

INFORMATION
ANALYSIS
DIRECTORATE



The Prevalence of Autism (including Asperger's Syndrome) in School Age Children in Northern Ireland 2014

INFORMATION ANALYSIS DIRECTORATE



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- *Provide up-to-date, quality information on children and adult social services and community health;*
- *to disseminate findings widely with a view to stimulating debate, promoting effective decision-making and improvement in service provision; and*
- *be an expert voice on social care information.*

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About Community Information Branch

The purpose of Community Information Branch (CIB) is to promote effective decision making in children and adult social services by providing quality information and analysis.

We collect, analyse, and publish a wide range of community information that is used to help monitor the delivery of personal social services policy. Information collected by CIB is used to assess HSC Trust performance, for corporate monitoring, policy evaluation, and to respond to parliamentary/assembly questions.

Information is widely disseminated through a number of regular key statistical publications and ad hoc reports details of which are available online.

We gratefully acknowledge the assistance of colleagues working within the Statistics and Research Team of the Department of Education and Demography and Methodology Branch

Introduction

Purpose of the Report

The need to develop and improve health and social care services for people of all ages who are affected by Autistic Spectrum Disorder (ASD) including Aspergers Syndrome has been apparent for some time. In order to provide effective services knowing the incidence (new cases) and prevalence (new and existing cases at a point in time over a defined period) of ASD including Aspergers is clearly important. Throughout this report, for ease of reading, the abbreviation ASD is used to signify Autistic Spectrum Disorder (ASD) including Aspergers Syndrome.

This report aims to show prevalence rates of ASD amongst compulsory school age children (attending grant-aided schools) (4 – 15 years old at the start of the school year), as it is clear that ASD persists and that children with ASD become adults with ASD, with their own individual needs.

What is ASD?

ASD is a developmental disability that influences a person's ability to communicate and relate to other people, as well as affecting how they make sense of the world around them. It is a spectrum condition, meaning that while all people with autism will have some similar problems, overall their condition will impact them in different ways. Some people may be able to lead fairly independent lives while others will require a lifetime of specialist support.

Children who have been identified with Aspergers Syndrome have been included in this study. Aspergers Syndrome shares some similarities with Autism; however people with Aspergers Syndrome do not generally experience the same language and learning disabilities associated with autism. They are more likely to have difficulties in the areas of social imagination, social communication and social interaction.

Recent Developments

The recent introduction of the Autism Act (Northern Ireland) 2011 and the accompanying increase in awareness via campaigns and consciousness raising events, many of which have been championed by the voluntary sector, may well contribute to a rise in the number of assessments carried out and positive diagnoses processing through the system. However it is too early to tell how much of an impact these developments will have on any underlying prevalence estimates.

Current Prevalence Estimates

It is estimated that there are over half a million people in the United Kingdom with ASD. This is approximately 1% of the population; if you include their families, autism affects the lives of over two million people¹. Autism is more prevalent in men than women with findings from a 2007 survey titled 'The Adult Psychiatric Morbidity Survey' indicating that 1.8% of men were affected by ASD compared to 0.2% of women².

¹ <http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx>

² <http://www.ic.nhs.uk/news-and-events/press-office/press-releases/one-in-a-hundred-adults-have-an-autism-spectrum-disorder-says-pioneering-new-study>

Previous estimates suggest that in Northern Ireland around three hundred children will be identified with ASD each year, with a current approximation that 20,000 – 30,000 people living in Northern Ireland have ASD³.

Methodology

Northern Ireland School Census

The Northern Ireland School Census collects a large amount of information including demographic information (such as gender), free school meal entitlement, Looked After Children numbers, Newcomer Children numbers and assessment data. This includes disability and a breakdown of those children affected by ASD.

The Department of Education provided figures from their annual Northern Ireland School Census from 2008/09 through to 2013/14. These figures showed the number of children identified with Autism, including Asperger's, across Health and Social Care Trusts, between Urban and Rural areas within Trusts and across Multiple Deprivation Measure areas as well as supplementary information on gender and school year of the pupils.

All pupils on the rolls of grant-aided primary, post-primary and special schools were included in this return comprising each child who was a registered pupil in a school in October of each given year and who attended for at least one day.

The available data was analysed in a number of ways.

1. Health and Social Care Trust and Urban/Rural area. The classification of urban and rural areas is set out in the Report of the Inter-Departmental Group on Statistical Classification and Delineation of Settlements⁴.
2. Multiple Deprivation Measure (MDM), with Decile One relating to the 10% most deprived areas within Northern Ireland and Decile Ten relating to the 10% least deprived areas⁵.
3. By gender of pupil.
4. By school year.
5. By Special Educational Needs stage.

Statistical Significance

The chi-square test can be used to establish whether or not two variables have any statistical relationship. A resultant value of 0.05 or smaller indicates that the result of the chi-square test is significant and that there is a relationship between the variables in the process.

Prevalence

In order to establish the prevalence of autism within the compulsory school age population, the number of children who were attending school and had been identified with ASD was divided by the total number of compulsory school age children attending school. This gave the proportion of children within the cohort who were identified with ASD.

³ <http://www.autismni.org/statistics.html>

⁴ NISRA, 2005

⁵ NIMDM 2010, NISRA

Limitations

There were a number of limitations to the data in this study and its use of establishing prevalence figures for ASD.

1. Data is sourced from the school census rather than a diagnostic source. While this is presently the most comprehensive data source available it only covers children of compulsory school age and those attending school. Figures for 2011/12 suggest that there were approximately 170 home taught children with no further details available.
2. The data only captures those children who have been assessed as having ASD. At any time, additional children may not have gone through the full assessment process and it is possible that a number of children may be identified with ASD at a later date.
3. There may be some sub regional data capture issues within the school census. For example it was not possible to place some children in either an urban or rural location or within a MDM Decile. However this is minimal, accounting for around 1% of the ASD population, and is unlikely to have had a large effect on results.
4. Low numbers in the Belfast Trust rural area in 2008/09 meant figures for children with autism were suppressed.

It should be noted that there are many factors which can lead to variances in the apparent prevalence rates within the different breakdowns commented on in this report, not least the assumption that there is consistency of approach in the care pathways as managed by the different Trusts. In this regard, care should be taken when considering the findings, i.e. it is likely that at least some of the observed variation in prevalence may be attributable to differences in organisational structure and arrangements in place between/within Trust areas.

Findings

School Census Figures

Table 1 below shows the number of children with a diagnosis of Autistic Spectrum Disorder and who were of compulsory school age and attending school in each of the last six years, the total number of children of compulsory school age attending school and the ASD prevalence rate. It can be seen that from the table that between 2008/09 and 2013/14 the prevalence rate rose by 0.8 percentage points equating to an increase of 67%.

