated them for putative aetiologies. Prior genetic investigation was associated with an increased likelihood that the CYP met the criteria for Intellectual Disability: as suspected Intellectual Disability is one of the most common reasons for a paediatrician to initiate this investigation, this suggests that the possibility of this diagnosis had been entertained.

This mainstream population had high rates of documented developmental delay and concerns in the preschool years, particularly in those affecting the speech and language domains. Indeed, almost all children in the Intellectual Disability group had received input from Speech and Language Therapy, compared with 60% of those who did not meet the criteria. Earlier developmental delay is not synonymous with a long term establishment of a significant impairment in intellectual functioning and Intellectual Disability (Riou et al., 2009), but it may be useful to consider along with other clinical features.

It is notable that there were relatively high rates of exposure to maternal tobacco in pregnancy in this mainstream population, particularly in the Intellectual Disability group, again is in line with previous studies (Ekblad et al., 2015).

When explored alongside other key clinical features and characteristics of the child, having one or both parents unemployed was also associated with Intellectual Disability. There is a complex relationship between neurodevelopmental disorders, special educational needs, poverty and the psychosocial determinants of poor developmental, educational and health outcomes (Pillas et al., 2014). It may be a proxy for the parents themselves having Intellectual Disability and finding it difficult to secure employment.

We suggest that further research is needed between paediatricians, children's allied health services, schools and educational services, individuals and families to understand why it is that this particular group of CYP with a disability are not formally diagnosed and whether this matters (Williams et al., 2015). The historic method of identifying CYP with Intellectual Disability through their association with special schooling is outdated and rates of special educational needs recorded across Europe are not capable of shedding light on which individuals have Intellectual Disability because of the highly variable methods of recording (European Agency for Special Needs and Inclusive Education, 2014). Information collected during developmental clinics, combined with child medical records, may be useful to prompt paediatricians to investigate a potential diagnosis of Intellectual Disability further and advocate for specialist assessment of intellectual skills and adaptive behaviour within multidisciplinary and multiagency working.

Disclosing a diagnosis of Intellectual Disability to young people is a complex task but without this knowledge they may lack support and empowerment (Williams et al., 2015). Previous research with families of children with Intellectual Disability indicate that getting a

diagnosis is a positive experience overall (McKenzie et al., 2019b), whilst a holistic approach to early intervention stressing the importance of relationship and capacity building within families, as well as comprehensiveness and continuity over time, is key to improving outcomes. The Children's Neurodevelopmental Pathway 2021, currently being implemented in Scotland, has these factors at its heart: future research will be needed to determine whether this is making a difference to children and families with Intellectual Disability (Scottish Government 2021).

1.4.1 Limitations

This is a very small study of 126 children, 28 of whom met the criteria for Intellectual Disability. The small numbers involved meant that the study was underpowered, and thus confidence intervals in the model are wide. Nonetheless, this small-scale study highlights the value of further larger studies of this nature to ensure that children attending developmental clinics are not left without diagnosis. This is an observational study and has no information on individuals and their families who either withheld their consent for examination of their clinical records or could not be traced. The study took place in South East Scotland, albeit including different clinical services within four different education authorities who manage all the state schools within their area. We conducted our predictive model for CYP attending mainstream school only, having made the reasonable assumption that only individuals with severe, and therefore clinically apparent, intellectual disabilities were likely to be educated in the small range of special schools or units. Data on clinical features and characteristics of the children were those readily available in routine data: items such as smoking and alcohol consumption in pregnancy appear low for this population, and are likely to be affected by under-reporting.

1.5 Conclusions

At present, Intellectual Disability is a 'hidden' issue in childhood and one which is associated with chronic functional challenges across many domains. As this study demonstrated, many children with Intellectual Disability now attend mainstream school. Almost a quarter of these children met criteria for Intellectual Disability once screened, although none had a previous diagnosis of Intellectual Disability, despite experiencing substantial numbers of concerns raised about them and undergoing investigations. This paper suggested that the combination of having multiple concerns and investigations, alongside one or both parents being out of work (which may be related to familial undiagnosed Intellectual Disability), should raise a flag for paediatricians to further investigate the possibility of an Intellectual Disability diagnosis, which previous evidence has suggested is a positive experience for most children and their families.

Competing interests

KM and GM are co-developers of the measure that was used in the earlier screening study that identified the population study presented here and receive a small income from its sale. The remaining authors have no interest that may be perceived as posing a conflict or bias.

Author Contributions

KM and GM are co-developers of the measure that was used in the earlier screening study that identified the population study presented here, and contributed to the main studies that this paper is linked to, including collecting, scoring, interpreting and analysing data that identified the children who were followed up in the later study. AOH and NK devised the current study. LD, AOH, LM and TS contributed to the analyses. LD and AOH drafted the first paper and LM redrafted. All authors read and commented on the final paper.

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Patient and Public Involvement

Prior to the current study commencing, the views of paediatricians were gathered in order to ascertain whether the research would be both feasible and helpful to families. This study resulted from the testing of a screening tool of Intellectual Disability. This wider study additionally sought the views of parents and paediatricians on the measures (CAIDS-Q).

