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Abstract

Background: Referrals to the Greater Glasgow Community Autism Team (CAT) made before the child's 6th birthday were analysed to obtain an estimation of the proportion of children in Greater Glasgow with childhood autism and investigate whether there were any variations in diagnosis rates, or in age at referral and diagnosis, depending on deprivation or geographical location.

Methods: An analysis was made of the database recording referrals to Greater Glasgow CAT, between 2004 and 2007 inclusive, of children referred by age 6 years, comprising 584 cases. Cumulative incidence was calculated for childhood autism. Ages at referral and diagnosis were also analysed.

Results: For this subset of children, there were 246 diagnosed cases of childhood autism, a cumulative incidence from 2004 until 2007 of 11.1 per year per 10,000 children aged 0-6 years. Of children with an eventual diagnosis of autism by age 6, 72% were referred by the age of 4 years. Deprivation was not found to have an association with diagnostic or referral rates, however, there was geographical variation in the cumulative incidence of autism.

Conclusion: Given that the populations were not known to differ in any manner that would lead to a true variation, the geographical variation in the cumulative incidence of autism in children up to 6 years in Greater Glasgow observed in this study is likely to represent differences in the care pathway between areas. Reasons for the variation are being explored.

Introduction

A recent systematic review estimated an average prevalence of childhood or typical autism (henceforth referred to as autism) at 20.6 per 10,000 (Fombonne 2009). Prevalence of typical autism has been significantly associated with: diagnostic criteria (over time diagnostic criteria have changed); age of the children screened; and study location (Williams *et al.* 2006). Highest rates are found in studies using active case ascertainment, with one such study estimating a prevalence of autism as 38.9 per 10,000 in South Thames UK (Baird *et al.* 2006). A prospective study of children in the South Wales valleys found prevalence of autism to be 12.7 per 10,000 (Latif & Williams 2007). In Scotland, a capture-recapture method was used to estimate prevalence of all pervasive developmental disorders in Lothian at 44.2 per 10,000 in children aged up to 15 years (Harrison *et al.* 2006).The study did not provide an estimate specifically for the subcategory of autism.

There is evidence that autism can be confidently diagnosed in children under the age of three years (Charman *et al.* 2005; Cox *et al.* 2005; Stone *et al.* 1999). While several studies find no association between socioeconomic status and incidence of autism (De Giacomo & Fombonne 1998; Larsson *et al.* 2005), others do find such a link (Croen *et al.* 2002; Durkin *et al.* 2010) and diagnosis may be more likely to be delayed in deprived circumstances. In a prevalence study of all autism spectrum disorders (ASD), children with a previous diagnosis plus those at risk of being an undetected case were screened for autism and ASD. Within the group of children with a statement of special educational needs and now an ASD, the 32% of those children with a parent who had completed secondary education were 5.0 times more likely to have a previously established ASD diagnosis than those whose parents were less educated (Baird *et al.* 2006).

Greater Glasgow includes some of the areas of greatest deprivation in the whole of the UK, but also some areas of significant affluence (Scottish Executive 2005a; Scottish Government 2010). The present study is part of a service evaluation looking at the diagnostic process for children with childhood autism and autism spectrum disorders in Greater Glasgow. This paper focuses on childhood autism as defined by World Health Organisation ICD-10 (International Classification of Diseases, 10th revision). The study aimed to discover the age at which children in Greater Glasgow were being diagnosed with autism and whether there was any variation in age of diagnosis depending on socio-economic or demographic circumstances, or on the structure of services locally. In particular, we sought to determine whether lower than expected numbers were accessing diagnostic services in areas of deprivation. Secondly, we wished to determine whether diagnoses were being made in older children where improvements could be made to services to find and diagnose those children earlier.

Methods

Greater Glasgow Community Autism Team

All children under the age of 6 years residing in the former National Health Service Greater Glasgow (NHSGG) Health Board area who are suspected of having autism or another autism spectrum disorder are referred to the Greater Glasgow Community Autism Team (CAT) for diagnostic assessment. Many older children are also referred to this team (up to age 15); however, children over the age of six might have an autism diagnosis made by Child and Adolescent Mental Health Services without involvement of the CAT team. Therefore, referrals up to age 6 years were analysed to derive an estimate of cumulative incidence of autism in a specific age group.

