

Children with learning disabilities whose behaviours challenge What do we know from national data?

*Anne Pinney
Independent Researcher*

November 2014

Contents

Executive Summary

1. Introduction

- 1.1 Purpose of this paper
- 1.2 Data sources
- 1.3 Estimating the overall number of children with learning disabilities whose behaviours challenge

2. What do we know from SEN (special educational needs) data?

- 2.1 Policy framework and definitions
- 2.2 Data sources
- 2.3 Number of children with learning difficulties or autistic spectrum disorders
- 2.4 Individual characteristics
- 2.5 Type of school attended
- 2.6 Residential and 'out of area' placements
- 2.7 Trends over time in special school placements
- 2.8 Cost of placements

3. What do we know from the Learning Disabilities Census?

- 3.1 Introduction
- 3.2 Individual characteristics
- 3.3 Nature of provision made
- 3.4 Anti-psychotic medication and incidents of concern
- 3.5 Progress towards Winterbourne View Concordat commitments
- 3.6 Cost of placements

4. Conclusions and recommendations for improving national data

- 4.1 Residential placements
- 4.2 Independent schools
- 4.3 Cost data

Glossary of abbreviations used in this report

Executive Summary

Children with learning disabilities whose behaviours challenge: What do we know from national data?

This data supplement presents the findings and recommendations from an analysis¹ of all the available national data on children with learning disabilities² and behaviour that challenges in England, in 2013.

It was written to accompany a briefing paper - [Early Intervention for children with learning disabilities whose behaviours challenge](#)³ - which draws on a wider evidence base and explores the implications for policy and practice, in particular, the urgent need to invest in evidence-based early intervention to improve outcomes for these children and their families.

There are just two national datasets which shed light on children with learning disabilities whose behaviours challenge. Firstly, SEN (Special Educational Needs) data is collected by the Department for Education (DfE). Secondly, the Learning Disabilities Census, which provides a snapshot of children and young people with a learning disability, autistic spectrum disorder and/or behaviour that challenges, who were in-patients in assessment and treatment centres in September 2013.

What do we know from national data?

National data does not provide a reliable overall figure for the number of children with learning disabilities whose behaviours challenge. Professor Eric Emerson, with the Expert Group advising this project, therefore developed a new methodology⁴ to establish a robust estimate of this group. This is described in a separate paper - [Estimating the number of children in England with learning disabilities and whose behaviours challenge](#). Their analysis found that:

- At all ages, children with learning disabilities are markedly more likely to show behaviours that challenge than their non-learning disabled peers.
- Overall, there are 41,547 children with learning disabilities whose behaviours challenge, aged 0-18 years, in England in 2014.

Schools data⁵

- **There were 179,320 children with learning difficulties⁶ in schools in England in January 2013.** This is almost one quarter of pupils at School Action Plus (SAP) and nearly one third of those with

¹ This report describes the national data on this group of children. We have not tested the statistical significance of the figures presented, but concerns such as small sample size or inconsistent reporting are highlighted where known.

² Learning disability is equivalent to the SEN classifications of moderate to more severe learning difficulties (MLD, SLD, PMLD) used by the Department for Education. It is synonymous with the term 'intellectual disability' as used in the US, Australia and by many international organisations.

³ See www.challengingbehaviour.org.uk/learning-disability-files/Briefing-Paper.pdf

⁴ See www.challengingbehaviour.org.uk/learning-disability-files/Estimating-the-Number-of-Children-with-LD-and-CB-in-England.pdf. The methodology is also described in brief in section 1.3 of this paper.

⁵ Data source unless otherwise indicated: SFR 30/2013 primary need tables (10A). Under the SEN Code of Practice 2001, children at SAP generally receive some specialist input from the local authority (LA) or health, and children with statements have had a statutory assessment to determine what special provision will be made by the LA and other agencies.

⁶ DfE SEN data uses the term 'learning difficulties' rather than 'learning disabilities', so this wording is used in the SEN sections of this report.

statements. In addition, there were 70,780 children with autistic spectrum disorders (ASD) - just over one in twenty of those at SAP and just over one in five of those with statements.

- **The great majority of children with learning difficulties or autistic spectrum disorders attend mainstream schools.** Nearly nine-tenths of children with moderate learning difficulties (MLD) are in mainstream schools, just over seven in ten of those with ASD, and around one in five of those with severe or profound and multiple learning difficulties (SLD or PMLD).
- **Children with learning difficulties or ASD account for nearly three-quarters of the special school population.** SLD is the most common need among children in special schools, followed by ASD and MLD.
- **In January 2013, 1360 children with statements for learning difficulties or autistic spectrum disorders were boarding in residential special schools, just over one third of them (480) in other local authority areas.**⁷ This does not include children placed in independent schools, leaving an important gap in the picture: in 2008 (latest available data⁸), an estimated 38% of children with statements who were boarding were in independent schools.
- **Very little data on residential placements is published, but a special request for this analysis shows that such placements are declining year on year.** In January 2014, 24% fewer children with statements (all types of need) were boarding in maintained and non-maintained special schools than in 2007.⁹ Again, this does not include placements in independent schools.

Learning Disabilities Census

- **236 children and young people aged 18 or younger were in-patients in assessment and treatment units in September 2013, including 31 children aged 10 or under.** 29% were being treated 100km or more from home.¹⁰
- **In the four weeks leading up to the Census, just under two-thirds of those under 18 were regularly given anti-psychotic medication, in spite of concerns about the appropriateness of such treatment.** This age group were the most likely to have experienced self-harm, hands-on restraint and seclusion during previous three months.¹¹

Cost data

- **Recent, robust cost data on specialist placements for children with SEN is lacking.** The best estimates put the average cost of placements in non-maintained and independent schools in 2011 at £46,252 for a day place and £167,268 for a 52-week placement.¹²

⁷ Source: School Census, Jan. 2013 (special request). Figures rounded to nearest 5, pupils with invalid postcodes excluded.