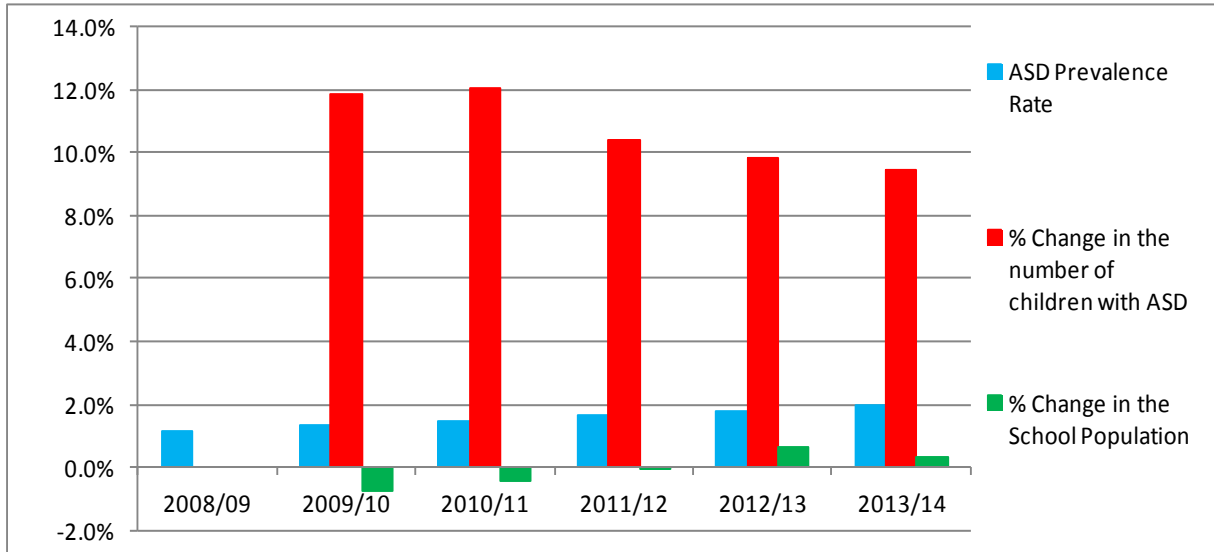
Table 1: The Number of Children with ASD, the Compulsory School Age Population and the ASD Prevalence Rate

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Children with ASD	3,278	3,668	4,111	4,540	4,986	5,458
Compulsory School Age Population	280,127	278,020	276,776	276,606	278,333	279,299
Prevalence	1.2%	1.3%	1.5%	1.6%	1.8%	2.0%

Source: Department of Education

This prevalence rate increase can be linked to two factors illustrated in Figure 1. There has been an annual average increase of 11% in the number of children identified with ASD, while at the same time the general school population has remained relatively static between 2008/09 and 2013/14.

Figure 1: The ASD prevalence rate, annual percentage change in the number of children with ASD and the annual percentage change in the school population

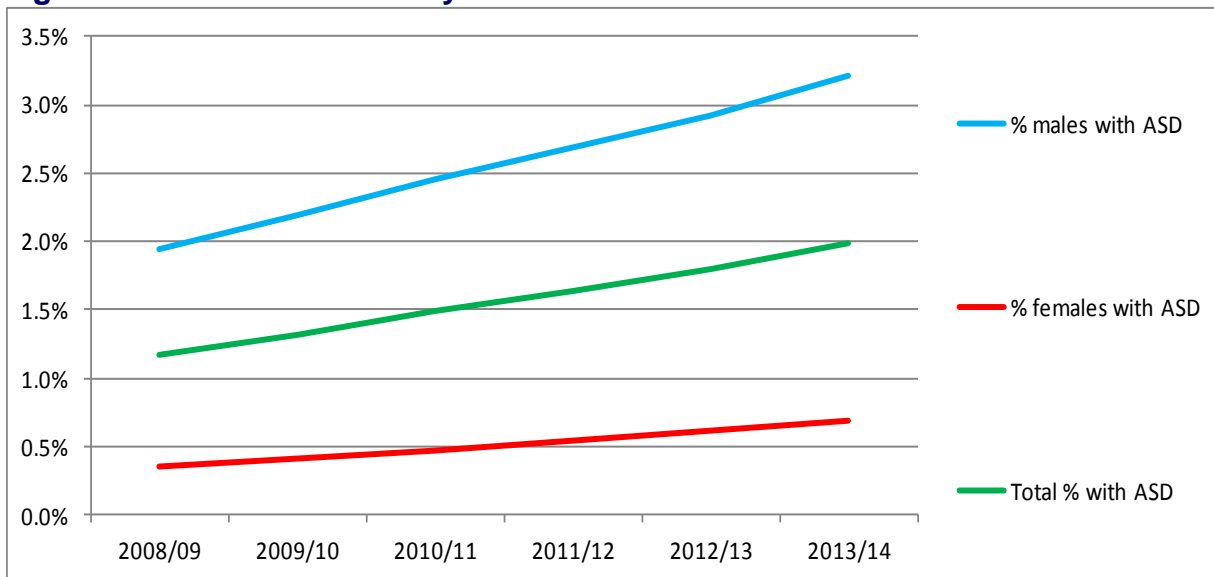


Source: Department of Education

Gender Prevalence

ASD is found to be more prevalent amongst males than females in the general population with a 2007 study⁶ estimating that 1.8% of males were affected by ASD compared to 0.2% of the female population. The School Census data provided by the Department of Education gives a gender split for the years 2008/09 – 2013/14. Figure 2, below, shows a steady parallel rise in the prevalence rate of ASD in both the male and female compulsory school age populations.

Figure 2: Prevalence Rates by Gender 2008/09 – 2013/14



Source: Department of Education

⁶ <http://www.ic.nhs.uk/news-and-events/press-office/press-releases/one-in-a-hundred-adults-have-an-autism-spectrum-disorder-says-pioneering-new-study>

Similar to the 2007 study, ASD was more prevalent in males than females. The 2013/14 figures show that Autism was almost five times more prevalent in the male population (3.2%) than the female population (0.7%). The female population with ASD did however increase on average by 14% each year from 2008/09 to 2013/14; in comparison the male population with ASD saw an average increase of 10% over the same period.

Statistical Significance

The following hypotheses were devised to establish any statistical significance in a relationship between the diagnosis of ASD and gender.

Null: The proportion of children identified with ASD is independent of gender

Alternative: The proportion of children identified with ASD is associated with gender

For each year of this study we can say that there is a significant relationship between the proportion of children identified with ASD and gender, as the chi-square scores were significant at the 0.001 level.

Table 2: Chi Square Scores for Multiple Deprivation Measures Decile Statistical Significance Test

	2009/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	1503.39***	1661.07***	1820.07***	1911.46***	2025.78***	2285.29***

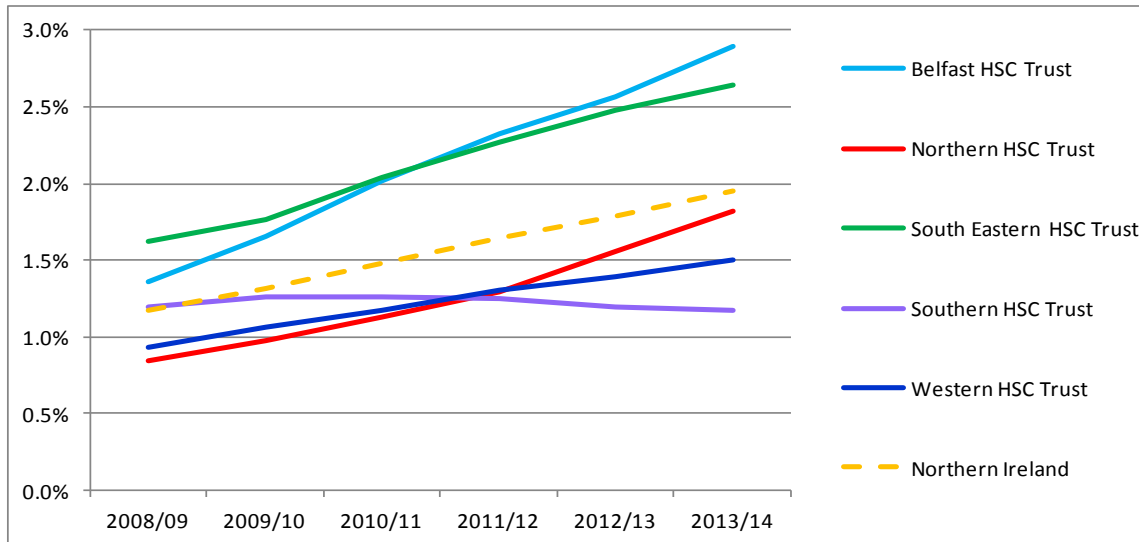
Source: Department of Education

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Urban/Rural Location Prevalence

