**Investigating the association between early years foundation stage profile scores and subsequent diagnosis of an autism spectrum disorder: A retrospective study of linked healthcare and education data**

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**Abstract**

**Objective:** We set out to test whether the Early Years Foundation Stage Profile score derived from 17 items assessed by teachers at the end of reception school year had any association with Autism Spectrum Disorders diagnosis in subsequent years. This study tested the feasibility of successfully linking education and health data.

**Design:** A retrospective data linkage study.

**Setting and participants:** The Born in Bradford longitudinal cohort of 13,857 children.

**Outcome measures:** We linked the Early Years Foundation Stage Profile (EYFSP) score at the end of reception year with subsequent diagnosis of an autism spectrum disorder, using all ASD general practitioner Read codes. We used the total EYFSP score and a sub-score consisting of 5 key items in the EYFSP, prospectively identified using a panel of early years autism experts.

**Results:** This study demonstrated the feasibility of linking education and health data using Autism Spectrum Disorders as an exemplar. A total of 8,935 children had linked GP and education data with 20.7% scoring below 25 on the total EYFSP and 15.2% scoring below 10 on a EYFSP sub-score proposed by an expert panel prospectively. The rate of diagnosis of Autism Spectrum Disorders at follow up just under 1% (84 children), children scoring below 25 on the total EYFSP had a 4.1% chance of ASD compared to 0.15% of the remaining children. Using the prospectively designed sub-score this difference was greater (6.4% and 0.12% respectively).

**Conclusions:** We demonstrate the feasibility of linking education and health data. Performance on teacher ratings taken universally in school reception class can flag children at risk of autism spectrum disorders. Further research is warranted to explore the utility of EYFSP as an initial screening tool for ASD in early school years.

**What is already known about this topic?**

* Routine education and health data are rarely linked.
* To date there is limited evidence that screening for autism spectrum disorders in the first 6 years of life is cost-effective.

**What this study adds?**

* It is feasible to link routine education and health data for a cohort of children in England.
* Performance on educational measures taken universally in school reception class can flag children at risk of autism spectrum disorders.
* Linking these data has the potential to decrease costs associated with undiagnosed childhood conditions to the individual as well as health and education services.

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**Introduction**

Large quantities ofelectronic data are generated routinely in health and education sectors. Linking these data could present an opportunity to improve information sharing and facilitate service user transitions within and across systems.

10% of children and young people aged 5–16 years have a clinically diagnosed mental disorder [1]. The short-term costs are estimated to be £1.58 billion per annum, with annual long-term costs calculated at £2.35 billion [2]. Neurodevelopmental impairments and conditions with high levels of need contributing to this cost have an estimated prevalence of around 3–4% of children in England [2]. The CMO suggested that “*Commissioners and providers of services to children in primary education should develop and agree arrangements to ensure all primary schools adopt a comprehensive whole school approach to children's social and emotional wellbeing. They should provide specific help for those children most at risk (or already showing signs) of social, emotional and behavioural problems*” [2]. The challenge facing policy makers and providers is how such a suggestion might be implemented. A useful starting point might arise from linking routine data across health and education services. ASD presents an exemplar condition that could elucidate the challenges and potential utility of data linkage across domains.

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders that lead to impaired reciprocal social interaction and repetitive or restricted patterns of behaviour [3] occurring in at least 1% of children in the UK [4]. The behavioural problems associated with the condition are a major cause of children being excluded from school [2]. A recent review showed that government policies and community resources impact upon early identification of ASD [5] with evidence of geographic variation. Socio-economic status and level of parental concern affect age of diagnosis [5]. Parents experience high levels of stress with the ASD diagnostic process, with over half dissatisfied with current UK services [6]. On average, families have to wait 3-4 years to receive a diagnosis [6, 7]. Many children are identified early with a range of difficulties but not given a diagnosis of autism until much later [7]. Box 1 provides typical testimony from a parent consulted in our patient and public involvement work (slightly abridged).