At the time of referral and diagnosis of cases in this study, service was centrally coordinated but

delivered through teams in each of the four Child Development Centres (CDCs) in Greater Glasgow. A central waiting list helped to ensure equitable waiting times across the CDCs. All of the diagnostic teams comprise a community paediatrician and specialist speech and language therapist with expertise in autism. The teams could also include an educational psychologist. The teams followed uniform protocols and used the World Health Organisation ICD-10 diagnostic criteria. Protocols included a joint initial assessment, history taking by both professionals, a period of observation of the child in nursery or school (including Autism Diagnostic Observation Schedule if needed), a developmental assessment and medical examination (if not already completed recently) and a feedback meeting with parents to discuss a detailed written report. Information on children referred by age 6 years was provided from two databases: preschool children (498 cases) and school age children (of which there were 86 cases up to the age of 6 years). These were combined to create one database, of 584 cases, containing information on children referred to the Greater Glasgow CAT. The data were anonymized and checks conducted to ensure there were no duplicates.

When a child is referred to CAT, an entry is created on the database. A school age database was created in 2002. Information on preschool-age children began to be entered from October 2003. Because of long waiting times for diagnostic assessment, at the time of data extraction many children referred in 2008 had not completed the assessment process, hence this analysis was limited to data collected from 2004 until the end of 2007.

The database cannot provide information on the overall prevalence of autism, as it catalogues only the diagnostic assessment. The data are unable to inform on cases that, after diagnosis, have moved out of the area, nor on cases diagnosed elsewhere moving in. Instead cumulative incidence was estimated. Cumulative incidence is the number of new cases of a disease during a specified time, divided by the population at risk (Kirkwood & Sterne 2003).

Some information was missing for some cases, therefore the number of cases available for differing analyses varies. The dataset does not include sex of child or details of which cases had co-morbidities (which may have an impact on the age at referral).

This report provides details of referrals, diagnoses, cumulative incidence of autism and source of referrals, and investigates links between diagnosis characteristics and deprivation using the Scottish Index of Multiple Deprivation (SIMD). The SIMD provides an indication of relative deprivation of a geographical area using indicators measuring income, employment, health, education, skills and training, housing, geographical access and crime (Scottish Government 2010). For this analysis, details of deprivation category used SIMD quintiles for the whole of Scotland, ranging from 1, least deprived, to 5, greatest deprivation, using postcode information to match to the appropriate SIMD quintile.

Statistical analysis

As the data consist of frequency counts, the chi-square test of association and the chi-square goodness of fit test were used for statistical analysis.

Ethics

A study protocol was submitted to the National Research Ethics Service and confirmation was received that, as the purpose was to identify potential improvements and inform diagnostic services, further ethical approval was not required.

Results

Diagnosis outcome

Of all children under the age of 6 years at referral to the Glasgow CAT, 42.1% were diagnosed with autism and 17.6% with Asperger's syndrome. Table 1 shows the number of all referrals each year. The category labelled 'other' included diagnoses of 'global delay', 'behaviour difficulties', and Fragile X. The table details diagnosis outcome, including number of cases 'incomplete' (i.e. not yet received diagnosis at time of data extraction), 'missing' (i.e. no data entry of the diagnosis), and 'discontinued' (i.e. moved from area or child/parent/carer decided to stop diagnostic process).

Cumulative incidence of autism

Population figures were sourced from NHSGG Community Health Index (CHI) data. CHI is the unique NHS identifier for Scottish residents. The age bands below 6 years for 2004 to 2007 were used, the figures extracted in December each year. Cases of autism, recorded for children referred by age 6 years 2004 to 2007 inclusive are presented in Table 2, with cumulative incidences. While no children were referred to CAT before the age of 1 year, there will be children in the community under the age of 1 year who will later be diagnosed with autism.