⁸ Data on residential placements in non-maintained and independent schools was last collected by the (SEN) Regional Partnerships in 2008 (see section 2.8). Estimate based on this data, School Census data on placements in non-maintained and independent special schools (DfE, 2009, *Children with SEN: an analysis*, table 1.1) and School Census data on residential placements (special request, see table 6 in section 2.6), all Jan. 2008.

⁹ Source: School Census, Jan. 2007-Jan 2014, placements of children with statements in maintained and non-maintained special schools. Special request.

¹⁰ Source: Learning Disabilities Census, September 2013, special request. Data quality checks by HSCIC raised some concerns about data reported for this younger age group, which could affect service user numbers – please see paragraph 3.1 and its footnote.

¹¹ HSCIC (April 2014), LD Census Report - Further Analysis. See commentary on p.13-17.

¹² Clifford J., Theobald C. (October 2012) Summary of findings: extension of the 2011 cost comparison methodology to a wider sample, NASS and Baker Tilly

- **The 185 young people under 18 who are in-patients in assessment and treatment centres cost an estimated £46 million per annum, with an average annual cost of £249,319.** Just over half of this age group are in placements costing more than £4,500 per week.¹³

What do we **NOT** know from national data?

An analysis of this sort inevitably raises more questions than it answers. It shines a spotlight on gaps in the data – in particular, how little information is published on placements for children with the most complex needs: children in residential placements, some of them far from home; children placed in independent special schools; and the cost of such placements.

Given that the thrust of policy for over two decades has been to reduce the need for residential and ‘out of authority’ placements through early intervention, family support and investment in specialist provision locally, the paucity of information on such placements and their cost is surprising. This must impede efforts to plan and commission services for these children and their families more effectively.

Recommendations

The report concludes with a number of recommendations for improving national data, with the aim of enabling a clearer policy focus on this group of children and better data to inform local and regional commissioning:

1. The annual ‘*Children with SEN*’ bulletin¹⁴ should include a section on children in residential placements, including analysis of distance from home and length of stay.
2. Independent schools catering primarily for children with SEN should be required to participate in the School Census¹⁵; and the annual ‘*Children with SEN*’ bulletin should include an analysis of ‘out of authority’ placements in independent and non-maintained schools.
3. LA reporting of SEN expenditure should provide a clearer picture of spending on maintained special school placements and placements in non-maintained and independent schools.

¹³ HSCIC (April 2014), LD Census Report - Further Analysis. Estimate based on data in table 6a.

¹⁴ The SEN (Information) Act 2008 requires the Secretary of State to publish every year information about pupils with SEN in England, fulfilled through the annual *Children with SEN* bulletin.

¹⁵ All maintained schools and non-maintained special schools are required to provide information on individual pupils and on the school itself, through the School Census: the source of most of the SEN data presented in this report. Independent schools return only school level information, through ‘SLASC’: the school level annual school census.

1. Introduction

1.1 Purpose of this paper

This data supplement provides an overview of what national data tells us about children with learning disabilities whose behaviours challenge. It is intentionally rich in data and light in commentary, as it has been written to accompany a briefing paper [[Early Intervention for children with learning disabilities whose behaviours challenge](#)].¹⁶ The briefing paper draws on a wider evidence base and considers the implications for policy and practice, in particular, the urgent need to invest in evidence-based early intervention to improve outcomes for these children and their families.

This report concludes with a number of recommendations for improving national data, with the aim of enabling a clearer policy focus on this group of children and better data to inform local and regional commissioning.

1.2 Data sources

There are just two national datasets which shed light on children with learning disabilities whose behaviours challenge:

- SEN (special educational needs) data, drawn primarily from the School Census collected annually by the Department for Education (DfE), which provides for a breakdown of data by type of need.
- The Learning Disabilities Census, which provides an annual snapshot of children and young people with a learning disability, autistic spectrum disorder and/or behaviour that challenges, receiving care in an in-patient setting.

Several data requests were made to supplement the published data, to provide a clearer picture of:

- Residential placements of children with statements, year-on-year (section 2.6, table 6)
- ‘Out of area’ residential placements of children with learning difficulties or autistic spectrum disorders (section 2.6)
- The number of children aged 0-18 years who are in-patients in assessment and treatment units (sections 3.2-3.3) broken down age (table 9), distance from home (table 10) and length of stay (Figure 4)
- Progress made towards Winterbourne View Concordat commitments¹⁷ in respect of 0-17 year olds, including transfer status and reasons given for not having a transfer date (section 3.5, table 11).

This report describes the national data on this group of children. We have not tested the statistical significance of the figures presented, but concerns such as small sample size or inconsistent reporting are highlighted, where known.

¹⁶ See www.challengingbehaviour.org.uk/learning-disability-files/Briefing-Paper.pdf

¹⁷ A key commitment in the Concordat was to “review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible.” Progress is monitored through regular surveys of providers, see <http://www.england.nhs.uk/2014/06/27/assuring-transformation/>

Other national datasets consulted, which do not allow for a sufficient focus on children with learning disabilities and behaviours that challenge include: DfE data on Looked After Children and Children in Need; and Department of Health (DH) data on Child and Adolescent Mental Health Service and Hospital Episode Statistics.

1.3 Estimating the overall number of children with learning disabilities and behaviour that challenges

It is impossible to say definitively how many children there are who have both learning disabilities and behaviours that challenge.