The overall prevalence rate for ASD in children of compulsory school age in Northern Ireland rose steadily between 2008/09 and 2013/14 by 0.8 percentage points overall. Figure 3 illustrates that the majority of HSC Trusts saw a rise in the prevalence of school children identified with Autism, except for the Southern HSC Trust which maintained a steady level of around 1.2%. The largest change occurred in the Belfast Trust which saw a 1.5 percentage point increase in those identified with ASD, from 1.4% in 2008/09 to 2.9% in 2013/14.

Figure 3: Prevalence Rates for ASD (children of compulsory school age) by Health and Social Care Trust

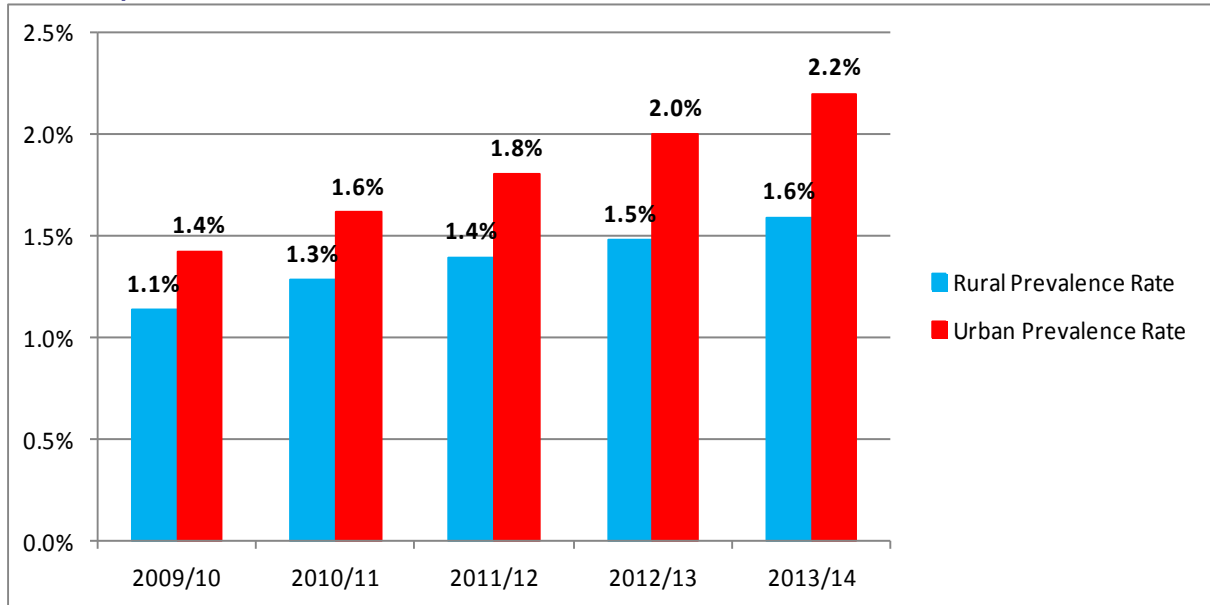


Source: Department of Education

It is also of note, in Figure 3, that the prevalence levels in the Belfast and South Eastern Trusts were consistently higher than the Northern Ireland average. These are the two Trust areas which have a significantly larger urban than rural population (see appendix one).

Both the urban and rural prevalence rates in Northern Ireland, from 2008/09 to 2013/14, have continued to rise (Figure 4). However it is evident that prevalence has been consistently higher in the urban population than the rural population with the largest difference registered in 2013/14 (0.6%). This is due to the year on year growth in the rural ASD population slowing from 13% between 2009/10 and 2010/11 to 9% between 2012/13 and 2013/14. Over the same period of time the urban ASD population has continued to increase at a steady rate of between 11% and 12%.

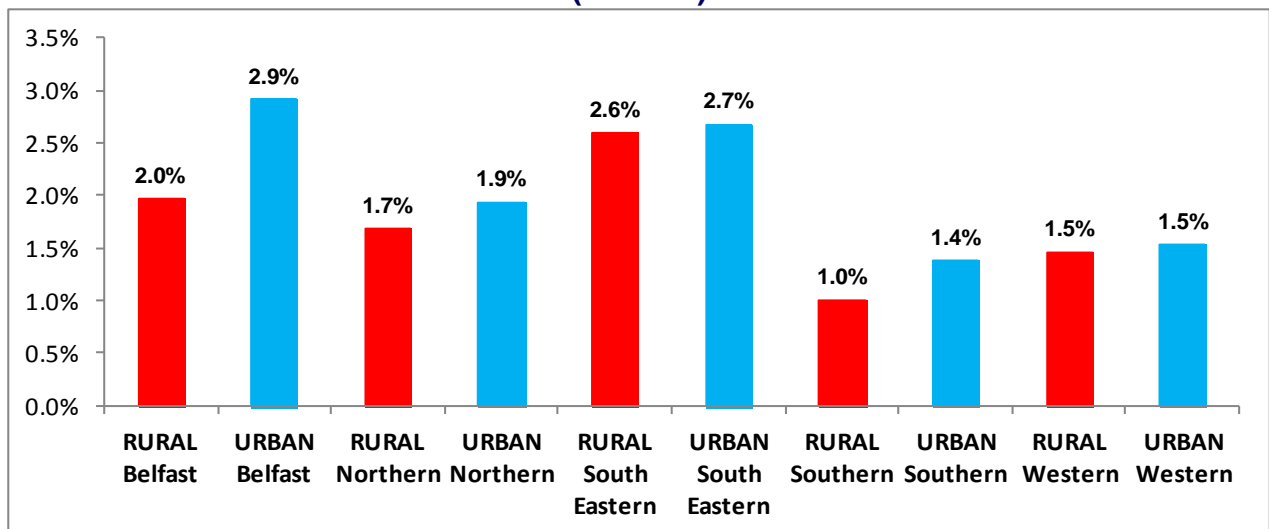
Figure 4: Rural and Urban Prevalence Rates in Northern Ireland (2009/10 – 2012/13)



Source: Department of Education Figures for 2008/09 have been excluded due to small numbers in rural areas figures for the Belfast HSC Trust could not be provided.

Figure 5 shows the Urban/Rural difference in prevalence rates across all of the HSC Trusts. The Trust with the largest difference between its Urban and Rural populations was the Belfast HSC Trust; however the Belfast Trust has a very small rural population which may skew the results (see appendix two). In the other HSC Trusts there was a much more even split between the populations. However it can be seen in the chart below that ASD is also more prevalent in the urban population in the Northern and Southern HSC Trusts. The Western and South Eastern HSC Trusts had similar prevalence rates in their urban and rural populations.