The estimated cumulative incidence of autism in children referred by age 6 years for NHSGG from January 2004 to December 2007 inclusive per year is 11.1 per 10,000 children aged 0 to 6 years.

Age at diagnosis and referral to CAT clinic

Of all referrals to Greater Glasgow CAT from age 0 to 15 years (1013 cases), of the 317 with a final diagnosis of autism, 77.6% (246 cases) were referred by age 6 years, the subset analysed in this study. Details of age at diagnosis and referral are outlined in Table 3. The table also shows the

proportion diagnosed and referred by age 4 years, ideally when diagnoses should be made in order to plan appropriate support in education prior to the child starting primary school.

Length of wait for diagnosis

Of the 202 cases with both referral date and date of autism diagnosis, the wait between the date at which the child was referred and the date they received a diagnosis was calculated. Mean wait was 11 months (95% CI 10.57 – 12.01), ranging from 1 to 32 months. Almost three quarters (72.3%) received a diagnosis within 12 months of being referred to the CAT, 90.6% diagnosed within 18 months of referral, 96.5% within 2 years.

Deprivation

Of the 246 cases of autism, data required to assign SIMD score (i.e. postcode) were missing for 40 cases, therefore Table 4 shows results for 206 cases. 'Autism per cent' shows the percentage of autism cases resident in each SIMD quintile. The ‘Population per cent’ column shows the proportion of relevant NHSGG population in each SIMD category as a percentage. Within the Greater Glasgow area there is a high proportion of people in the most deprived category. The results show a lower-than-expected number of children with autism was diagnosed in the least deprived quintile, while a higher-than-expected number was diagnosed in the most deprived. Using a chi-square goodness of fit test, this association between increased deprivation and increased numbers of diagnosed cases of autism was found to be statistically significant.

Autism by geographical area

The Greater Glasgow CAT database contains referrals from 10 primary care areas. For six of these, the whole area is covered by the service, whilst the other four are only partly covered. Table 5 shows the population for each of the 10 areas, for age 0 to 6 years, as a percentage of the total

relevant population (222,281) covered by the service. The third column shows the number of autism cases diagnosed from each area for 2004 to 2007. The fourth column calculates how many cases of autism one might expect to find in each area according to the population proportion of the total autism cases with information identifying their area (224 cases). For example, for Area 1, the population is 12.45% of the total population, so it would be expected (all else being equal) that 12.45% of the 224 autism cases would be from Area 1. Of course, there will be variation due to chance. However, while most areas roughly match the estimation, Areas 5, 6 and 8 show a particularly large difference between actual number and expected.

The expected numbers of autism cases were used to calculate a chi square goodness of fit test, with the population percent providing the expected value proportions. The results indicate a difference between areas.

Discussion

Analysis of this data gathered as part of a service evaluation of referrals to Greater Glasgow CAT, from 2004 to 2007 inclusive, found a mean cumulative incidence of 11.1 per year per 10,000 children aged 0 to 6 years. While the dataset does not record children moving out of the catchment area after diagnosis, nor those previously diagnosed moving in, hence not allowing an accurate estimation of prevalence, this cumulative incidence could be taken as a crude estimate of prevalence, acknowledging the fore-mentioned caveats. Nevertheless, if the cumulative incidence rates for the four years 2004-2007 are collapsed, the rate of 44.3 per 10,000 would probably be a crude indication of the prevalence of autism under age 6 years in Greater Glasgow. Cumulative incidence for autism in children up to age 5 years, was found to be 27.2 per 10,000 in one Japanese study (Honda *et al.* 2005). However, Honda's figures were obtained from a mass screening for autism at a universal health check-up. In Greater Glasgow during this period, diagnoses were

frequently made at age 6 and above, so we believe our figure to be a considerable underestimate of the total prevalence for autism. Age of children in the study is one reason for variance between studies (Williams *et al.* 2006). While, as mentioned above, cumulative incidence and prevalence are not directly comparable, the cumulative incidence found here is close to the prevalence estimate of 12.7 per 10,000 for South Wales (Latif & Williams 2007).

