INFORMATION
ANALYSIS
DIRECTORATE

The Prevalence of Autism (including Asperger Syndrome) in School Age Children in Northern Ireland 2017

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Our Vision and Values

- *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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Introduction

Autism 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. It is a spectrum condition, meaning that while all people with autism will have similar problems, overall their condition will impact them in different ways. Some people may be able to lead independent lives while others will require a lifetime of specialist support. Asperger Syndrome is a similar condition to autism; however these children 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, communication and interaction.

The need to develop and improve health and social care services for people of all ages who are affected by autism (including Asperger Syndrome) has been apparent for some time. In order to provide effective services, knowing the incidence and prevalence of this condition is clearly important. This report aims to show the prevalence of autism amongst children of compulsory school age (4–15 year olds at the start of the school year), as it is clear that autism persists and that children with autism become adults with autism, each with their own particular needs.

The introduction of the Autism Act (Northern Ireland) 2011 and the accompanying increase in awareness via campaigns and consciousness raising events, may well contribute to a rise in the number of assessments carried out and positive diagnoses processing through the system. The Health and Social Care Board have developed a routine monitoring process which identifies those children who have undergone an assessment for autism and those who have received a positive diagnosis. These figures are reported quarterly by the Department and can be found at the following link: https://www.health-ni.gov.uk/articles/autism-statistics

> *For the purposes of this paper children identified as having Asperger Syndrome are included in all calculations of autism prevalence*

2008/09 → **2016/17**
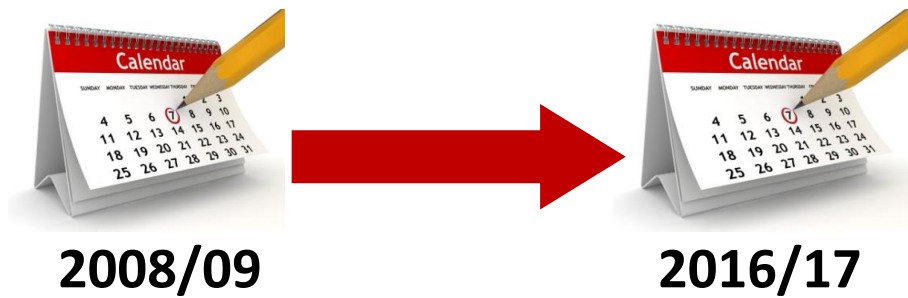
| The autism[1] prevalence rate: | 1.2% | → | 2.5% |

| The autism prevalence rate for males: | 1.9% | → | 3.9% |

| The autism prevalence rate for females: | 0.4% | → | 1.0% |

| The proportion of children with autism at stage 5 of the SEN[2] assessment: | 74% | → | 63% |

The inequality gap continues to grow with autism levels 42% higher in the most deprived decile compared to the Northern Ireland average during 2016/17

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[1] Refers to all children of compulsory school age (4 – 15 years old)

[2] Special Educational Needs

Overall Prevalence in Northern Ireland

2.5%

of school age children were identified with autism

The figures extracted from the Northern Ireland School Census show that the estimated prevalence of autism within the school aged population has increased by 1.3 percentage points, from 1.2% in 2008/09 to 2.5% in 2016/17. (See Appendix D for totals)

Autism Prevalence in School Aged Children
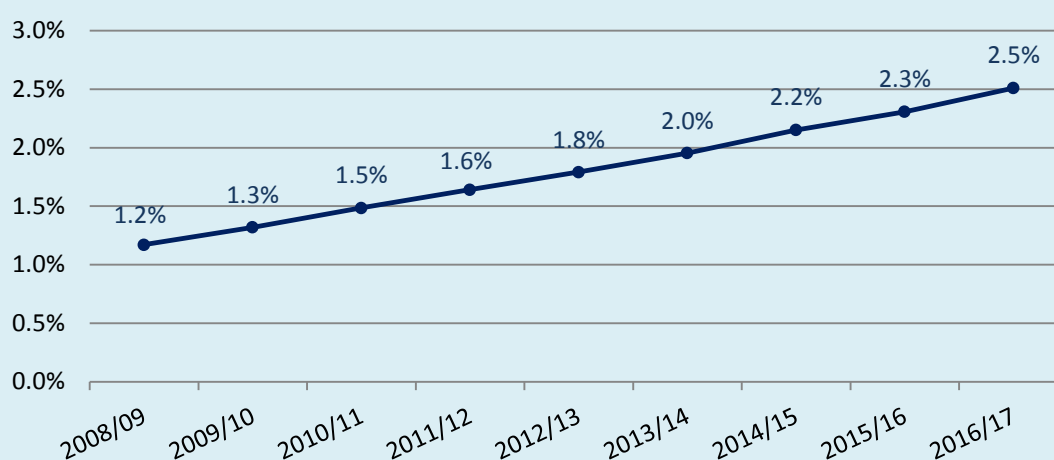
The increase in prevalence of children with autism can be attributed to an annual average increase in the number of children identified with autism of 10% between 2009/10 and 2015/16, against a background of a relatively static school population.

**Annual % Change in School & Autistic Populations**
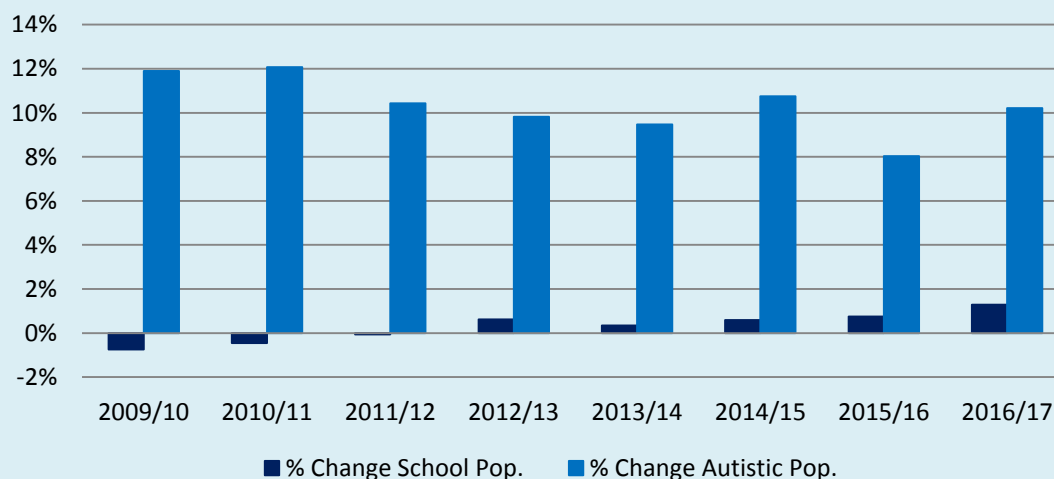
Gender

Males were **4 times** *more likely to be autistic than females*

Previous studies have shown that more males than females have been diagnosed with autism, with ratios ranging from 2:1 to 16:1. The National Autistic Society (NAS) state that in 2015 the ratio of males to females using their adult services was 3:1 and those that use NAS schools was 5:1.

The information derived from the 2016/17 Northern Ireland School Census follows the pattern outlined above with figures showing that 3.9% of males were identified with autism compared to 1.0% of females.