Figure 5: Prevalence Rates for ASD (children of compulsory school age) by HSC Trust and Urban/Rural Location (2013/14)



Source: Department of Education

Note: Appendix One contains a figure detailing the prevalence rates by urban/rural location and HSC Trust for 2008/09 – 2013/14

Statistical Significance

To test if a diagnosis of ASD was independent of Urban or Rural location null and alternative hypotheses were established.

Null: The proportion of children identified with ASD is independent of location (urban/rural)

Alternative: The proportion of children identified with ASD is associated with location (urban/rural)

In each year from 2008/09 to 2013/14, at a regional level, the chi square statistic located on the chi square distribution significance table gave a score lower than 0.05. This meant that the alternative hypothesis was accepted and that the proportion of children identified with ASD was associated with their location, i.e., urban or rural.

Table 3: Chi Square Scores for Urban Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	40.38***	41.36***	48.21***	67.82***	100.67***	129.60***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Performing this test at HSC Trust level resulted in varied outcomes (see appendix 3). The results for the Southern HSC Trust consistently indicated that there was a relationship between the proportion of children identified with ASD and location. However no significant relationship was established in either the Belfast or South Eastern Trusts in any of the years studied.

The Northern and Western HSC Trusts produced mixed results. In the Northern Trust the results for the first (2008/09) and last two years (2012/13 & 2013/14) of the study indicated a relationship between children identified with ASD and location. The Western Trust showed an association between the proportion of children identified with ASD and location for the first two years of the study (2008/09 & 2009/10).

Multiple Deprivation Measure Decile

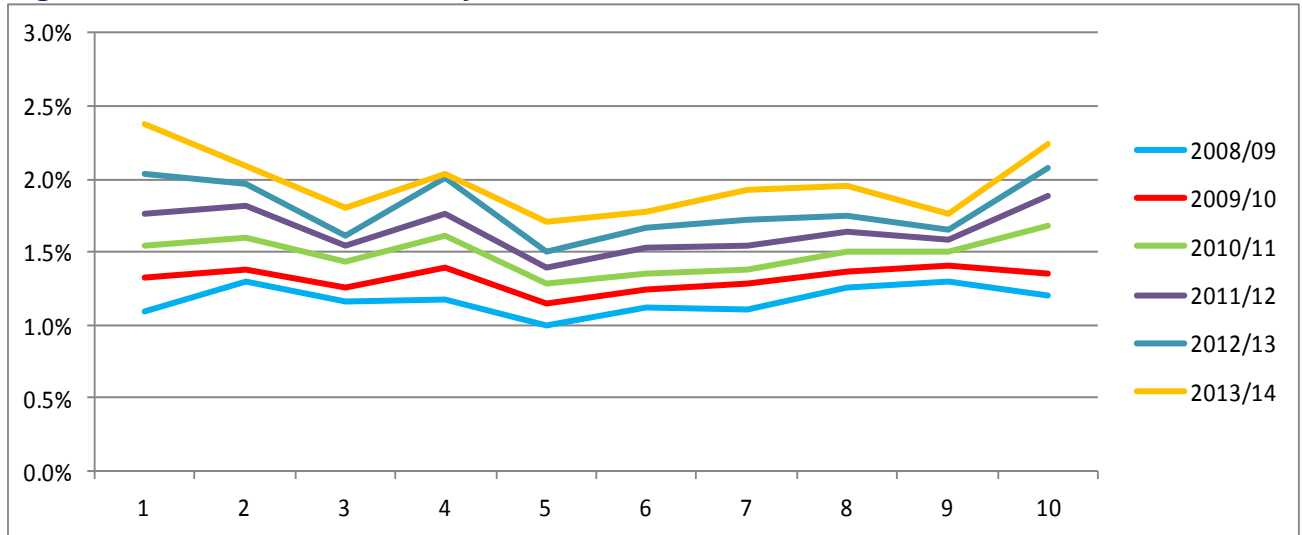
Prevalence

As set out in Figure 6, year on year across all MDM Deciles there was an increase in the prevalence rates of ASD at the regional level. It is difficult to interpret a pattern in Figure 6, however it appears the extreme deciles appear to have higher prevalence rates.

This pattern may exist due to access to services, with those in the most deprived areas having a greater level of state intervention in their lives, while those in the least deprived areas have greater levels of resources which allow them better access to services.

A majority of the most and least deprived deciles are located in urban areas (see appendix 4). This correlates with previous findings where the prevalence of autism was higher in urban populations.

Figure 6: Prevalence of ASD by Year and MDM Decile



Source: Department of Education

Statistical Significance

The following hypotheses were devised to establish any statistical significance in a relationship between the diagnosis of ASD and the MDM score of the area in which the child was living.

Null: The proportion of children identified with ASD is independent of MDM Decile

Alternative: The proportion of children identified with ASD is associated with MDM Decile

For 2009/10 the chi square score produced was not significant. For this year the Null hypothesis was accepted meaning that the proportion of children identified with ASD was independent of MDM Decile. However for the other five years the opposite was true with significance levels less than 0.05, meaning that for these years the alternative hypothesis was accepted, the proportion of children identified with ASD was associated with MDM Decile.

Table 4: Chi Square Scores for Multiple Deprivation Measures Decile Statistical Significance Test

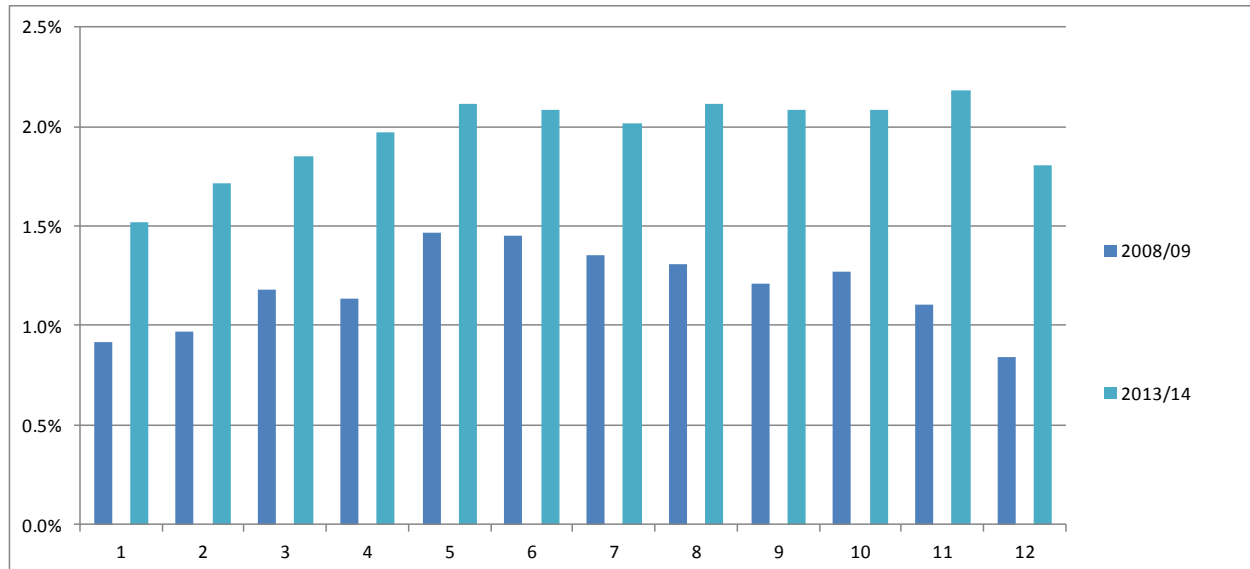
	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	20.27*	13.51	25.29**	35.97***	57.45***	62.09***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

School Year Prevalence

Data for children in each school year identified with ASD for 2008/09 and 2013/14 was provided from the Northern Ireland School Census. This information can be used to compare school year prevalence rates within and between school years.