Age at referral to Glasgow CAT is presented to provide further understanding regarding points along the pathway of detection and diagnosis where services might be improved. Age at referral is also important as it indicates that the possibility of the diagnosis has been discussed with the family, at which point autism-friendly strategies may be introduced, (e.g. in nursery), even before a diagnosis has been confirmed. Early intervention has been shown to produce positive outcomes (Howlin *et al.* 2009; McConachie & Diggle 2007; Smith 1999). As noted in Introduction, this dataset does not include details of which cases had co-morbidities which may impact on age at referral. Nor is there information on whether a child is already receiving assistance as autism is strongly suspected and the diagnosis more a formality than the beginning of assistance.

Analysis of differences in autism frequency by SIMD attained statistical significance, with a diagnosis being more likely in the most deprived group. While it is reassuring to find therefore that there is no evidence of this most deprived group 'slipping through the net' in terms of accessing services, it is not possible to determine whether this represents a real difference in incidence according to socio-economic status, or whether Glasgow's most deprived category are just being identified earlier than other children, more of whom are perhaps referred at age 6 years or older. There were differences noted by service delivery areas that are unlikely to be due to chance. The comparison of expected and actual cases of autism within areas of Greater Glasgow is particularly interesting. Areas 1 to 5 are all covered by one local authority, whilst each of the other areas has its

own local authority. Areas 1 and 2 have the highest levels of deprivation, whilst Areas 6 and 8 are the most affluent. In most health statistics, Areas 6 and 8 would be expected to follow a similar pattern, and yet in Area 6 only one third of the expected number of autism cases are being identified for referral by age 6, whilst in Area 8 there is a small over-representation. This would support a hypothesis that at least part of the variation seen by deprivation must be explained by local service factors rather than true differences in incidence. Possible explanations for these differences are being explored. The proportion of private as opposed to local authority nursery provision is high in Area 6, so one hypothesis would be that staff in private nurseries are less confident than their local authority counterparts in recognising developmental difficulties and discussing possible referrals with parents. Potentially an intervention in the form of "autism awareness" training and facilitation of referral pathways for these private nurseries may be of benefit. Conversely, some affluent parents with an older child with autism may have moved into Area 8 specifically to access perceived high-quality educational provision. And a subsequent younger sibling with autism has been diagnosed earlier because of parental awareness.

Conclusion

This is the first paper to give a frequency estimate for childhood autism in the population of Greater Glasgow. The estimate is within the range expected from reports published from elsewhere. There were significant differences found according to socioeconomic status. Differences were also noted between geographic areas within Greater Glasgow, which are more likely to represent differences in case ascertainment than in true prevalence. While not possible within the scope of this study, analysis of patients' birth records might determine whether there might be a contribution to the geographic differences resulting from migration due to service availability. During the period of study, waiting times for autism diagnostic assessment were equitable across the Board area, as there was one single specialist diagnostic team, but differences exist in Local Authority and primary care

provision and practice leading to referral. These are now being explored, in the hope of intervening in pursuit of equity. After referral, processes are specific to autism, but many of the early processes in terms of recognising that a child has an additional need, and navigating the pathway through primary care and beyond, are not unique to autism. Children with all manner of other disabilities and developmental difficulties face similar challenges in reaching diagnosis, and are also likely to benefit from work done in early years' settings to raise awareness of appropriate care pathways. Health for all Children 4: Guidance on Implementation in Scotland (2005) recommended the development of local care pathways describing referral and access arrangements for assessment and treatment for a variety of developmental concerns, and that these pathways should be monitored and evaluated on an ongoing basis to ensure their effectiveness (Scottish Executive 2005b). Six years on, we are just beginning to realise that vision.

Key messages

The estimated cumulative incidence of autism in Greater Glasgow was 11.1 per year per 10,000 children aged 0-6 years.

Cumulative incidence varied by area within the city.

Cumulative incidence did vary by deprivation on this dataset of children referred by age 6 years.