Autism Prevalence by Gender
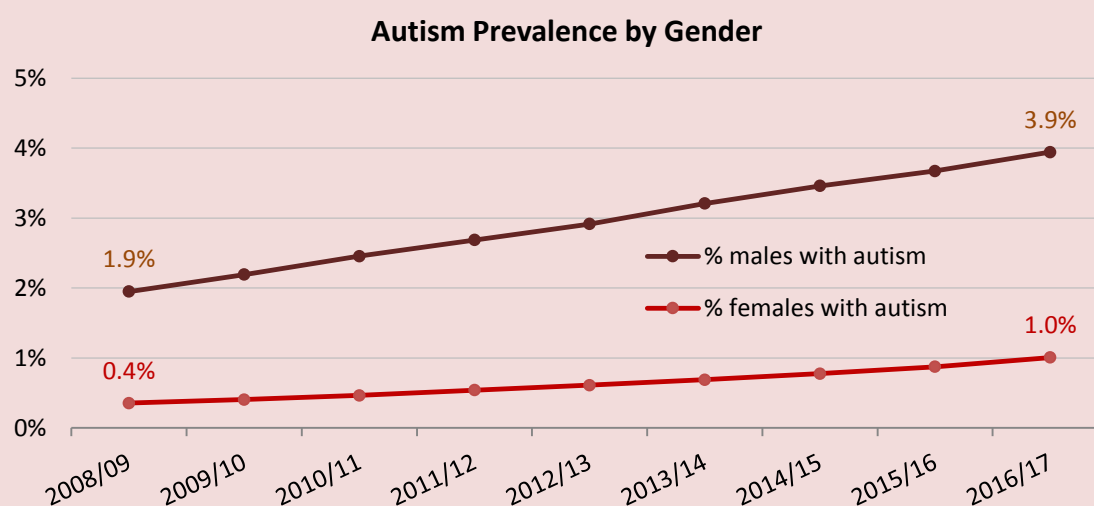
There was an increase of two percentage points in the prevalence of autism in the male population between 2008/09 and 2016/17. Over the same period of time the increase in the prevalence of autism in females was 0.6 percentage points.

There have been a number of possible explanations for the identified gender differences of those with autism. Researchers[3] have suggested that females may present differently than males and that the current diagnostic criteria do not recognise these differences.

A further premise is that the higher prevalence of autism amongst males is an exaggeration of normal differences in gender, as in general females have better communication skills

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[3] Gould, J. & Ashton-Smith, J. Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice,* 2011, 12(1), 34 – 41

while males are more likely to be better at visual and spatial awareness tasks. Autism could therefore be considered to be an extreme of the normal male profile[4].

Another hypothesis put forward is that the differences in autism can be explained by genetic differences between males and females[5].

[4] Baron-Cohen, S. The extreme male brain theory of autism. *Trends in Cognitive Sciences,* 2002, 6(6), 248 – 254
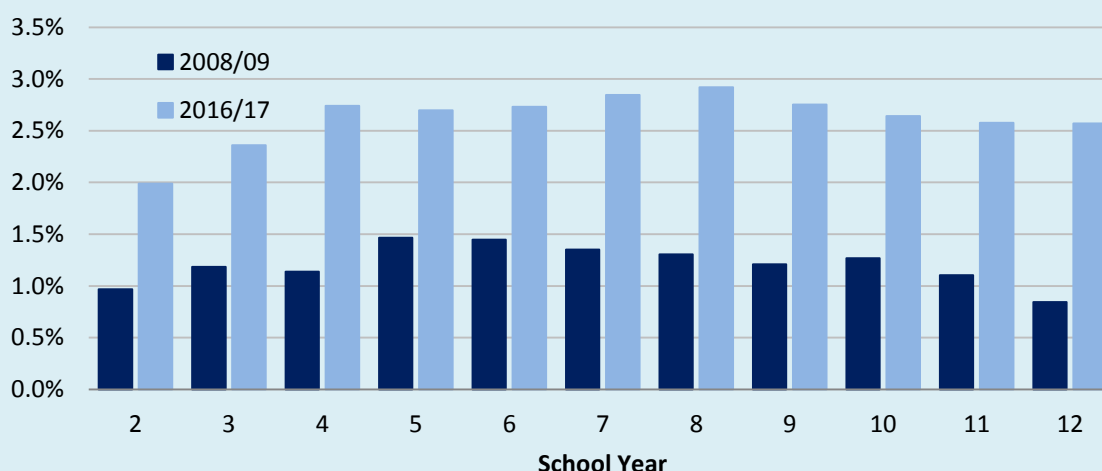[5] Skuse, D.H. Imprinting, the X-Chromosome, and the Male Brain: Explaining Sex Differences in the Liability to Autism. *Pediatric Research,* 2000, 47, 9 – 9

2.9%

of children in Year 8 were identified with autism

Autism Prevalence by School Year 2008/09 & 2016/17

Prevalence across all school years was higher during 2016/17 compared with 2008/09. During 2008/09 the highest prevalence rate recorded was 1.5% for those in Year 5 (children aged 9) and the lowest was 0.8% for those in Year 12 (children aged 16). In comparison, during 2016/17, the highest prevalence rate recorded was 2.9% for those in Year 8 (children aged 12) and the lowest was 2.0% for those in Year 2 (children aged 6). Year 12 had the largest percentage point change between 2008/09 and 2016/17 of 1.7 percentage points.

Looking at Years 2–4 (6–8 year olds) in 2016/17 there is a steady rise in the prevalence rate of autism. This may indicate that most identification of autism is occurring when children are aged between 6 and 8 years old.[6]

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[6] Please note that due to small numbers it was not possible to provide figures for those in Year 1 during 2016/17.

Special Educational Needs Stage

63%

of children with autism were at Stage 5 of the Special Educational Need Assessment

The Code of Practice on the Identification and Assessment of Special Educational Needs (SEN)[7,8] 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 initial three stages are dealt with by the school, while at stages 4 and 5 the education authority shares responsibility with the school. Children are reviewed on a yearly basis and may move up or down the assessment scale, depending on performance.

Autism Prevalence by SEN Stage
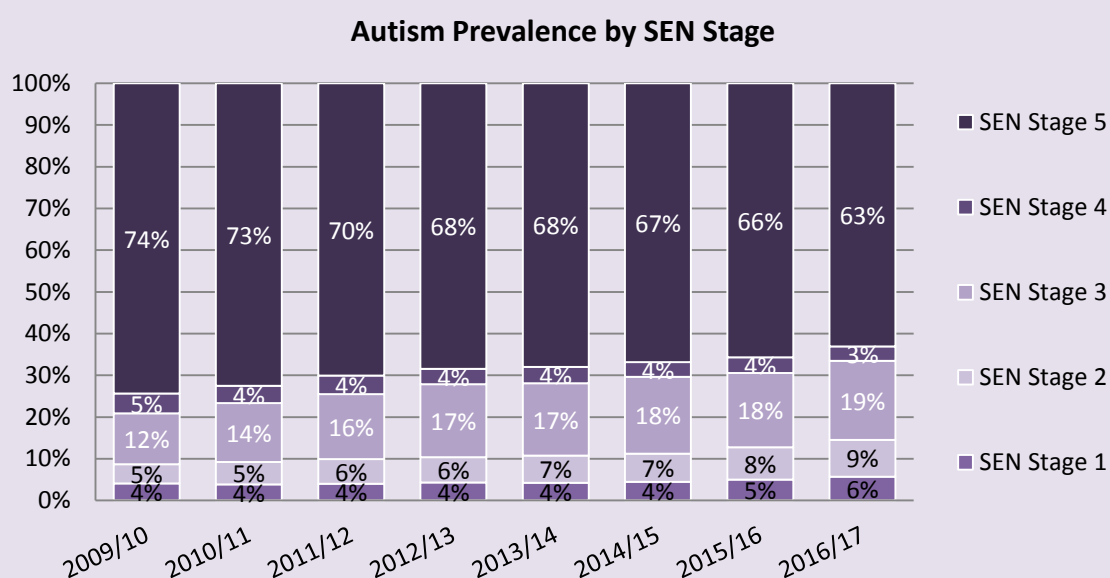
There has been a noticeable decline in the relative percentage of children at SEN stage 5 as opposed to stages 2 and 3, over the 8 years analysed. This indicates that of all the children identified as autistic, a lesser percentage required the level of intervention warranted by a stage 5 statement. It must be remembered that the overall numbers of children indentified with autism have increased so while the relative percentage of stage 5 children has decreased the absolute number has increased.