School Census data enables a focus on children with primary needs of moderate learning difficulties (MLD), severe learning difficulties (SLD), profound and multiple learning difficulties (PMLD) and autistic spectrum disorders (ASD).¹⁸ Information on children's secondary needs is also available from the School Census, but this is reported for only a minority of children and is not analysed other than in relation to primary needs.¹⁹

The seemingly simple solution of extracting data on children with primary needs involving a learning difficulty and secondary needs involving behavioural, emotional and social difficulties (BESD) - or the other way around - could not be used, not just because of doubts about the completeness and the reliability of the secondary needs data, but because BESD cannot be equated with the challenging behaviours associated with learning disabilities.²⁰

Professor Eric Emerson and the Expert Group advising this project developed a new methodology to establish, for the first time, a robust estimate of the number of children with learning disabilities whose behaviours challenge, in the UK in 2014. This is described in a separate paper [[Estimating the number of children in England with learning disabilities and whose behaviours challenge](#)].

In brief, a three-step process was used, drawing on ONS population projections, SEN data and analysis of the UK's Millennium Cohort Survey. This follows a cohort of 18,000 children born in 2000/2001, collecting information at regular intervals, including on mental health and behaviour, and cognitive ability and development. Their analysis found that:

- At all ages, children with learning disabilities are markedly more likely to show behaviours that challenge than their non-learning disabled peers
- Overall there are 41,547 children with learning disabilities whose behaviours challenge, aged 0-18 years, in England in 2014.

¹⁸ Specific learning difficulties, such as dyslexia, dyspraxia and dyscalculia were not considered relevant to this analysis, as they do not affect a child's overall intelligence and level of functioning.

¹⁹ 78% of children at School Action Plus (see paragraph 2.1 for SEN definitions) and 59% of those with statements do not have identified secondary needs. DfE SFR 30/2013 Additional tables 1 (primary needs tables), G1 and G2.

²⁰ The category of 'BESD' as used in the education system does not align with the challenging behaviours associated with learning difficulties. In particular, the strong association between severity of learning disabilities and challenging behaviours suggested by DfE data is inconsistent with research in this area.

2. What do we know from SEN data?

Summary: What do we know from SEN data?

- There are 179,320 children with learning difficulties (from moderate to profound and multiple) in schools in England, representing almost one quarter (23.5%) of pupils at School Action Plus (SAP) and nearly one third (33%) of all those with statements.
- There are 70,780 children with autistic spectrum disorders (ASD) in schools in England: just one in twenty of those at SAP (5%) and just over one in five (22%) of those with statements. ASD and learning difficulties often occur together, particularly among children with severe learning difficulties.
- Over the past 8 years (2005 to 2013), the number of children with MLD (at SAP or with a statement) fell steadily – from 170,360 in 2005 to 138,355 in 2013. Meanwhile the number with PMLD rose gradually, 8050 to 10,525; and the number with ASD more than doubled, from 34,920 in 2005 to 70,780 in 2013.
- Just over 85% of pupils with ASD are male. There is less of a gender split among children with learning difficulties, ranging from 56% of those with PMLD to 66% of those with MLD
- The great majority of children with MLD (87.5%) and ASD (71%) attend mainstream primary or secondary schools, as do significant numbers of those with more severe learning difficulties: 22% of those with SLD and 17% of those with PMLD.
- Children with learning difficulties and/ or autistic spectrum disorders make up almost three-quarters (73%) of the special school population. Children with SLD are the largest group in special schools, accounting for nearly one in four children (25%), followed by children with ASD (21.5%) and children with MLD (18%).
- 660 children with statements for MLD, SLD or PMLD board in residential special schools, 35% (230) of them in another local authority area ('out of area'). 700 children with statements for ASD are boarding in special schools, 36% (250) of them out of area. This does not include placements in independent schools, representing an important gap in the picture.
- Very little data on residential placements is published, but data requested for this analysis shows that residential placements are declining year on year – in January 2014, 24% fewer children with statements (across all types of need) were boarding than in 2007. Again, this excludes placements in independent schools.

Notes: SEN data uses the term 'learning difficulties' rather than 'learning disabilities', so this wording is used throughout this chapter. Please see main body of this chapter for data sources and references.

2.1 Policy framework and definitions

New arrangements for meeting children's special educational needs (SEN) came into force in September 2014, with a new SEN and Disability Code of Practice. However, the data presented in this section relates (mainly) to children in schools in England in January 2013, when arrangements under the 2001 SEN Code of Practice and the Education Act 1996 were still in place.

Under this legislation, a child had SEN if:

"he has a learning difficulty which calls for special educational provision to be made for him"; where learning difficulty means "significantly greater difficulty in learning than the majority of children of his age" or "a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area ...".²¹

Special education provision is defined as *"additional to or otherwise different from the educational provision made generally for children of this age".²²*

The 2001 SEN Code of Practice set out a graduated approach to meeting children's special educational needs, at "School Action", "School Action Plus" or through a Statement of SEN. The data presented in this section relates to children at the two higher levels of need:

- *School Action Plus (SAP)*, where a school needs to seek specialist advice or support from outside agencies;
- with a *Statement of SEN*, where a child's needs have been assessed by the local authority to determine what provision must be made by the school and other agencies.²³

2.2 Data sources

The data presented in this section relates principally to children with SEN in maintained and non-maintained schools in England in January 2013²⁴, whose primary need involved a learning difficulty²⁵ or autistic spectrum disorders.

The main data source is the School Census, which gathers information on individual pupils and on schools themselves, and is returned by all maintained and non-maintained schools in England. Independent schools provide only school level data, which does not enable a focus on children with these particular needs. This means that children placed in independent schools are excluded from most of the data presented here.