Figure 7: Prevalence Rates by School Year for Compulsory School Age Children in 2008/09 & 2013/14



Source: Department of Education

Figure 7 shows that prevalence across all school years was higher during 2013/14 compared with 2008/09. During 2008/09, 1.4% was the highest prevalence rate (Year 5 – children aged 9) and 0.8% the lowest (Year 12 – children aged 16). In 2013/14, Year 11 had the highest prevalence rate (2.2%) while Year 1 had the lowest prevalence rate (1.5%). Year 11 had the largest percentage point change between 2008/09 and 2013/14 of 1.1 percentage points.

Looking at Years 1 – 4 (5 – 8 year olds) in 2013/14, as in 2012/13, there was a steady rise in the ASD prevalence rate. This may indicate that as awareness of autism has increased, there is an increased focus on early identification of the disorder with more children identified at this stage in their development. Table 5, below, would support this conclusion as some of the biggest increases in the numbers of children identified with ASD have occurred in Years 1 – 4.

Table 5: The Number of Children Identified with ASD by School Year (2008/09 & 2013/14)

School Year	1	2	3	4	5	6	7	8	9	10	11	12
2008/09	202	209	256	246	326	337	320	318	283	303	270	208
2013/14	382	432	443	451	481	468	444	466	460	472	524	435
% Change	89%	107%	73%	83%	48%	39%	39%	47%	63%	56%	94%	109%

Source: Department of Education

Note: The percentage change is based on absolute values, the base population for the academic years is different

Special Educational Needs Stage

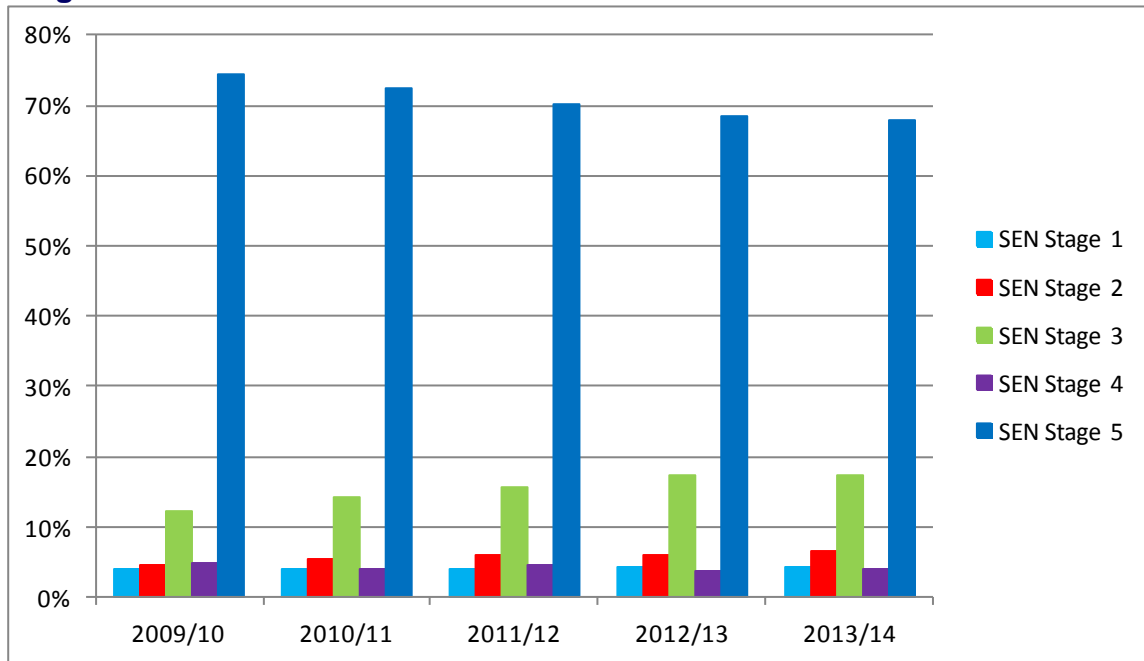
Prevalence

Data for those children with a diagnosis of ASD from 2009/10 to 2013/14 was provided from the Northern Ireland School Census against stages 1 – 5 of Special Educational Needs assessment.

The 'Code of Practice on the Identification and Assessment of Special Educational Needs' implements a five stage approach to the identification of children with learning difficulties, the assessment of their educational need and the making of whatever special educational provision is necessary to meet those needs. The opening three stages are based within the school, while at stages 4 and 5 the requisite Education and Library Board shares responsibility with the school. The stages are as follows:

- Stage One - teachers identify and register a child's special educational needs and, working with the schools special educational needs (SEN) co-ordinator, take initial action.
- Stage Two – the (SEN) co-ordinator leads in collecting and recording information and for co-ordinating the child's special educational provision.
- Stage Three – teachers and the SEN co-ordinator are supported by specialists from outside school.
- Stage Four – the appropriate Education and Library Board considers the need for a statutory assessment and may make a multi-disciplinary assessment.
- Stage Five – the appropriate Education and Library Board consider the need for a statement of special educational needs; if necessary it makes a statement and arranges, monitors and reviews provision.

Children are reviewed on a yearly basis and may move up or down the assessment scale, depending on performance.

Figure 8: Prevalence Rates of ASD by Special Educational Needs Assessment Stage

Source: Department of Education

Figure 8 shows that the majority of children, identified with ASD have been assessed to be at Stage 5 of the special educational needs assessment process as at the time of the annual school census. There has been a small but noticeable decline in the relative percentage of children at stage 5 as opposed to stage 3, over the 5 years analysed. This could indicate that of all the children identified a lesser percentage need the level of intervention warranted by a Stage 5 statement. It must be remembered that the overall numbers of children identified with ASD have increased so while the relative percentage of Stage 5 children has decreased the absolute number has increased.

As the SEN process is a dynamic one with children moving between stages this “snapshot” graph must be treated only as indicative.