As the SEN process is dynamic with children moving between stages this 'snapshot' graph must be treated only as indicative[9].

[7] https://www.deni.gov.uk/articles/special-educational-needs-code-practice
[8] The stages of the SEN process are detailed in Appendix B
[9] The 2015/16 Northern Ireland School Census includes all pupils on the school roll at 9th October 2015, who have attended for at least one day, whether or not accommodated on the school's premises

Health and Social Care Trust

3.9%

of children in the Belfast HSC Trust were identified with autism

**Autism Prevalence by HSC Trust**
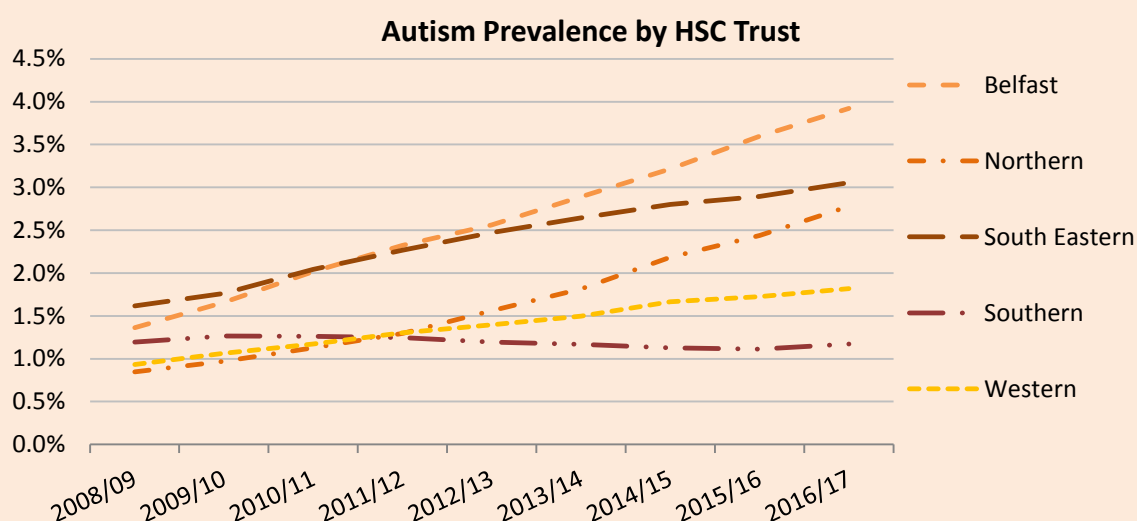
For four of the Health and Social Care (HSC) Trusts, between 2008/09 and 2015/16, there has been an increase in the prevalence of autism, ranging from 2.6 percentage points in the Belfast HSC Trust to 0.9 percentage points in the Western HSC Trust. Over the same period of time there was no change in the prevalence rate of autism in the Southern HSC Trust.

The autism prevalence rate in both the Belfast and South Eastern HSC Trusts has been consistently higher than the Northern Ireland average between 2008/09 and 2016/17. The rate of prevalence in the Northern HSC Trust was higher than the Northern Ireland average in each of the last three years, and has also had the largest percentage increase in the number of children identified as having autism in the past year.

Urban/Rural Location

Children in urban areas were **1 ½ times** *more likely to be autistic than those in rural areas*

Autism Prevalence by Location
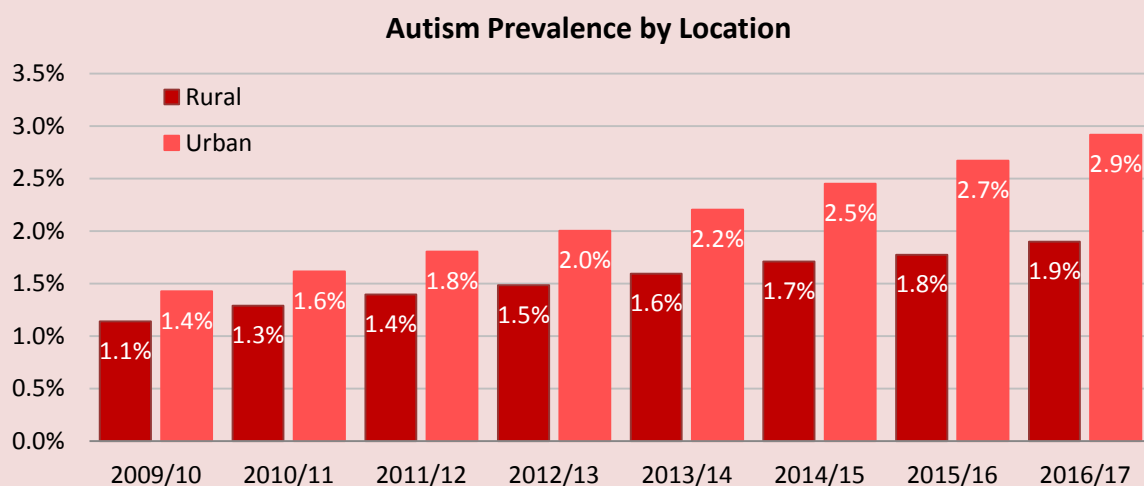
The autism prevalence rates have increased year on year in both urban and rural areas, between 2009/10 and 2016/17. It is evident that prevalence has been consistently higher in the urban population than the rural population with the largest difference registered in 2016/17 (1.0 percentage point).

The HSC Trust with the largest difference in prevalence rates between the urban and rural populations was the Belfast HSC Trust. It should be noted that this HSC Trust has he highest overall prevalence rate and is almost exclusvely urban which has a significant impact upon the Northern Ireland figure. In each of the other HSC Trusts, there was a much more even split between the populations.