**Box 1:** *We requested a referral to paediatrician as we suspected autism when my son was four years. The SENCO in his nursery had been involved when he was 3.5 years old as staff said he wasn't listening and his attention span was poor. We approached our health visitor after this to express our concerns. They referred him for speech and language therapy. The speech and language therapist referred him to the Paediatrician. We waited nearly 2 years to be seen. After an initial appointment we were told they wanted to wait and see. This meant that our son did not get appropriate treatment until he was eight years of age. Should there not be a more systematic way of assessing children in need early?*

Early intervention in ASD is associated with long-term symptom reduction [8]. This includes identifying appropriate educational placement early and parenting support interventions [8]. There has been a call for more sophisticated approaches to screening (such as stepped approaches or at-risk group identification) since whole population approaches have not proved cost-effective [9].

A universal educational assessment is conducted on *all* children in their first year of schooling in the UK (the Early Years Foundation Stage Profile; EYFSP). We predicted that scores on this developmental assessment might identify children at risk of neurodevelopmental problems. This could lead to earlier intervention to prevent the poor outcomes associated with undiagnosed conditions. Our prediction was motivated by the fact that information collected through the EYFSP routinely covers key domains of autism symptomatology, providing information about child’s language development, social skills and emotional development.

**Methods**

***Design***

This was a retrospective data linkage study. To test our hypothesis, we focused on ASD as an exemplar and retrospectively examined the EYFSP scores collected on the 13,857 children within the Born in Bradford (BiB) longitudinal birth cohort study [10]. This cohort has been followed up since birth. The BiB cohort comprises 12,453 women recruited at 28 weeks of pregnancy, who gave birth at the Bradford Royal Infirmary to 13,857 children between the period 2007 and 2011 [10]. Half of all BiB families live within wards classed amongst the 20% most deprived within England and Wales, and 45% are of Pakistani origin [10].

*Patient and public involvement*

A key strength of BiB has been its effective community engagement with considerable time and effort invested to ensure genuine co-production of research. There is an active parent governor group and they advised on the protocol and materials used for this study. BiB has an active approach to partnership with families through regular newsletters, Facebook, and Twitter with regular family network days and an annual family science festival.

Full informed consent was obtained for all participants. Ethical approval was granted by Bradford NHS Research Ethics Committee (Ref 07/H1302/112). Cohort members gave their consent to access and link routine GP records via SystmOne, which currently has complete coverage of all GP practices in Bradford with secondary care records and education records. Figure 1 provides an overview of the recruitment process and the final sample included in the current study. Table 1 provides a comparison of the characteristics of the current sample with the whole Born in Bradford cohort.

**Table 1. Sample characteristics**

|  |  |  |
| --- | --- | --- |
|  | **Sample in the current study**  (n = 8,935) | **Sample in the whole cohort** (n = 13,857) |
| **Gender** |  |  |
| Female | 49.1% | 49.0% |
| Male | 50.9% | 51.0% |
|  |  |  |
| **Ethnicity** |  |  |
| White British | 36.1% | 37.0% |
| Pakistani Heritage | 51.8% | 48.6% |
| Other | 12.1% | 14.4% |
|  |  |  |
| **Free school meal status** |  |  |
| In receipt | 24.7% | 25.1% |
| Not in Receipt | 75.3% | 74.9% |

***Outcome measures***

*Early years foundation stage profile score*

Table 2 displays the 17 items of The Early Years Foundation Stage Profile, each scored 2 (meeting the level of development *expected*), 3 (*exceeding* this level) or 1 (not yet reaching this level - *emerging*). The items are designed to measure a range of educational, socio-emotional, communicative and developmental factors. We used the total EYFSP score (the ‘total score’) and a sub-score developed by a small group of ASD assessment experts prior to study (and so blind to the results) (a 5 item ‘sub-score’) (see Table 3). The experts were academic and clinical child psychiatrists and psychologists with many years of ASD experience between them. The five items were chosen from the four main symptom areas defined in the World Health Organisation (1992) [3] research diagnostic criteria for ASD namely social reciprocity, language and communication, imagination delays and repetitive and stereotyped patterns of behaviour. Because the social reciprocity domain is given more weight in this classification system it was decided to include two items from the EYFSP to reflect this weighting. Children who underwent EYFSP assessment before 2013 were excluded from this study because the items measured in the EYFSP assessment were changed in 2013. The pre-2013 version is not compatible with the current EYFSP assessment.