As DfE data uses the term 'learning difficulties' rather than 'learning disabilities', this wording is used throughout this chapter.

We have not tested the statistical significance of the figures presented, but concerns such as small sample size or inconsistent reporting are highlighted, where known.

2.3 Number of children with learning difficulties or autistic spectrum disorders²⁶

There are 179,320 children with learning difficulties ranging from moderate to profound and multiple in schools in England, representing almost one quarter (23.5%) of pupils at School Action Plus (SAP) and nearly one third (32.7%) of all those with statements [Table 1].

²¹ Education Act 1996, section 312. These definitions are almost identical in the Children and Family Act 2014.

²² Ibid. This definition is almost identical in the new Act and Code.

²³ The new SEN and Disability Code of Practice ends the categories of School Action and School Action Plus, but retains a graduated approach. These categories (for data-reporting purposes) were expected to be replaced by a single category of 'SEN Support' (email correspondence with DfE statisticians, Sept. 2014).

²⁴ As reported in the School Census. Independent schools do not provide pupil-level information, leaving an important gap in the picture, particularly as regards children in specialist residential placements.

²⁵ Moderate learning difficulties, severe learning difficulties and profound and multiple learning difficulties are included, but specific learning difficulties (e.g. dyslexia, dyscalculia, dyspraxia) are excluded.

²⁶ Data in this section drawn from SFR 30/2013 primary need tables (table 10A)

Moderate learning difficulties (MLD) are the second most common type of need among children at SAP, after behavioural difficulties. Just over three-quarters (75.8%) of pupils with MLD have their needs met at SAP, while more than nine-tenths of those with severe learning difficulties (SLD, 90.5%) or profound and multiple learning difficulties (PMLD, 92.3%) have statements.

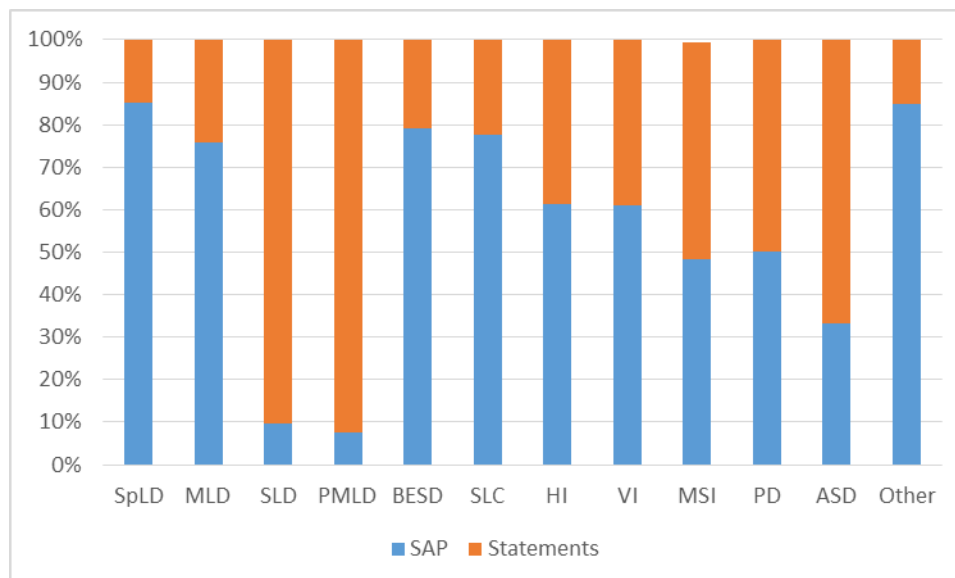
Children with autistic spectrum disorders (ASD) represent just over one in ten of pupils with SEN: just over one in twenty of those at SAP (5.1%) and over one in five (21.9%) of those with statements. Two thirds of children with ASD have statements. ASD is the most common type of SEN for children with statements, by some margin.

Overall, children with SLD, PMLD or ASD are more likely to have statements than those with any other type of SEN [Figure 1].

Table 1: Children with learning difficulties or autistic spectrum disorders at SAP or with statements

	No. at SAP	As % of pupils at SAP	No. with statements	As % of pupils with statements	At SAP or with statement	As % of pupils at SAP or with statement
MLD	104,900	22.7%	33,455	15.5%	138,355	20.4%
SLD	2,900	0.6%	27,540	12.7%	30,440	4.5%
PMLD	805	0.2%	9,715	4.5%	10,525	1.6%
All LD	108,605	23.5%	70,710	32.7%	179,320	26.5%
ASD	23,560	5.1%	47,225	21.9%	70,780	10.4%

Source: School Census, January 2013, England only. Data extracted from DfE SFR 30/12 Table 10A State-funded primary, state-funded secondary and special schools, number and percentage of pupils by type of need.



Source: School Census, January 2013, England only. Data extracted from DfE SFR 30/12 Table 10A State-funded primary, state-funded secondary and special schools, number and percentage of pupils by type of need.

Figure 1: Proportion of children at SAP or with statements, by type of primary need

Children with autistic spectrum disorders and learning difficulties

Special educational needs often do not occur in isolation and many children have both learning disabilities and autistic spectrum disorders. As well as reporting on pupils' primary SEN, schools can record a secondary SEN but, as illustrated below, there are doubts about the reliability of these figures.²⁷ These data suggest that among children with statements:

- 9.9% of those with a learning difficulty as a primary need have ASD as a secondary need, including 16.3% of children with SLD.
- 14.8% of those with ASD as a primary need have a learning difficulty as their secondary need, again the greatest number of whom have SLD.