Autism Prevalence by Location & HSC Trust (2016/17)
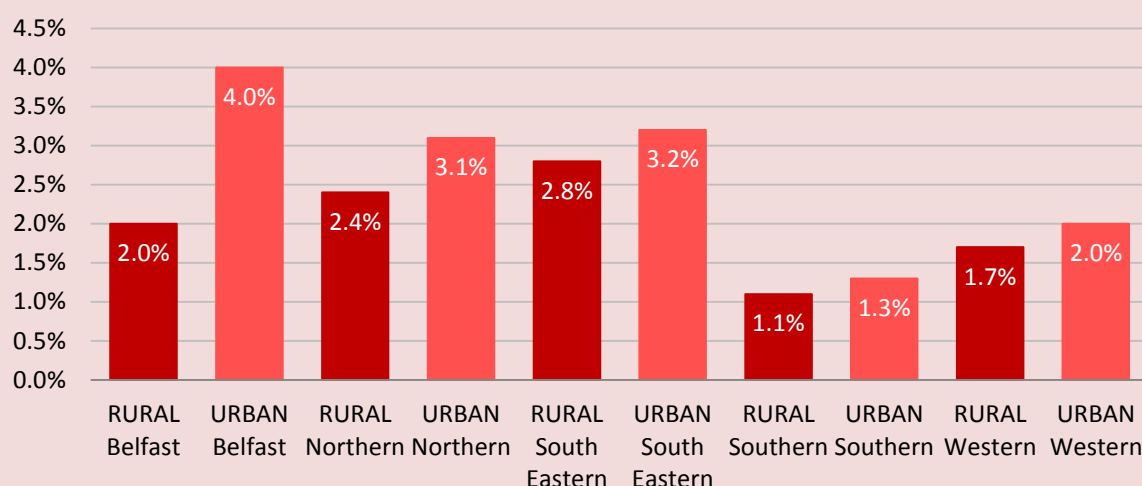
The difference in the proportion of children identified with autism in urban and rural areas at a regional level were statistically significant. This means that it is unlikely that the difference has occurred by chance alone.

Results at HSC Trust levels, however, resulted in varied outcomes. Analysis for the Southern HSC Trust had consistently, over the last years, indicated that there is a relationship between the proportion of children identified with autism and location. However analysis of the 2016/17 data indicated no sginficant realtionship. No significant relationship was established in the Belfast HSC Trust in any of the years analysed. Low numbers in the rural population may contribute to this result.

The Northern, South Eastern and Western HSC Trusts produced mixed outcomes. In the Northern HSC Trust the analysis for the last five years indicated a realtionship between children identified with autism and location. The South Eastern HSC Trust showed a realtionship between these variables in the last two years examined. Figures for the Western HSC Trust only showed a relationship in the first and last years studied.

Therefore, at regional level, there is a significant relationship between urban/rural location and the prevalence of autism, however this trend is not so evident when assessing lower level geographies.
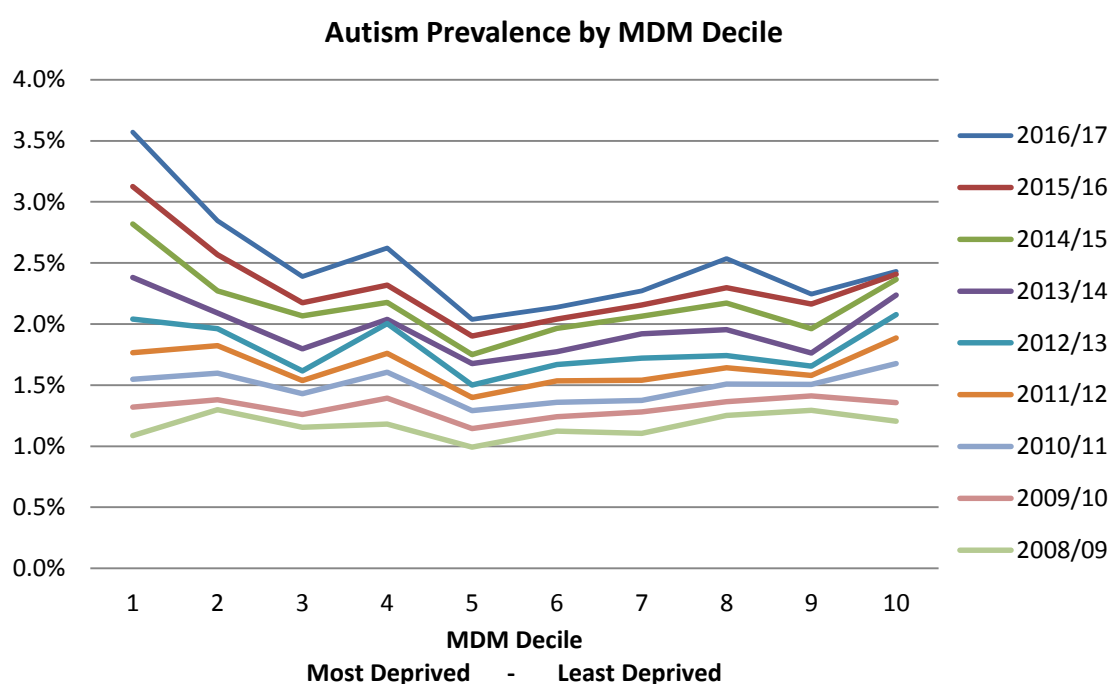
Multiple Deprivation Measure Decile[10, 11]

14%

of children identified with autism were living in the most deprived decile of Northern Ireland

During 2016/17, 14% of children identified with autism were from the most deprived decile in Northern Ireland, while 8% of children identified with autism were located in the most affluent decile of the country.

The statistical significance of the prevalence of autism and MDM Decile has been assessed each year. It has been found that the proportion of children identified with autism is associated with MDM Decile for each year from 2010/11 onwards.

Autism Prevalence by MDM Decile

We can see from the graph above an increase year on year in the prevalence of autism in each Multiple Deprivation Measure (MDM) Decile. It is hard to discern a clear pattern, however it would appear that the prevalence of autism among school aged children is higher in the most deprived areas. The lowest rate of prevalence (2.0%) was recorded in decile 5, this was the same in each of the eight years that figures have been reported.

It is however worth noting that over the last three years the increase in the prevalence of autism in the least deprived decile (10) has only increased incrementally. The prevalence of

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[10] Further information on the Northern Ireland Multiple Deprivation Measure can be found at the following link:
http://www.nisra.gov.uk/deprivation/nimdm_2010.htm
[11] Maps showing the most and least deprived deciles of Northern Ireland can be found in Appendix D

autism in the most deperived decile (1) has increased by 2.5 precentage points between 2008/09 and 2016/17, compared to a 1.2 percentage point increase in the least derpived decile over the same period of time.
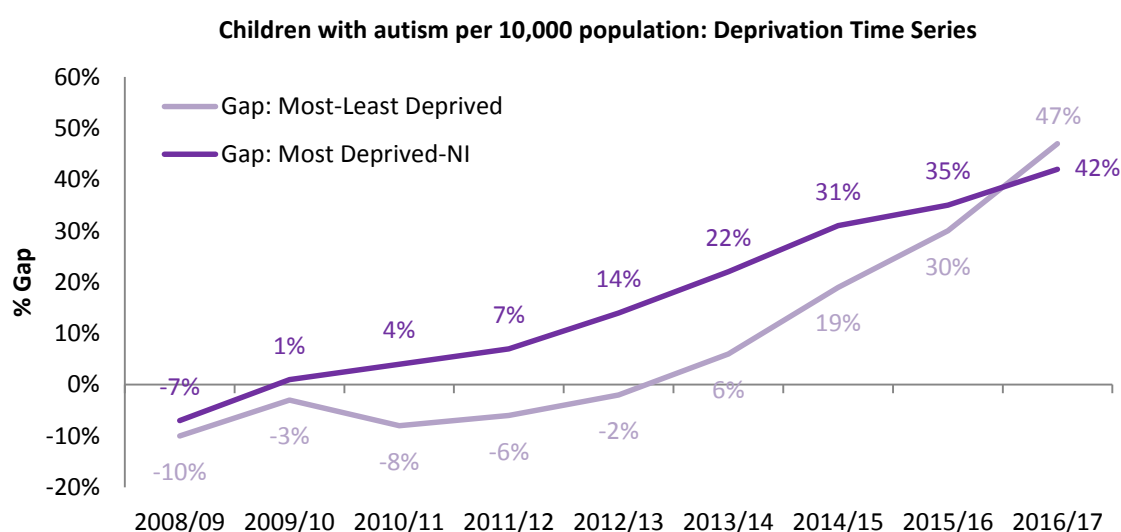
Inequality Gap

The rate of autism in the most deprived decile was 42% *higher than the Northern Ireland average*

The following analysis of the autism inequality gap was carried out through the NI Health & Social Care Inequalities Monitoring System (HSCIMS)[12] within the Department of Health which provides in-depth assessment of inequality gaps across a range of health and social care indicators.