Conclusions

1. The figures provided by the school census have shown that the estimated prevalence of autism has increased by 67% across all Health and Social Care Trusts between 2008/09 and 2013/14, from 1.2% of the compulsory school age population to 2.0%.
2. There is a significant difference in the estimated prevalence rates of ASD between the genders, with males almost five times more likely to be affected by ASD than females. However the analysis has indicated that the female ASD population (of compulsory school age) in recent years has increased at a slightly higher rate than the male population.
3. The figures also suggest that at a regional level there is a relationship between the estimated prevalence of autism and location, with the urban Northern Ireland

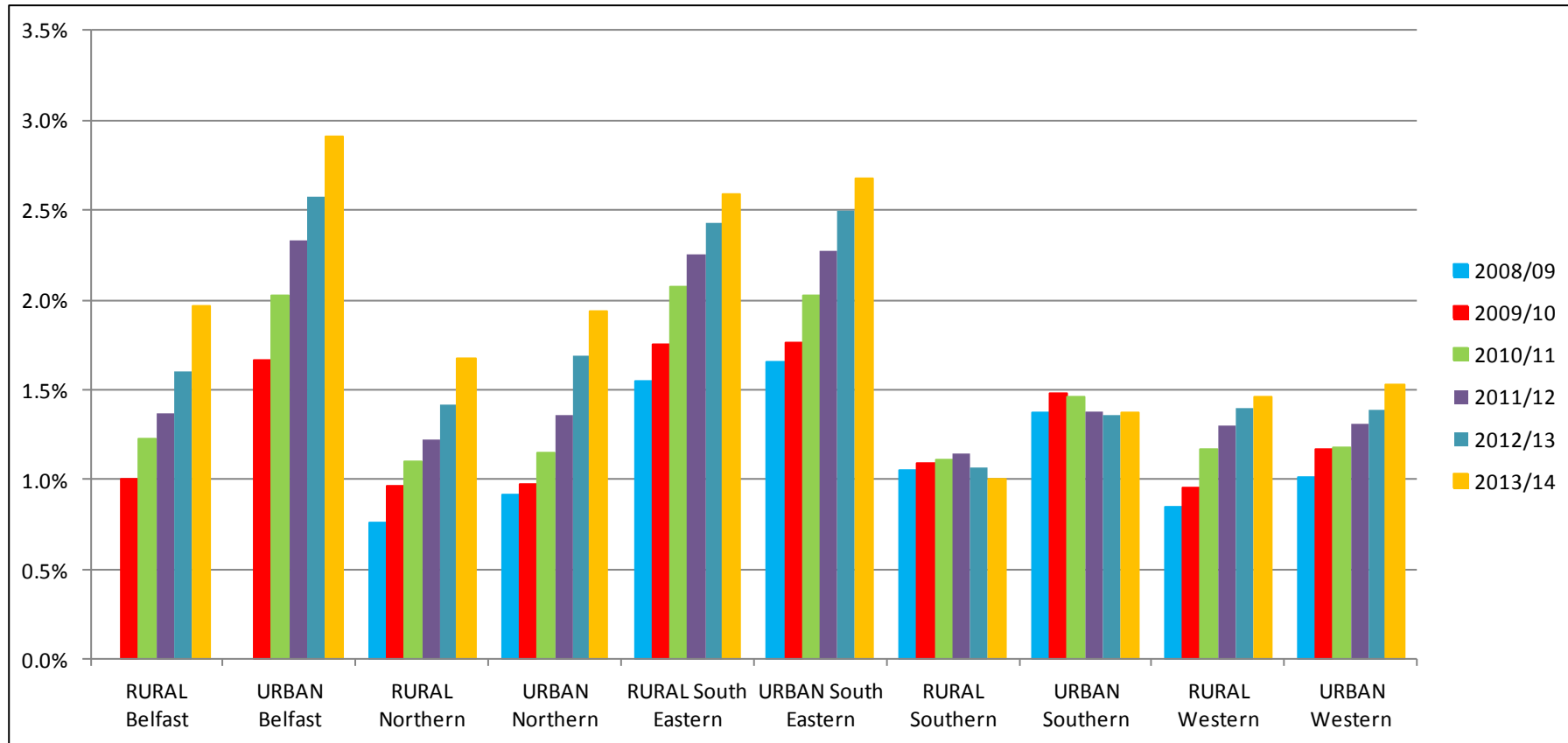
population having a statistically significant higher prevalence rate than the rural population. This result was not fully replicated at Trust level, with only the Southern Trust showing consistent significance between location and the number of children identified with ASD.

4. Over time a significant relationship between the estimated prevalence of autism and levels of deprivation has emerged. This can be seen in the fact that those children in the least and most deprived areas appear to have the highest prevalence rate of ASD, with those children in MDM deciles closer to the middle of the scale having the lower rates of ASD prevalence. There are exceptions to this (Decile 4) which indicates this area may require further study. As many of the most and least deprived MDM deciles are located in urban areas there is likely some cross cutting relationship with the results seen for ASD diagnosis and the urban rural spilt (see appendix 3).
5. Looking at prevalence across school years over time we can see that the estimated prevalence of ASD has increased across all school years with the greatest increases in the numbers of children identified with ASD occurring in the youngest (5 – 8 year olds) and oldest (13 – 16 year olds) groups of children.
6. Finally, the data shows that the majority of children with ASD have been assessed to be at Stage 5 of the Special Educational Needs assessment process. The 5 year analysis indicates that there is a small but constant movement in the relative percentage of identified children at Stage 5 during the school census snapshot.

Appendices

Appendix One

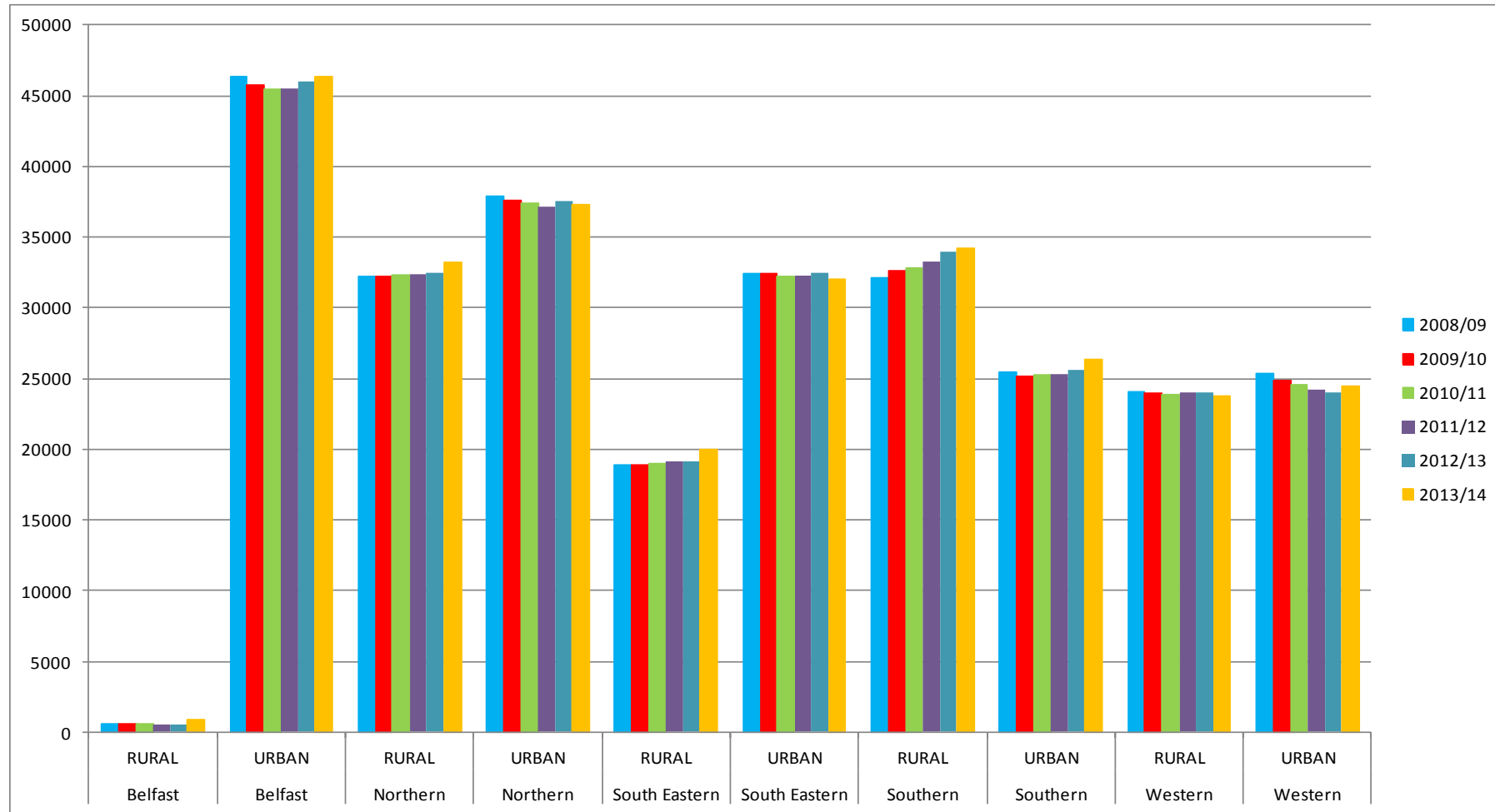
Figure 9: The Rural and Urban Populations (Compulsory School Age Children) of each Health and Social Care Trust 2008/09 – 2012/13