These data underestimate the extent to which learning disabilities and autistic spectrum disorders occur together, as demonstrated by a number of major studies. A review of epidemiological studies and high quality literature reviews (Emerson and Baines, 2010²⁸) points to much higher rates of learning disabilities and autistic spectrum disorders occurring together:

- Among children with autism, the average reported prevalence of learning disabilities is 52.5% (upper estimate 67%, lower estimate 40%)
- The estimated percentage of children with learning disabilities who have autism is 34% (average figure, estimates range from 12% to 72%).

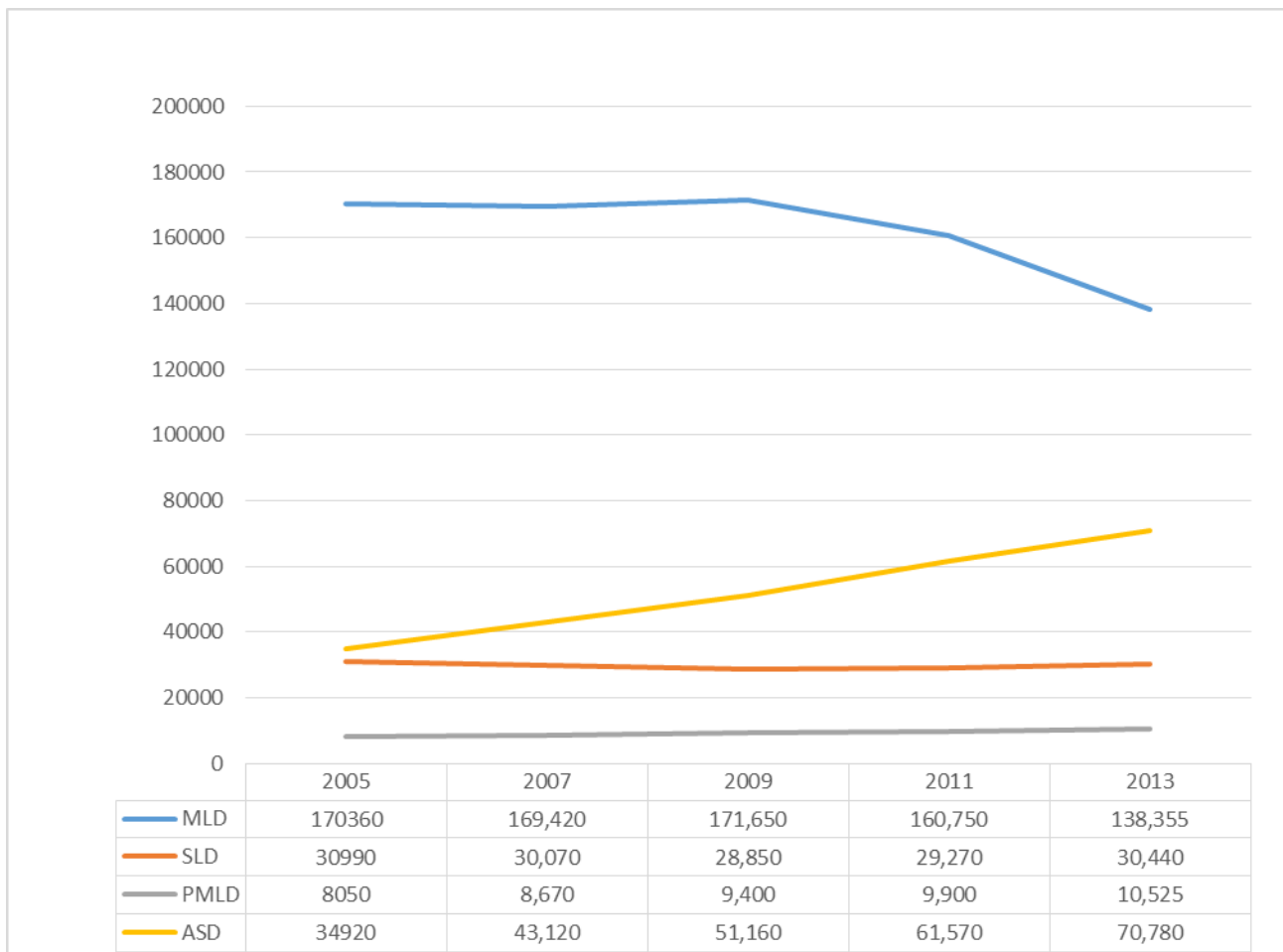
Trends in type of SEN over the last decade

Data on type of SEN was first collected in 2004. Looking back over the last 8 years, from January 2005 to January 2013, some distinct trends are evident across the different types of SEN [Figure 2]:

- The number and proportion of children with MLD fell steadily, from 170,360 children (28.5% of those at SAP or with a statement) in 2005 to 138,355 (20.4%) in 2013.
- Meanwhile, the number and proportion of children with PMLD rose gradually, from 8050 (1.3%) to 10,525 (1.6%), and the number of children with SLD fluctuated from year to year.
- The number of children with ASD at SAP or with a statement more than doubled over this time period, from 34,920 (5.8%) in 2005 to 70,780 (10.4%) in 2013.

²⁷ No secondary SEN is identified for 60% of children with statements and 78% of those at SAP. Data drawn from DIE SFR 30/2013 tables G1 and G2.

²⁸ Emerson, E., Baines, S. (2010). *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*. Durham: Improving Health & Lives: Learning Disability Observatory, pp.7-8. Available at http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf.



Source: School Census, Jan. 2005 to Jan 2013, England: State funded primary, secondary schools and all special schools: No. and % of pupils by type of need. Data extracted from annual 'SEN in England' bulletins, 2 yearly intervals from 2005.