The simple gap analysis, below, shows that the rate of autism in school aged children in the most deprived decile in Northern Ireland stood at 3,570 cases per 100,000 population in 2016/17. This was over a third higher than the rate in the least deprived decile (2,432 cases per 100,000 population).

In the years prior to 2013/14, rates were slightly higher in the least deprived areas than in the most deprived areas. However in the last four years the rate of autism amongst children in the most deprived areas has increased at a faster rate than in the least deprived. This has resulted in higher rates of autism being seen in the most deprived areas and a subsequent widening of the inequality gasp.

Children with autism per 10,000 population: Deprivation Time Series

Further analysis using the Slope Index of Inequality (Sii) and the Relative Slope of Index (Rii) can be found in Appendix C.

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[12] https://www.dhsspsni.gov.uk/topics/dhssps-statistics-and-research/health-inequalities-statistics

Appendix A – Technical Notes

Data Collection

The information presented in this bulletin derives from the 'Northern Ireland School Census' collected by the Department of Education (NI). 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 Census collects a large amount of information including demographic data, free school meal entitlement, looked after children numbers, newcomer children numbers and assessment data. This includes disability and a breakdown of those children identified with autism.

The data extracted from the 'Northern Ireland School Census' for use in this publication includes the number of children identified with autism (including Asperger's Syndrome) by Health and Social Care (HSC) Trust, multiple deprivation measure, urban/rural split, gender and school year.

Data Quality

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

Data is sourced from the school census which is not a diagnostic source. This is presently the most comprehensive data source available, it only covers those children of compulsory school age attending school. Information would suggest that there were approximately an additional 230 home taught children known to the education authority with no further details available.

The data only captures those children identified with autism, at any time there may be additional children who may be progressing through the full assessment process and it is possible that a number of children may be identified as having autism at a later date.

It should also 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 bulletin, not least the assumption that there is consistency of approach in the care pathways as managed by the different HSC 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 HSC Trust areas.

Rounding Conventions

Percentages have been rounded and as a consequence some percentages may not sum to 100. A figure of 0% may reflect rounding down of values under 0.5%.

Revisions Policy

These data are revised by exception. If this occurs the circumstances of the revision are reported on our website and the dates figures are revised are noted both on the website and within the publication. The full revisions policy for statistics published by Information and Analysis Directorate is published on the Department's website.

Main Uses of Data

Data from this bulletin meets the information requirements of a wide range of internal and external users. It is used to monitor the delivery of social care services to children, to help assess HSC Trust performance, corporate monitoring, to inform and monitor related policy, and to respond to parliamentary/assembly questions. The bulletin is also used by academics/researchers, the voluntary sector and those with an interest in autism.

Related Publications

Data is published on the Department's website each quarter on the number of children referred for an assessment for autism and the number of children diagnosed with autism. Figures are provided for Northern Ireland and each HSC Trust area. This data can be found at the following link:

https://www.health-ni.gov.uk/articles/autism-spectrum-disorder-asd-statistics

User Engagement

If you have any comments on this publication please contact:

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Iain.waugh@health-ni.gov.uk
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Next Release

The next release of these statistics is scheduled for July 2018. The publication release dates for statistical bulletins produced by Community Information Branch are available from the Department's website at:

https://www.health-ni.gov.uk/publications/statistical-releases-calendar

Appendix B – Definitions

School Age

Children aged 4 – 15 years at the start of the school year are of compulsory school age.

Autism

Autism is a lifelong developmental disability that affects how a person communicates with and relates to other people and how they experience the world around them. Autism is often described as a 'spectrum disorder' because the condition affects people in many different ways and to varying degrees.

Asperger Syndrome

Asperger Syndrome is similar to autism; however people with this condition 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.

Autism Act (Northern Ireland) 2011

The Autism Act (Northern Ireland) 2011 required the Department of Health, Social Services and Public Safety to lead on the development; implementation; monitoring and reporting of a cross-departmental Autism Strategy. The Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016) was subsequently approved by the Northern Ireland Executive and launched in January 2014.

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 autism 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 autism.

Statistical Significance

In order to test whether or not the relationship between two variables was statistically significant we used the chi-square test.

Special Educational Needs (SEN) Assessment Stages

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 Education Authority considers the need for a statutory assessment and may make a multi-disciplinary assessment.

Stage Five

The Education Authority consider the need for a statement of special educational needs; if necessary it makes a statement and arranges, monitors and reviews provision.
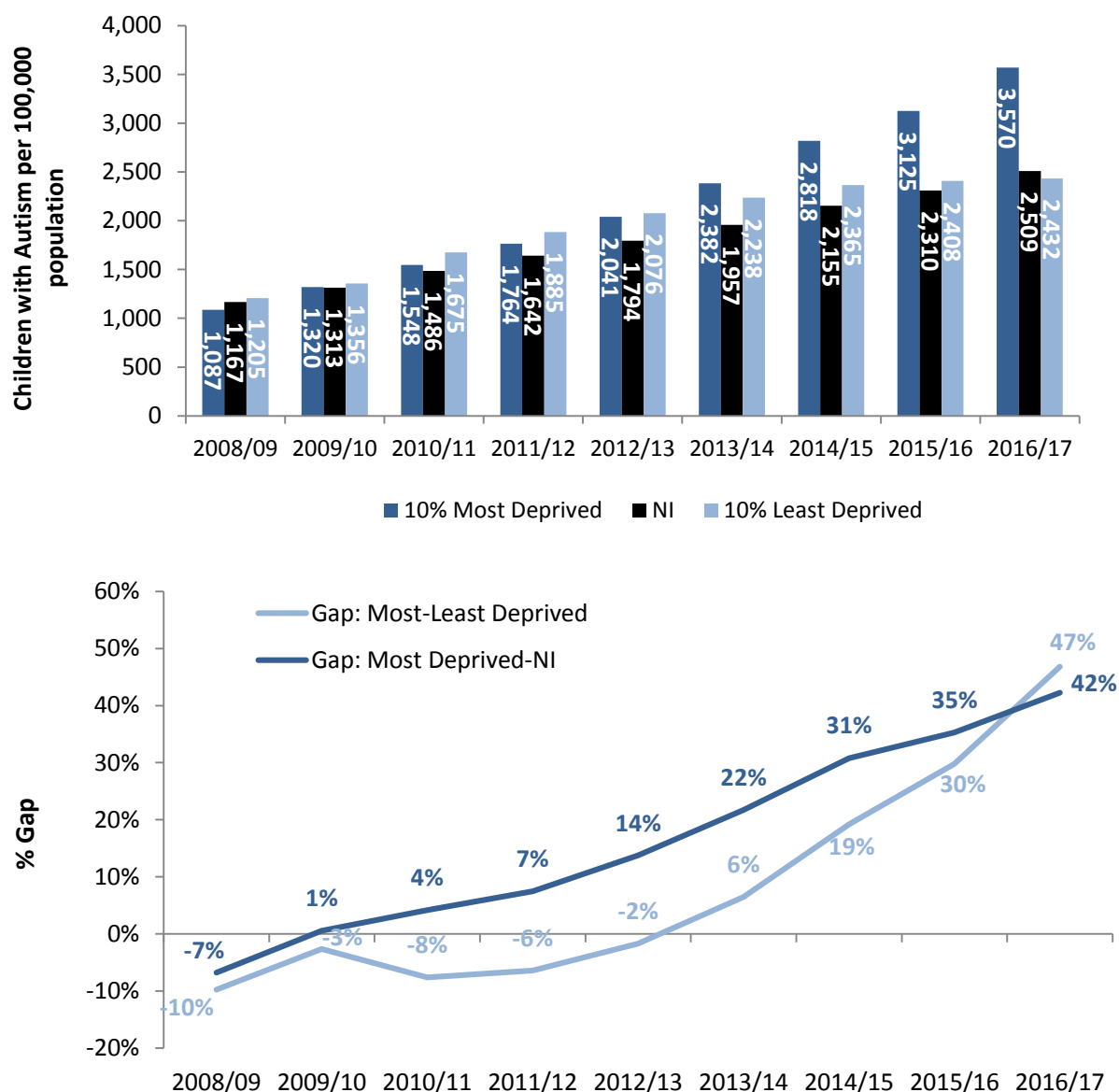