*Read Code Diagnosis of ASD*

The outcome measure for this study was the presence of a ‘Read code’ for an ASD recorded in a child’s primary care records. A validated Read code list (see Supplementary Material 2) has been shown in previous published work in ASD to be reliable and used with confidence to study ASD [11].

|  |  |
| --- | --- |
| **Table 2: Early Years Skills Foundation Profile: All items** | |
|  |  |
| Physical development: Health and self-care | EYFSP05 |
| Communication and language: Listening and attention | EYFSP01 |
| Personal, social and emotional: Managing feelings and behaviour | EYFSP07 |
| Communication and language: Understanding | EYFSP02 |
| Expressive arts and design: Being imaginative | EYFSP17 |
| Understanding the world: People and communities | EYFSP13 |
| Personal, social and emotional: Self-confidence and self-awareness | EYFSP06 |
| Communication and language: Speaking | EYFSP03 |
| Personal, social and emotional: Making relationships | EYFSP08 |
| Expressive arts and design: Exploring and using media and materials | EYFSP16 |
| Mathematics: Shapes, space and measures | EYFSP12 |
| Physical development: Moving and handling | EYFSP04 |
| Understanding the world: The world | EYFSP14 |
| Mathematics: Numbers | EYFSP11 |
| Literacy: Reading | EYFSP09 |
| Literacy: Writing | EYFSP10 |
| Understanding the world: Technology | EYFSP15 |

|  |
| --- |
| **Table 3: Early Years Skills Foundation Profile (EYFSP): Weighted sub-score** |
| Using a weighted sub-score, where four aspects of childhood autism (social, language and communications, imagination and repetitive behaviour) were mapped onto EYFSP elements |
|  |
| **The social aspect mapped onto:** |
| * Personal, social and emotional: Managing feelings and behaviour/ |
| * Personal, social and emotional: Making relationships |
|  |
| **Language and communications aspect mapped onto:** |
| * Communication and language: Listening and attention |
|  |
| **Imagination aspect mapped onto:** |
| * Expressive arts and design: Being imaginative |
|  |
| **Repetitive and stereotyped behaviours mapped onto:** |
| * Physical development: Health and self-care |
|  |

**Procedure**

In collaboration with our primary care electronic health provider across Bradford, linkage was carried out using a complete deterministic match on NHS number, surname, gender and date of birth (99% of BiB children matched to their health record) by the BiB data team. Routine electronic datasets include primary care data from the GP practice, hospital data, community care and education data. Hospital and maternity data was provided by Bradford Teaching Hospitals NHS Foundation Trust. The community care data was provided by Bradford District Care Trust. In collaboration with our local provider of electronic health records across primary care, the GP records were extracted by The Phoenix Partnership, SystmOne. The education dataset was provided by Bradford Metropolitan District Council. Our local authority, Bradford Metropolitan District Council linked BiB children to their Unique Pupil Identification Number (UPN) resulting in a match rate of 84% with their education records. The Unique Pupil Identification Number is a 13-character code that identifies each pupil in the local-authority school system. As the local authority match on an iterative deterministic approach based on combinations of surname, date of birth, gender and postcode, if more than one match is made, then we do not receive any UPNs. At the point of analysis, 8,935 children were included. 2068 children could not be linked mainly because the children were born in Bradford but moved outside the area (approximately 1,200 children) or had moved in after EYFSP (approximately 200) children. The other reason for exclusion was an inability to match to pre-determined quality standards.