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Table 1: Comparison of clinical features of those with and without Intellectual Disability

CLINICAL FEATURE	NON-INTELLECTUAL DISABILITY	INTELLECTUAL DISABILITY	BASE	p VALUE
	Mean (Standard Deviation)	**Mean (Standard Deviation)**		***p-value***
IQ score	82.9 (14.7)	56.2 (7.9)	121	<0.001
GAC score	76.2 (13.9)	59.3 (7.8)	122	<0.001
Age at referral to paediatrics (months)	60.0 (38.1)	62.8 (46.8)	88	.99
Age at study (months)	116.8 (30.0)	111.4 (28.9)	124	.40
	n. (%)	**n. (%)**		***p-value***
Socio-economic characteristics				
One or both parents in employment	64 (65.3)	11 (39.3)	126	.01
*SIMD quintile - 1	19 (19.4)	9 (32.1)	126	.37
SIMD quintile - 2	18 (18.4)	6 (21.4)		
SIMD quintile - 3	17 (17.3)	2 (7.1)		
SIMD quintile - 4	10 (10.2)	-		
SIMD quintile - 5	34 (34.7)	10 (35.7)		
Services involved with child				
**Child planning meeting at school	41 (41.8)	20 (71.4)	126	.01
Speech and language therapy	68 (69.4)	27 (96.4)	126	.003
Occupational Therapy	47 (48.0)	20 (71.4)	126	.03
Child Protection	24 (24.5)	8 (28.6)	126	.66
Child and Adolescent Mental Health	38 (38.8)	14 (50.0)	126	.29

Developmental Concerns in Early Years				
Speech and language	61 (62.2)	22 (78.6)	126	.11
Gross and fine motor skills	46 (46.9)	13 (45.4)	126	.96
Attention and concentration	33 (33.7)	10 (35.7)	126	.84
Learning	12 (12.2)	8 (28.6)	126	.04
Social and emotional	48 (49.0)	11 (39.3)	126	.37
Behavioural	45 (45.9)	13 (46.4)	126	.96
Vision/hearing	17 (17.3)	3 (10.7)	126	.40
Physical	17 (17.3)	4 (14.3)	126	.70
Developmental Delay	19 (19.4)	11 (39.3)	126	.03
Health and Past History				
***Neurodevelopmental diagnoses	59 (60.2)	10 (37.5)	126	.02
Dysmorphic features	20 (20.4)	6 (21.4)	126	.91
Multiple health problems in past	47 (48.0)	22 (78.6)	126	.004
Genetic tests carried out	46 (46.9)	20 (71.4)	126	.02
Genetic abnormality identified	14 (14.3)	-	126	.32
Maternal tobacco use during pregnancy	13 (13.3)	12 (42.9)	126	.001
Maternal alcohol use during pregnancy	12 (12.2)	5 (17.9)	126	.44
Maternal drug use during pregnancy	15 (15.3)	-	126	.89
Maternal infection during pregnancy	9 (9.2)	-	126	.10
Significant perinatal event	21 (21.6)	4 (14.3)	125	.39
Significant delivery event	10 (10.3)	-	125	.73
Significant postnatal event	32 (32.7)	11 (39.3)	126	.51

Immediate family history of confirmed/ suspected learning difficulties	40 (40.8)	16 (57.1)	126	.13
Past history of health problems likely to impact on development	21 (21.4)	9 (32.1)	126	.24
Current height and weight	**Mean (Standard Deviation)**	**Mean (Standard Deviation)**		***p-value***
Weight (centile)	59.1 (31.1)	52.8 (34.6)	101	.42
Height (centile)	57.7 (33.6)	46.6 (34.6)	103	.17

*Scottish Index of Multiple Deprivation (SIMD) is a measure widely used in Scotland to describe small area concentrations of material deprivation. It is split into quintiles, with 20% of the population in each group.

**Child Planning Meeting refers to involvement with a multi-disciplinary team including education, health and social services

***Refers to other neurodevelopmental diagnoses that can result in functional and/or academic difficulties, eg dyslexia, developmental coordination disorder

Where cell sizes were fewer than 5, data are not displayed.

Table 2: Multivariable Logistic Regression Predicting Likelihood of Meeting Criteria for Intellectual Disability

	Model 1					Model 2					Model 3				
Clinical Feature	**Beta coefficient**	**Odds Ratio**	**Min (95% CI)**	**Max (95% CI)**	**p**	**Beta coefficient**	**Odds Ratio**	**Min (95% CI)**	**Max (95% CI)**	**p**	**Beta coefficient**	**Odds Ratio**	**Min (95% CI)**	**Max (95% CI)**	**p**
Child Planning Meeting	1.12	3.08	0.74	12.88	0.12										
Speech and language delay in EYs	1.01	2.73	0.36	20.78	0.33										
Learning delay in EYs	0.80	2.23	0.51	9.78	0.29										
Developmental delay in EYs	0.62	1.87	0.46	7.60	0.38										
Immediate family with diagnosed or suspected Learning Difficulties	0.52	1.68	0.40	7.05	0.48										
Health problems which are likely to impact of development	-1.86	0.16	0.03	0.94	0.04	0.18	1.20	0.37	3.91	0.77					
Multiple other health problems	1.78	5.95	1.18	29.98	0.03	1.28	3.60	1.17	11.08	0.02	1.32	3.76	1.27	11.14	0.02
Genetic tests carried out	1.87	6.47	1.12	37.26	0.04	1.42	4.13	1.39	12.24	0.01	1.43	4.16	1.41	12.33	0.02
Maternal smoking in pregnancy	2.08	7.97	1.78	35.66	0.01	1.23	3.42	1.17	10.00	0.03	1.23	3.43	1.17	10.01	0.02
Height centile	-0.02	0.99	0.96	1.01	0.15										
Other neurodevelopmental diagnoses	-1.71	0.18	0.04	0.75	0.02	-1.27	0.28	0.10	0.82	0.02	-1.23	0.29	0.10	0.82	0.02
One or both parents in work	-2.11	0.12	0.03	0.58	0.01	-1.23	0.29	0.10	0.85	0.02	-1.27	0.28	0.10	0.80	0.02