Inequalities[13]

Statistical techniques such as the slope index of inequality and the relative index of inequality have been used to analyse socioeconomic inequalities between children identified with autism. More information on these can be found in the appendix.

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[13]This method was used to analyse ASD figures against the Multiple Deprivation Measure

Appendix C – Further Information

Children with Autism – Deprivation Analysis

Simple Gap

Children with Autism per 100,000 population

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17
10% Most Deprived	1,087	1,320	1,548	1,764	2,041	2,382	2,818	3,125	3,570
NI	1,167	1,313	1,486	1,642	1,794	1,957	2,155	2,310	2,509
10% Least Deprived	1,205	1,356	1,675	1,885	2,076	2,238	2,365	2,408	2,432

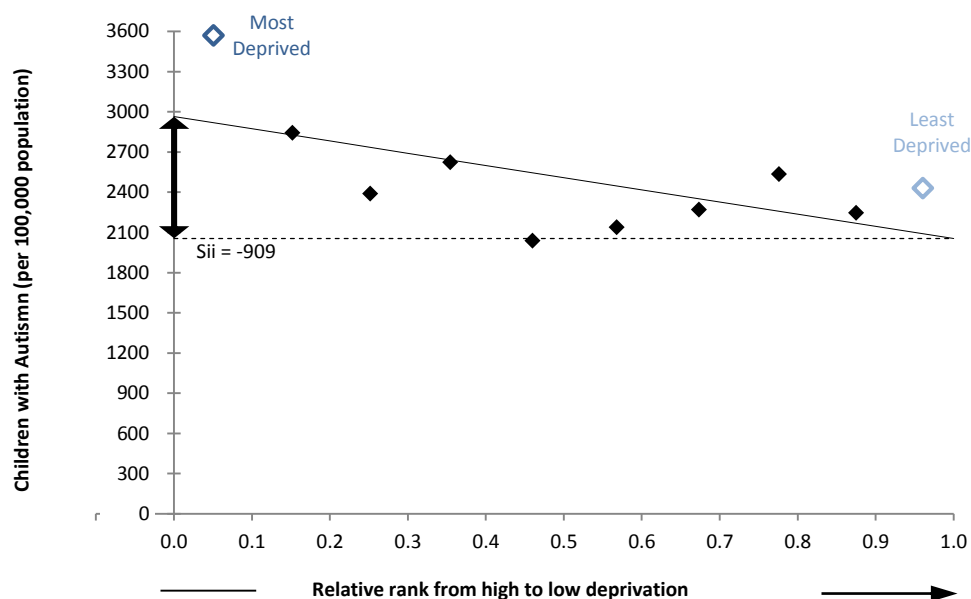■ 10% Most Deprived   ■ NI   ■ 10% Least Deprived

In 2016/17, the rate of autism amongst children in the 10% most deprived areas stood at 3,570 cases per 100,000 population which was more than two-fifths (42%) higher than the regional average (2,509 cases per 100,000 population), and 47% higher than the rate in the 10% least deprived areas (2,432 cases per 100,000 population).

Prior to 2013/14, rates were slightly higher in the least deprived areas than in the most deprived areas however in the last four years the rate of autism amongst children in the most deprived areas has increased at a faster rate than in the least deprived resulting in higher rates in the most deprived areas and a widening of the inequality gap.
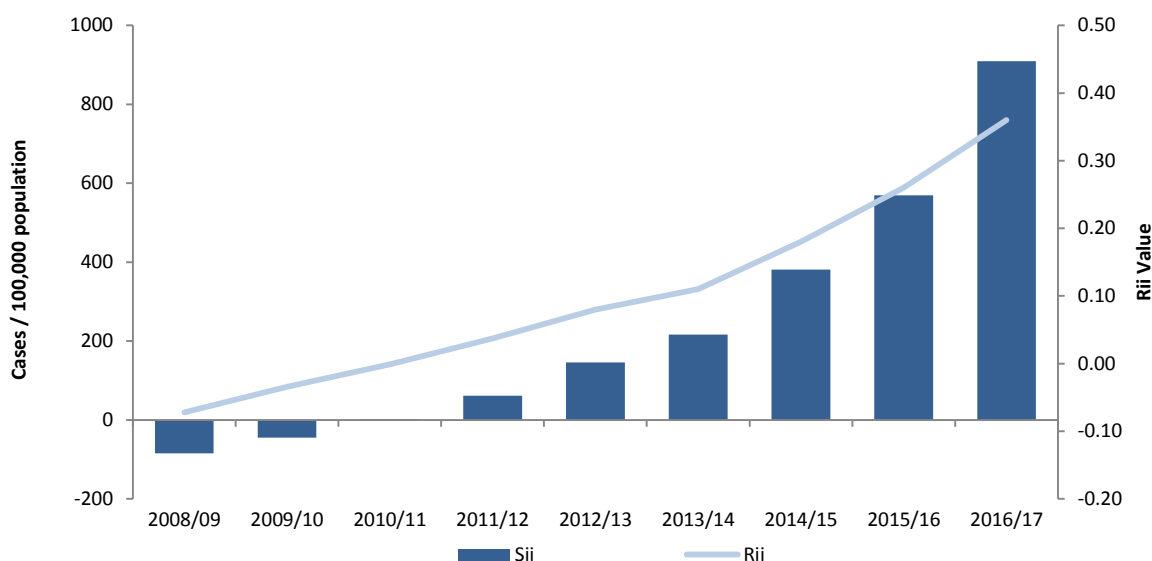
Slope Index of Inequality

In addition to the simple deprivation gap analysis presented above, the following social gradient analysis has been undertaken to provide a fuller assessment of inequalities across all socio-economic groups in Northern Ireland. Further information on this follows the analysis below

Slope Index of Inequality – Children with Autism/Asperger's per 100,000 population (2016/17)

The slope of index of inequality (Sii) shows that the absolute gap in the rate of autism amongst children between the most and least deprived was 909 cases per 100,000 population in 2016/17.