Source: Department of Education

Appendix Two

Figure 10: The Rural and Urban Populations (Compulsory School Age Children) of each Health and Social Care Trust 2008/09 – 2012/13



Source: Department of Education

*Appendix Three – Chi Score Results***Table 6: Belfast HSC Trust Chi Square Scores for Urban Rural Location Statistical Significance Test**

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	-	1.61	1.85	2.37	2.08	2.71

Note: Significance figures less than 0.05 are statistically relevant, due to small numbers in 2008/09 it was not possible to provide an urban rural split for children with ASD. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 7: Northern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	5.06*	0.01	0.46	2.42	8.14**	6.57**

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 8: South Eastern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	0.78	0.11	0.11	0.03	0.28	0.38

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 9: Southern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

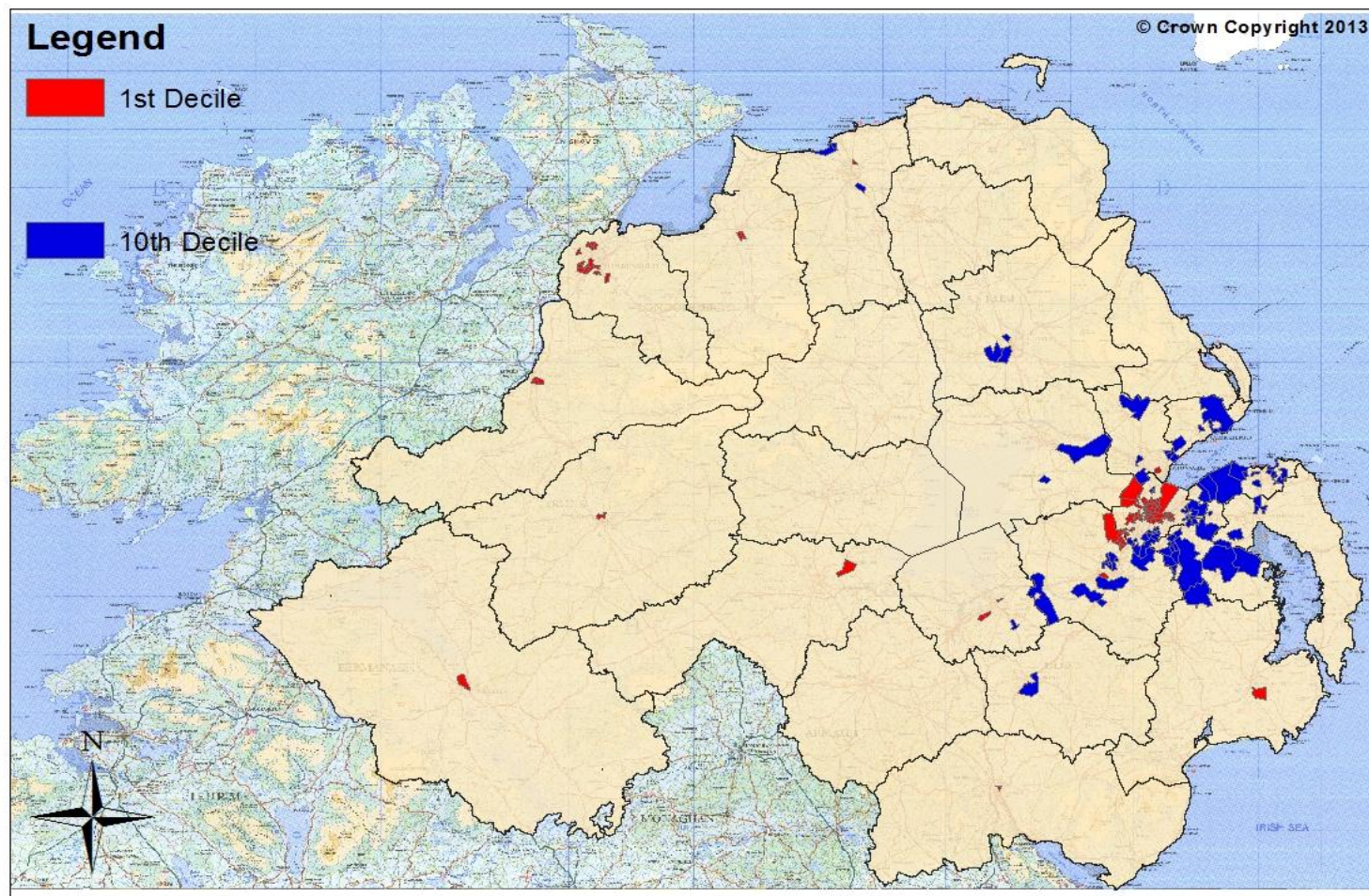
	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	12.33***	17.04***	14.74***	6.49**	10.55***	17.64***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table10: Western HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