Note: Up to (and including) 2009, pupils dual-registered (part-time at a special and a mainstream school) were excluded from the figures. Since then, dual registered pupils have been included. Children in independent and general hospital schools are excluded.

Figure 2: Number of children with SEN (at SAP or with a statement) by type of primary need, 2005 to 2013

2.4 Individual characteristics²⁹

Gender

Among children with statements, boys are more likely to have SEN across all types of need, most markedly for behavioural, emotional and social difficulties (BESD, 87.5% boys) followed by autistic spectrum disorders (85.2% boys).

The gender split among children with learning difficulties with statements is less pronounced, ranging from 55.8% of those with PMLD to 65.6% of those with MLD.

Age

The age profile of children with statements varies greatly across different types of SEN. This section focuses on children with statements, aged 5 to 15, as the data for this age range are considered reliable.³⁰

The number of children with MLD rises more than sevenfold between the ages of 5 and 15 years, from 650 to 4875, representing a steadily increasing proportion of pupils with statements (6.4% to 21.8%).

The number of children with SLD rises more gently, from 1485 at 5 years to 2230 at 15 years. Year-on-year increases are evident in the first 3 years of school, with slight decreases from ages 8-10 years, then rising again at age 11 and beyond. This could, in part, reflect statementing practice: with more statements being issued at the start of each stage of education when new support needs become apparent.

The number of children with PMLD follows a different trend - peaking at 780 at age 6, then falling to 520 at age 15. This is likely to reflect changes in the prevalence of PMLD in age cohort³¹ as well as possibly, the transfer of some children to independent special schools, who do not report data on individual pupils.

The number of children with ASD rises from 2,755 at age 5 to a peak of 4,410 at 13 years, then falls slightly. The proportion of children with this primary need falls from 27.1% to 19.4% between 5-15 years, reflecting the more rapid growth in numbers of children with MLD and BESD.

Ethnicity

National data indicate that there is much variation between ethnic groups in the incidence of different types of SEN, but these figures must be treated with caution, due to differences in the size of ethnic populations and in the incidence of SEN within each population. With those important provisos, the clearest trends in relation to children with learning difficulties or ASD are that:

- The incidence of PMLD among Asian children with statements is much higher (8.4%) than for other ethnic groups, at twice the level among all pupils with statements (4.2%).
- The incidence of SLD among Asian children with statements is also well above average, at 17.8%, compared to 12.6% among all pupils with statements.
- The incidence of ASD among black children with statements is higher than for all children with statements, at 29.9% compared to 21.6%.

²⁹ Data in this section are drawn from DfE SFR 30/2013 primary need tables

³⁰ Emerson E., Hatton C., Robertson J. et al (2013), People with Learning Disabilities in England 2012, Learning Disabilities Observatory (p.21)

³¹ Emerson E. (June 2009), Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England, Centre for Disability Research Report 2009:1

Family income

The School Census includes information on if children are eligible for and take up free school meals, which is often used as a proxy measure for family income.

Overall children with SEN are more likely to be from low income homes - nearly one third of those at SAP (32.5%) or with a statement (32.1%) are on free school meals, compared to just over 17% of all pupils.³² This varies across different types of need. Focusing on children with learning difficulties and/or autistic spectrum disorders (with statements and at SAP):

- Those with MLD are more likely to be from poorer homes than children with any other type of SEN, except for BESD.
- Children with PMLD or ASD are more likely to be from affluent homes, compared to all children with SEN.

Across all four types of need that are the focus of this analysis - MLD, SLD, PMLD and ASD - children with statements are more likely to be from a low income background, than those at SAP with the same needs [Table 3]. In other words, children with greater support needs are more likely to be from low income homes.

Table 3: Children with SEN by free school meal eligibility and type of need

	No. of children at SAP	% at SAP on FSM	No. with statements	% with statements on FSM
MLD	104,900	37.6%	33,455	38.1%
SLD	2,900	32.4%	27,540	35.6%
PMLD	805	24.7%	9,715	28.5%
ASD	23,560	22.6%	47,225	25.8%
All types of SEN	462,045	32.5%	216,030	32.1%

Source: School Census. Data extracted from DfE SFR 30/2013 Primary Need Tables (table D) Stated-funded primary, state-funded secondary and special schools: Number and percentage of pupils with SEN by free school meal eligibility and primary SEN.

Looked after status

The special educational needs profile of children who are 'looked after'³³ by local authorities is broadly similar to other children, with a few exceptions [Table 4]. Children who are looked after and have SEN are:

- Most likely to have behavioural, emotional and social difficulties (BESD), accounting for 51% of looked after children at SAP and just over 40% of looked after children with statements
- Slightly more likely to have MLD (17.7%), compared to all children with statements (15.5%)
- Much less likely to have ASD (8.7%), compared to all children with statements (21.9%).

³² Including pupils in nursery, special and alternative provision. Source: SFR 21/2013 table 3A.

³³ Under the Children Act 1989, children may be looked after by the local authority, which assumes the role of 'corporate parent'. The most common reasons for entering care are abuse and neglect.