Year	Simple Gap (MD-LD)	Sii	Rii
2016/17	47%	909.1	0.36
2015/16	30%	569.8	0.25
2014/15	19%	380.8	0.18
2013/14	6%	216.2	0.11
2012/13	-2%	146.1	0.08
2011/12	-6%	61.3	0.04
2010/11	-8%	1.9	0.00
2009/10	-3%	-45.2	-0.03
2008/09	-10%	-84.4	-0.07

The relative index of inequality (Rii) gives a proportionate gap of 0.36 in 2016/17 i.e. the Sii gap is equivalent to 36% of the average rate of autism amongst children in NI. As with the simple gap analysis, Rii indicates that the deprivation gap has changed from negative (higher rates in least deprived than most deprived) to positive (higher rates in most deprived than least deprived) over the analysed period. However, despite the simple gap indicating that this change in direction has only occurred in recent years, Rii shows that this change occurred much earlier and that the deprivation gap has been gradually widening since 2010/11.

Further Information

Social Gradient

Health and social care inequalities are often considered in terms of the gap between the most and least deprived quintiles/deciles of the population. However, this does not account for those areas of intermediate levels of deprivation that may also be relatively disadvantaged to some degree. This is reflected in the Marmot Review[14] which demonstrated that there is a social gradient in health and its wider determinants that runs from top to bottom of the socioeconomic spectrum. The social gradient is also a global phenomenon whereby socio-economic factors have considerable impact on the health and mortality of populations in low, middle and high income countries. The social gradient in health means that inequalities affect everyone.

The slope index of inequality (Sii) is a robust method for analysing and monitoring the socioeconomic inequalities in health and social care over time by measuring changes in the social gradient. This approach involves calculating the mean status of each socioeconomic group and then ranking classes by their socioeconomic status[15]. The Sii is then defined as the slope of the "best fit" regression line showing the relationship between the status of a particular group and that group's relative rank on the deprivation scale. An equal rate across

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[14] *Fair Society, Healthy Lives: The Marmot Review* can be accessed at http://www.marmotreview.org

[15] Deprivation deciles as defined by the Northern Ireland Multiple Deprivation Measure (NIMDM).

all deprivation categories would give a horizontal line with a slope of zero ($Sii=0$) indicating that there is no evidence of inequality. The level of inequality is shown by the magnitude of the gradient, regardless of direction.

Relative Index of Inequality

The relative index of inequality (Rii) is a non-dimensional coefficient of inequality representing the proportionate change in the health outcome over the population by socioeconomic status. Rii is calculated by dividing Sii by the mean outcome for the health indicator across the entire population. It allows inequalities to be compared and contrasted across a number of different health indicators as well as over time, with higher Rii values indicating greater inequalities across the analysed deprivation groups. As with Sii, a value of zero for Rii indicates no evidence of inequality. The higher the Rii value is, the higher the level of inequalities that exist in the population. For example, a Rii of 1.5 means that the absolute gap between the most and least deprived is one and a half times the regional average for that indicator.

Sii vs. Simple Gap

The simple gap analysis presented earlier (i.e. difference between the most and least disadvantaged groups) is useful in that it is easy to produce and can be easily interpreted, however it is limited to an extent in that it only reflects the difference between the highest and lowest socioeconomic or deprived groups and can be potentially affected by extreme values for each of these groups. Sii however reflects on the experience of the entire population and is sensitive to the distribution of the population across all socioeconomic groups and for this reason the measures are not directly comparable. In addition, as outlined above, the R_{II} can be calculated from S_{II} allowing for inequalities to be monitored over time and to be compared and contrasted across a number of different health indicators. The gap analysis however retains value in that it is based on a relatively easy concept to understand and can be calculated easily without the need for statistical modelling. Comparing trends in the simple gap analysis outlined earlier in the report with trends in the social gradient generally shows similar patterns in inequalities in terms of narrowing, widening or remaining broadly constant.
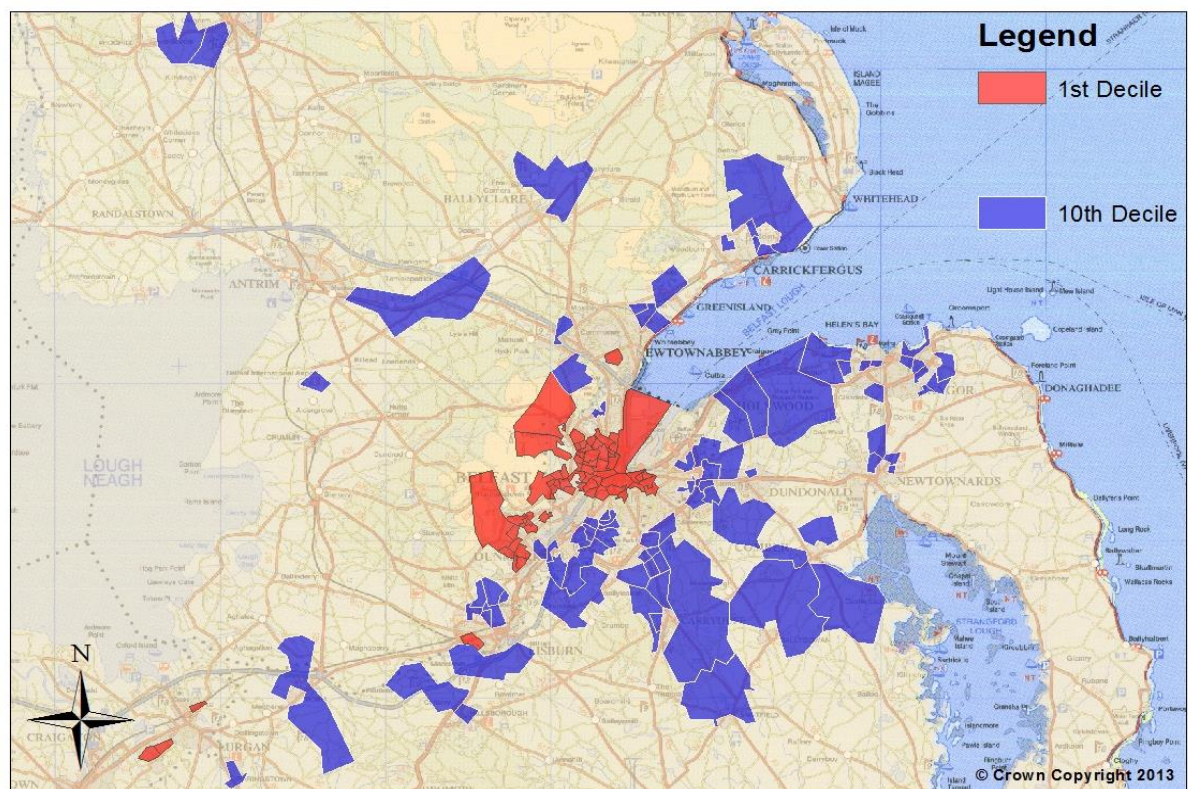
Appendix D – Deprivation Maps