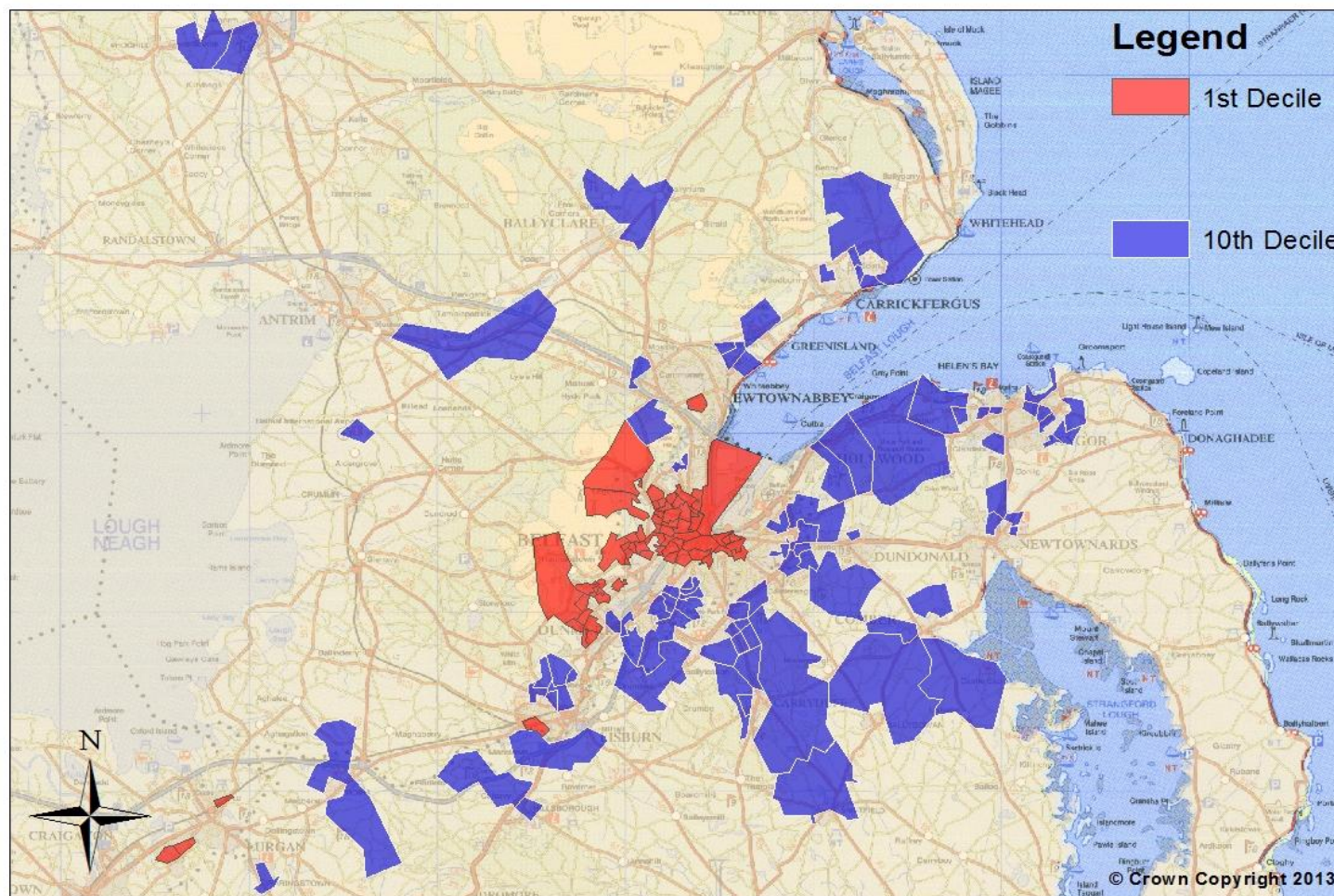
	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Chi Square Score	3.98*	5.43*	0.00	0.02	0.00	0.41

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

*Appendix Four – Deprivation Maps***Figure 11: Map Showing the Most (Red) and Least (Blue) Deprived Areas in Northern Ireland**

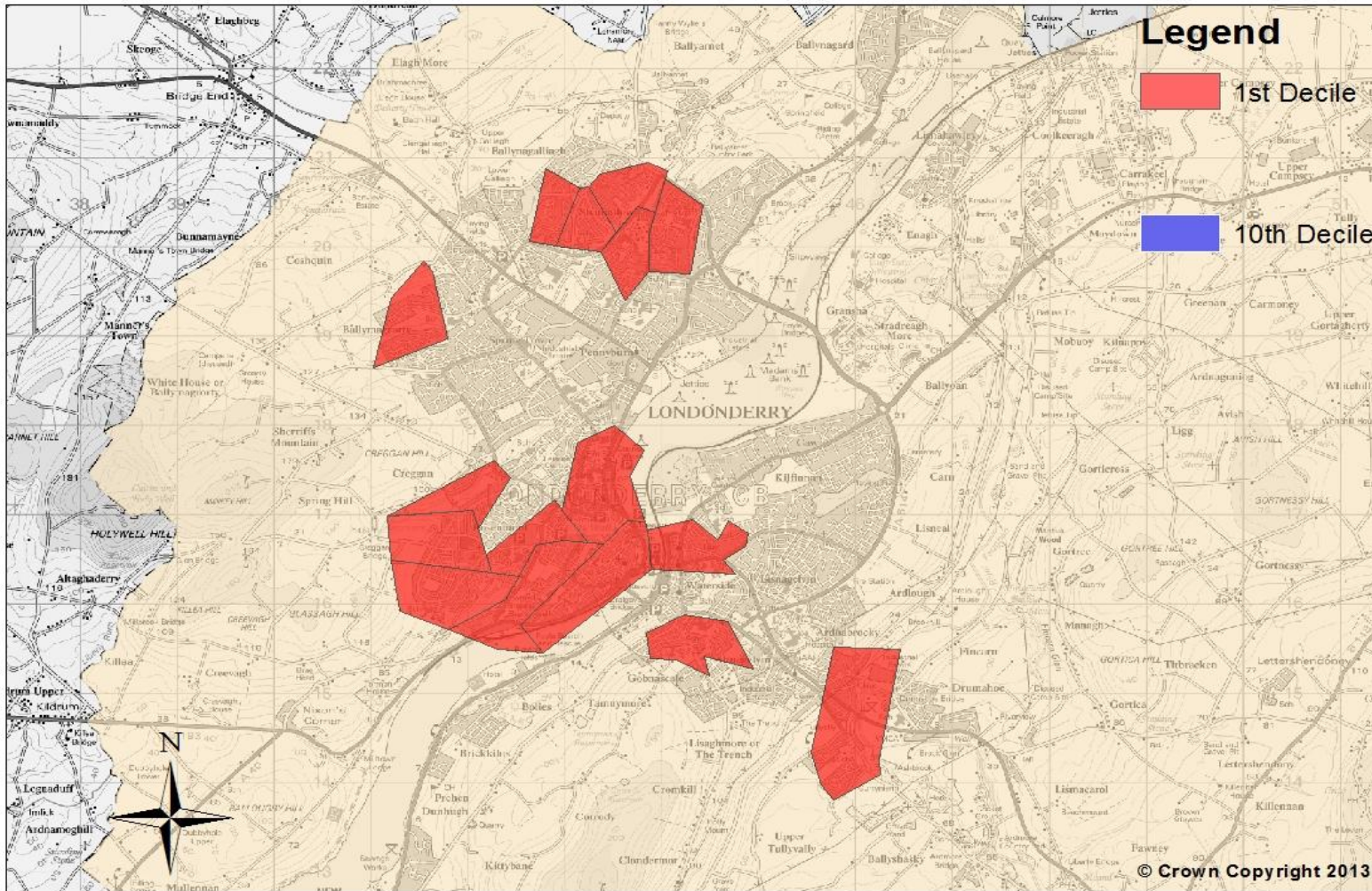
Source: NISRA – Demography and Methodology Branch

Figure 12: Map Showing the Most (Red) and Least (Blue) Deprived Areas in the Greater Belfast area



Source: NISRA – Demography and Methodology Branch

Figure 13: Map Showing the Most (Red) and Least (Blue) Deprived Areas in Londonderry



Source: NISRA – Demography and Methodology Branch

Additional Information

For further information on **The Prevalence of ASD in School Age Children in Northern Ireland**

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