Table 4: Children with statements by type of need (looked after children vs all children)

	LAC with statements by type of need	% LAC with statements by type of need	All children with statements by type of need	% all children with statements by type of need	Difference in percentage points
MLD	1,330	17.7%	33,455	15.5%	+ 2.2
SLD	930	12.5%	27,540	12.7%	-0.2
PMLD	410	5.4%	9,715	4.5%	+0.9
ASD	650	8.7%	47,225	21.9%	-13.2

Sources:

1. SSDA903-NPD matched data, published in SFR 50/2013 Table 9: Children who have been looked after continuously for at least 12 months at March 2013 by type of Special Educational Need. Note: this includes children in PRUs, but involving low numbers which were suppressed in relation to the above needs.
2. School Census, published in SFR 42/2013 Table 1.4 State-funded primary, state-funded secondary and special schools: number and percentage of pupils by type of need (January 2013, England)

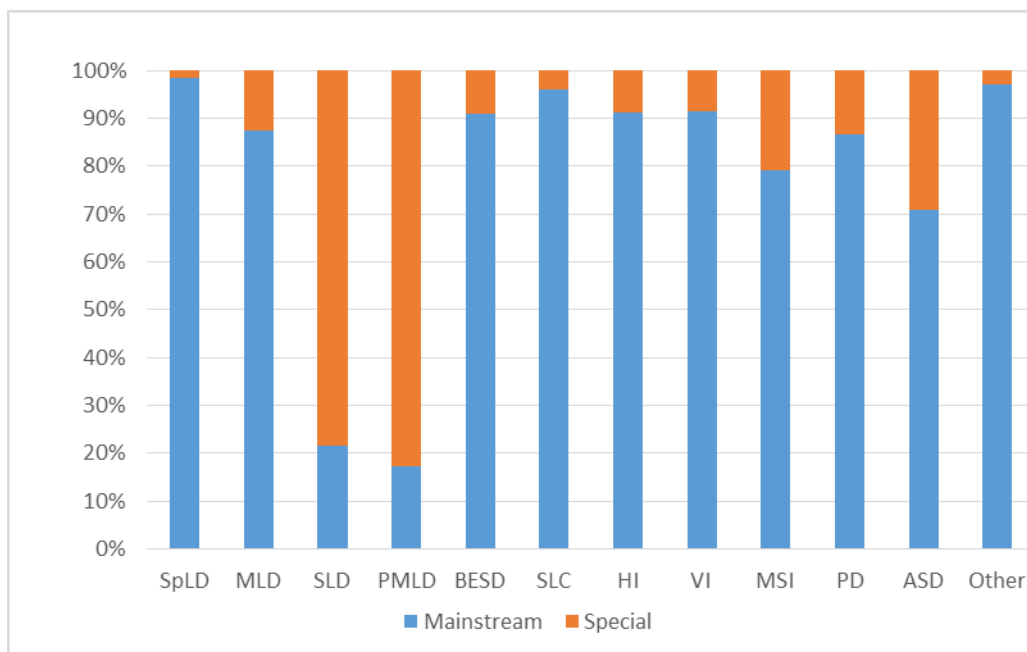
2.5 Type of school attended³⁴

Mainstream schools

A great many children with learning difficulties or autistic spectrum disorders are included in mainstream schools. The vast majority of those with MLD (87.5%) and ASD (70.7%) at SAP or with statements attend mainstream primary or secondary schools. Significant numbers of children with more severe learning difficulties also attend mainstream schools: 21.7% of those with SLD at SAP or with a statement, and 17.4% of those with PMLD [Figure 3].

The number of children with severe or profound and multiple learning difficulties is much higher in mainstream primary schools than at secondary level, when many children transfer to special schools.

³⁴ Data in this section from SFR 30/13 National tables (table 10A)



Source: School Census, January 2013, England only. Data extracted from DfE SFR 30/12 Table 10A State-funded primary, state-funded secondary and special schools, number and percentage of pupils by type of need.

Figure 3: Proportion of children with SEN (SAP or with a statement) in special and mainstream schools

Special schools³⁵

Children with learning difficulties and/or autistic spectrum disorders make up almost three-quarters (73%) of the special school population. Children with SLD are the largest group in special schools, accounting for nearly one in four children (24.7%), followed by children with ASD (21.5%) and children with MLD (17.8%). Children with PMLD make up a further 9% of the special school population.

The proportion of children with SEN being educated in special schools varies considerably between different local authority areas and at regional level, influenced primarily by variations in local specialist provision. For example, in 2013:

- In 9 LAs, all children with MLD were in mainstream schools. However in one local authority (Medway), 41 per cent of children with MLD were in special schools, more than three times the national average (12.5%).
- 100% of children with SLD were in special schools in York and Halton, compared to just over 11% in the London Borough of Newham.
- In 20 local authorities, all children with PMLD were in special schools, compared to none (or almost none)³⁶ in two authorities.
- Nationally, 29.3% of children with statements with ASD were in special schools, rising to more than 50% in eight local authorities and 71.8% in one local authority (Trafford).³⁷

³⁵ Figures include children in maintained and non-maintained schools, but not those in independent schools, which cater for nearly 5% of children with statements (see section 2.7).

³⁶ Numbers of 1 or 2 were suppressed in the source data, so actual values may be just above zero.

³⁷ LA and regional data derived from SFR 42/2013 local authority tables 1.6-1.8.

At the regional level, variations are also evident, particularly for children with MLD and to a lesser extent, ASD [Table 5].

Table 5: Regional variations in special school placements by type of need

	MLD	SLD	PMLD	ASD
Lowest proportion in special schools	6.8% (Inner London)	59.6% (Inner London)	72.1% (Inner London)	21.0% (East of England)
Highest proportion in special schools	17.6% (South East)	85.2% (West Midlands)	88.8% (West Midlands)	37.6% (North East)
National average	12.5%	78.3%	82.6%	29.3%

Source: School Census. Analysis based on SFR 42/2013 tables LA1.6-1.8, number and percentage of pupils with statements of SEN or at SAP by type of need. January 2013, England.