Map One: The Most (Red) and Least (Blue) Deprived Areas in Northern Ireland (MDM 2010)
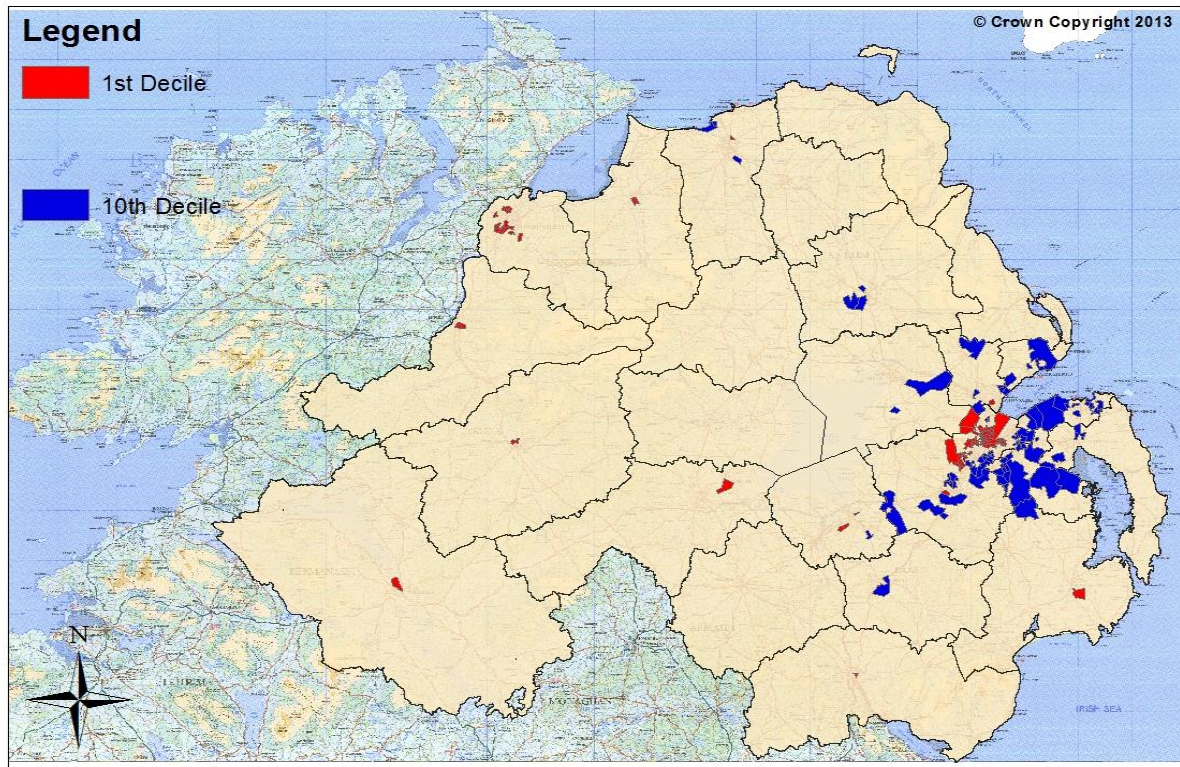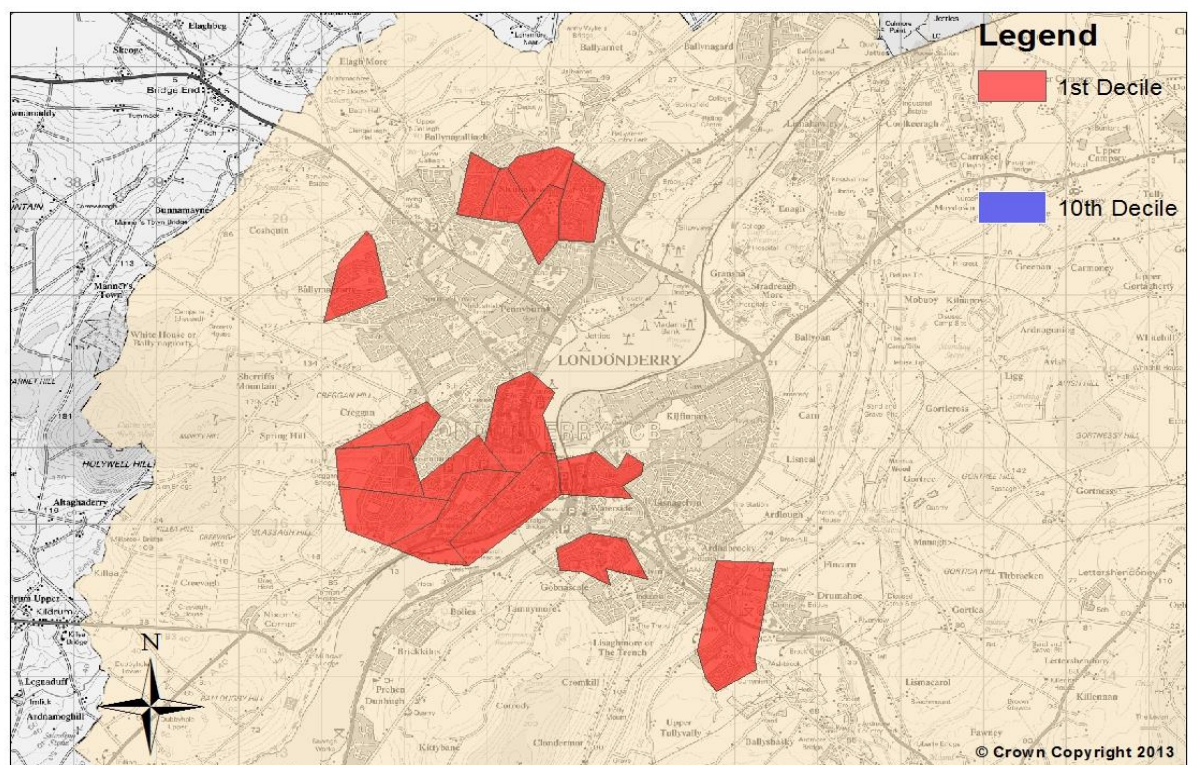

Source: NISRA – Demography and Methodology Branch (2010)

Map Two: The Most (Red) and Least (Blue) Deprived Areas in the Belfast Metropolitan Urban Area

Source: NISRA – Demography and Methodology Branch (2010)

Map Three: The Most (Red) and Least (Blue) Deprived Areas in the Derry Urban Area

Source: NISRA – Demography and Methodology Branch (2010)

Appendix D – No. of children identified with Autism

Trust	Year				
	2012/13	**2013/14**	**2014/15**	**2015/16**	**2016/17**
Belfast	1,195	1,366	1,539	1,739	1,932
Northern	1,094	1,280	1,543	1,728	1,982
South Eastern	1,278	1,377	1,465	1,522	1,627
Southern	712	708	691	690	741
Western	670	724	805	832	884
Unknown	37	3	2	17	32
Northern Ireland	**4,986**	**5,458**	**6,045**	**6,528**	**7,198**

For further information on **The Prevalence of Autism (including Aspergers Syndrome) in School Age Children in Northern Ireland**

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