**Analysis**

Logistic regression was employed to model the relationship between EYFSP score and the outcome of ASD diagnosis using Stata 13 [12]. A number of covariates were included in the analysis; gender (classified as male or female), ethnicity (White British, Pakistani Heritage and Other), free school meal status (whether in receipt of free school meals or not) and the age of the child (in years) at the date of GP data extract. Marginal effects were estimated [13] to produce predicted rates of ASD diagnosis for children based on whether they had a low EYFSP score.

The total EYFSP score ranged from 17 to 51, with a mean of 31.8 and a standard deviation of 8.0. The five item sub-score ranged from 7 to 21, with a mean of 13.6 and a standard deviation of 3.4 (see Figure 2). However, the EYFSP scores are not normally distributed; mostly children score average on each item, but there are some who score higher and a fairly distinct group of children who have low scores resulting in a bimodal distribution of EYFSP scores, as indicated in figure 3. For this reason, the EYFSP scores are dichotomised for the purposes of analysis. Those scoring below 25 in the total EYFSP score and below 10 in the five item sub-score were categorised as low scores; these cut points equate to scores less than one standard deviation below the mean (see Figure 3).

**Results**

Just under 1% (84 children) of the 8,935 children with matched GP and education records had a diagnosis of autism. Of the 8,935 children had linked GP and education data. 1,852 (20.7%) children scored below the cut off on the total EYFSP score, 72 of these children had an autism diagnosis. 1,355 (15.2%) children scored below the cut off on the EYFSP sub score, 72 of these children had an autism diagnosis (see Table 4).

Table 4: Autism diagnosis and EYFSP scores

|  |  |  |  |
| --- | --- | --- | --- |
|  | Total EYFSP Score | | |
|  | Low Score | Not Low Score | Total |
| With Autism Diagnosis | 72 | 12 | 84 |
| No Autism Diagnosis | 1,780 | 7,071 | 8,851 |
| Total | 1,852 | 7,083 | 8,935 |
|  |  |  |  |
|  | EYFSP Sub-Score | | |
|  | Low Score | Not Low Score | Total |
| With Autism Diagnosis | 72 | 12 | 84 |
| No Autism Diagnosis | 1,283 | 7,568 | 8,851 |
| Total | 1,355 | 7,580 | 8,935 |

We found that children with a low EYFSP sub-score were approximately 50 times more likely to have a diagnosis of autism compared to children without a low score. Males were twice as likely to have a diagnosis of ASD, whilst White British children and children not inreceipt of free school meals had higher rates of diagnosis recorded in the GP records, apart from age of the child, all differences were statistically significant and all covariates improved the model (see Supplementary Material 1 for full model results). Analysis was carried out using the scores derived from all items and produced similar results; though the association was stronger for the EYFSP sub-scores (see Figure 4).

Children with a low total EYFSP score (A) have a rate of autism of around 41 per 1,000 children (4.10%, 95% CI: 3.08 - 5.13), far higher than children who do not have a low total EYFSP score (0.15%, 95% CI: 0.05 - 0.25).

Children with a low five item EYFSP sub-score (B) have a rate of autism of around 64 per 1,000 children (6.38%, 95% CI: 4.76 - 8.00), far higher than children who do not have a low five item EYFSP sub-score (0.12%, 95% CI: 0.04 - 0.20).

**Discussion**

Our linkage of routine education and health data has revealed an association between school EYFSP score profile and the diagnosis of ASD. We focused this proof-of-concept study on ASD as: (i) the issues with late diagnosis are well documented; (ii) early diagnosis is known to lead to enhanced parental interventions; and (iii) improved educational pathways lead to better outcomes. The linkage process and subsequent analyses of the linked datasets has illustrated a potentially powerful way to create a smoother, more joined-up and timely early patient pathway to autism assessment by linking data across the currently tortuous pathway to referral for ASD assessment.