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Table 1 Diagnosis outcome by year of referral

Diagnosis	Year of referral				
	2004 No. (%)	**2005 No. (%)**	**2006 No. (%)**	**2007 No. (%)**	**Total No. (%)**
Autism	57 (40.1)	68 (41.2)	63 (46.7)	58 (40.8)	246 (42.1)
Asperger's syndrome	27 (19.0)	27 (16.4)	20 (14.8)	29 (20.4)	103 (17.6)
Language disorder	21 (14.8)	22 (13.3)	8 (5.9)	1 (0.7)	52 (8.9)
"not ASD"	22 (15.5)	27 (16.4)	17 (12.6)	20 (14.1)	86 (14.7)
Incomplete	1 (0.7)	1 (0.6)	0 (0)	8 (5.6)	10 (1.7)
Other	6 (4.2)	2 (1.2)	1 (0.7)	0 (0)	9 (1.5)
Discontinued	3 (2.1)	5 (3.0)	8 (5.9)	4 (2.8)	20 (3.4)
Diagnosis missing	5 (3.5)	13 (7.9)	18 (13.3)	22 (15.5)	58 (9.9)
Total	142 (100)	165 (100)	135 (100)	142 (100)	584 (100)

Table 2 Cumulative incidence of autism per 10,000 by year of referral and age group

Year	Age group (years, inclusive)	No. cases autism*	Population	Cumulative incidence (per 10,000)
2004	0-1	2	18,334	1.1
	2-3	46	18,366	25.0
	4-5	9	18,863	4.8
	Total	**57**	**55,563**	**10.3 (Mean)**
2005	0-1	4	18,468	2.2
	2-3	40	18,159	22.0
	4-5	24	18,517	13.0
	Total	**68**	**55,144**	**12.3 (Mean)**
2006	0-1	2	18,442	1.1
	2-3	45	18,732	24.0
	4-5	16	18,211	8.8
	Total	**63**	**55,385**	**11.4 (Mean)**
2007	0-1	1	18,936	0.5
	2-3	37	19,106	19.4
	4-5	20	18,147	11.0
	Total	**58**	**56,189**	**10.3 (Mean)**

*of cases referred in each of the years 2004 to 2007, the number of cases referred that year who subsequently received a final diagnosis of autism. The diagnosis could have been made in a subsequent year.

Table 3 Age at diagnosis and referral to Community Autism Team clinic

	Mean age (months)	95% CI	Range (months)	Diagnosed by age 4 years (%)	Referred by age 4 years (%)
Age at diagnosis*	54	52.38 – 56.35	29 – 98	34.2%	-
Age at referral	43	40.89 – 44.2	19 – 71	-	72%

* Diagnosis frequently made subsequent to study referral cut off age of 6 years.

Table 4 SIMD quintiles: comparison of autism cases with general population

SIMD quintile	Autism frequency[a]	Autism per cent*	Population per cent**
1 least deprived	28	13.6	20.0
2	23	11.2	12.2
3	15	7.3	9.9
4	30	14.6	15.1
5 most deprived	110	53.4	42.9
Total	206	100	100

. [a] χ^2 =11.0077, d.f .=4, p=0.026.
*Autism per cent: the percentage of autism cases resident in each SIMD quintile.
**Population per cent: the proportion of relevant NHS Greater Glasgow population in each SIMD category as a percentage. SIMD: Scottish Index of Multiple Deprivation.

Table 5 Actual and expected autism cases

CH(C)P area	Population per cent (%)	Actual autism cases[a] (n)	Expected autism cases (n)
Area 1	12.45	27	27.9
Area 2	13.73	30	30.8
Area 3	13.59	30	30.4
Area 4	12.53	26	28.1
Area 5	14.63	51	32.8
Area 6	10.85	8	24.3
Area 7	5.23	9	11.7
Area 8	7.72	23	17.3
Area 9	2.5	5	5.6
Area 10	6.77	15	15.2
Total	100	224	224

[a] χ^2=23.861, df=9, p=.005
CH(C)P: Community Health (and Care) Partnership