Gold standard assessment for ASD is lengthy and expensive [14] so care needs to be taken to ensure that screening has good specificity and sensitivity to avoid large numbers of unnecessary assessments. Further research is therefore necessary. Population screening for ASD is also expensive [14] and to date, the effectiveness of different screening strategies for ASD in reducing time to diagnosis has not been adequately tested [9]. Whilst researchers have recommended that screening for ASD only be carried out in ‘at risk’ groups [15], no localities or nations have yet successfully implemented or researched this. Our study suggests that a promising focus for future research lies in the use of routine educational data to identify children at risk. This could be highly cost-effective given the universal availability of this educational data.

Related school-based information is often collected as part of the assessment for neurodevelopment disorders (including ASD). Consequently, correlation between EYFSP scores and neurodevelopmental disorders may be expected. Routinely collected national school data may therefore be a cost-effective way of initially identifying children at risk, however larger studies are required to adequately test this across neurodevelopmental disorders.

**Clinical and Research Implications**

Encouraged by strong stakeholder support, we are now prospectively researching whether children identified by the EYFSP is a suitable ‘at risk’ group for specific ASD screening and assessment for ASD in terms of acceptability, ethics and cost-effectiveness, and whether it is a sensitive and specific method of enabling prompt assessment leading to early intervention.

If successful it would substantially increase efficiencies in the delivery of current services. These include assessment resources and appropriate school placement/support earlier. It may also prevent multiple assessments from different professionals over time. We have recently shown an inequality of diagnosis as a function of socioeconomic position [16] and the use of routine linked health and education data could be a powerful tool to help tackle such health inequalities.

Routine electronic data that are relevant to health and care pathways exist in fragments, spread across multiple organisations, each fragment with its own data controller. The challenges of cross-organisation coordination and information governance make it difficult to obtain linked data, and so most care providers and researchers have been unable to use it as a means of understanding whole-system healthcare. In Bradford, we have addressed this as part of The Connected Bradford Project, by reaching data sharing agreements with each of the health and social care organisations in the Bradford city region. Identifiable information is removed at source, and so personal information is not available to the project, which enables whole population data to be analysed. The pseudonym is derived from the NHS number, which crosses organisations, so that data can be linked after pseudonymisation. The Connected Bradford project at Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) applied to the Confidentiality Advisory Group (CAG) for approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. Approved applications enable the data controller to provide specified information for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable. Support was granted on the 3rd September 2018 (CAG ref: 18/CAG/0091 and REC ref:18/YH/0200). BTHFT have permission under these regulations to provide personal details to the local authority to enable the linkage of education records for approximately 220,000 individuals of the Bradford population. There is good scope for this approach to be used across multiple Trusts.

**Conclusions**

Our ‘proof-of-concept’ study suggests that linking education and health data could improve the detection and support of children with neurodevelopmental problems such as ASD earlier – a priority area identified by the Chief Medical Officer [2]. The use of linked data to benefit outcomes is an important future goal [17]. In this context our demonstration has implications beyond autism. It is becoming clear that the routine linkage of education and health data has the potential to drive efficiencies in children’s services, facilitate early intervention and ultimately, improve quality of life for large numbers of children and their families.

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**Abbreviations:** ASD - Autism Spectrum Disorders; CMO – Chief Medical Officer; EYFSP – Early Years Foundation Stage Profile Score; NHS – National Health Service;

**Provenance:** Not commissioned; externally peer-reviewed

**Data sharing statement:** The Born in Bradford (BiB) dataset is available from: https://borninbradford.nhs.uk/research/how-to-access-data/

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**Figure legends**

**Figure 1: Recruitment flow chart**

**Figure 2: Early Years Foundation Stage Profile (EYFSP): Weighted sub-score**

**Figure 3: Distribution of EYFSP Scores - standardised with standard deviation shown**

**Figure 4: Predicted rates of ASD for children by (A) total EYFSP score and (B) five item EYFSP sub-score (designed to map more closely to items that measure factors associated with autism)**