2.6 'Out of area' placements and residential (or 'boarding') placements

Although national data is published on the extent of 'cross-border' movement for mainstream and special school pupils - i.e. children living in one local authority area and attending school in another – unfortunately this largely excludes pupils who are boarding.³⁸

To shed light on the number of children with learning difficulties or ASD who are boarding in other local authority areas, we requested data from the Department for Education. Due to low numbers (figures were broken down by local authority), children with learning difficulties were grouped together. This showed that in 2013:

- 660 children with statements for MLD, SLD or PMLD were boarding, 35% (230) of them 'out of area'
- 700 children with statements for ASD were boarding, 36% (250) of them 'out of area'.³⁹

Actual numbers are likely to be higher, as children in independent schools are not included in these totals. In 2008 (latest available data⁴⁰), an estimated 38% of children with statements who were boarding were in independent schools.

A breakdown by local authority was provided, but low numbers meant that many figures were suppressed. Only a small number of authorities were sending 5 or more children with statements for these primary needs to board 'out of area':

- 17 local authorities had 5 or more children with ASD boarding 'out of area', including 3 local authorities which made 10 or more such placements;

38 DfE (2013) SFR 21/2013 Table 12c (special schools). This table gives a detailed breakdown of pupils living in one LA and attending school in another. Children who are boarding not included, other than a single column which reports on the number resident in each LA who are boarders (without knowing if their home is, or is not, in the same LA).

39 School Census data for England, January 2013 (special request). Totals are rounded to nearest 5. Excludes pupils with invalid postcodes. LA table available but this includes many suppressed figures <3.

40 Data on residential placements in non-maintained and independent schools was last collected by the (SEN) Regional Partnerships in 2008 (see section 2.8). Estimate based on this data, School Census data on placements in non-maintained and independent special schools (DfE, 2009, *Children with SEN: an analysis*, table 1.1) and School Census data on residential placements (special request, see table 6 above), all Jan. 2008.

- 10 local authorities had 5 or more children with learning difficulties boarding out of area, including 3 local authorities (all in Outer London) which made 10 or more such placements.

Detailed data on the type of residential placement (whether 52-week, termly, fortnightly or weekly) is not available, but the School Census includes information on if pupils are boarding for 6 nights a week or less, or 7 nights a week or less. This showed that, among children with ASD who were boarding out of area:

- 140 (56%) were boarding 6 nights a week or less, on a weekly or fortnightly basis
- 110 (44%) were boarding 7 nights a week or less, probably in termly or 52 week placements.

Among children whose primary need was a learning difficulty who were boarding out of area:

- 120 (52%) were boarding 6 nights a week or less, on a weekly or fortnightly basis
- 110 (48%) were boarding 7 nights a week or less, probably in termly or 52-week placements.⁴¹

Very little data on residential placements is published, but a special request for this analysis shows that residential placements of children with SEN are declining year on year – in January 2014, 24% fewer children with statements (across all types of need) were boarding than in 2007 [Table 6].⁴² Again, this excludes placements in independent schools, leaving an important gap in the picture.

Table 6: Children with statements who are boarding, January 2007-2014

	Pupils with statements who are boarders	% Pupils with statements who are boarders
2007	5,065	2.3
2008	4,945	2.3
2009	4,630	2.2
2010	4,390	2.1
2011	4,235	2.0
2012	4,080	1.9
2013	3,970	1.8
2014	3,855	1.8

Source: School Census, special request to DfE.

Notes: Includes sole and dual registered pupils. Excludes general hospital, independent schools and pupil referral units. Figures rounded to nearest 5 with percentage figures based on unrounded numbers.

Non-maintained and independent special schools (NMISS)

Nearly five per cent of children with statements (11,265 children) are educated in independent special schools or independent schools approved for pupils with SEN. A further 1.8% (4085) are in non-maintained special schools (NMSS).⁴³

Non-maintained and independent special schools are often used because local authorities lack suitably

⁴¹ School Census data for England, January 2013 (special request). Totals are rounded to nearest 5. Excludes pupils with invalid postcodes. LA table available but this includes many suppressed figures <3.

⁴² Source: School Census, Jan. 2007-Jan 2014. Special request.

⁴³ DfE (2013) SFR 42/2014 Table 1.1

specialist provision in their area, so it can be assumed that this sector accounts for many 'out of area' placements, including residential placements of children with SEN.

Independent schools are not required to return information to the Department for Education on individual pupils, leaving an important gap in the data available on children with learning difficulties and behaviour that challenges. However information published termly by DfE to help parents considering a non-maintained or independent special school for their child, suggests that these schools play a significant role in catering for children with these needs.

In March 2014⁴⁴ there were 543 non-maintained or independent special schools (NMISS) in England, the great majority of which (nearly 88%) were approved to work with children and young people with learning difficulties, autistic spectrum disorders or behavioural, emotional and social difficulties (BESD)⁴⁵:

- 26 % were approved for children with learning difficulties (MLD, SLD or PMLD).
- 24.5% were approved for children with ASD.
- 63% were approved for children with BESD.

Many such schools are approved to work with more than one type of SEN, so there is much overlap between the above categories. Of the 477 NMISS schools approved to work with children with learning difficulties, ASD or BESD:

- The great majority (434) are independent and less than one in ten (43) are non-maintained.
- 89% are mixed schools. Nearly 9% cater for boys only and just over 2% for girls only.
- Over half (53%, 254 schools) are boarding schools, most of which (79%) are registered as children's homes, able to offer 52-week provision for children and young people requiring highly specialist care and support.

2.7 Trends over time in special school placements across different sectors

Although 'time series' data is published on trends in the number of maintained and non-maintained special schools and pupils in them, data on independent schools is published on a different basis. Drawing together the available data:

- The number of maintained special schools has fallen year on year over the last decade, from 1,088 in 2003 to 964 in 2014⁴⁶. The number of pupils dipped until 2006, but has risen gradually since. In 2014, there were 7% more pupils (97,395) in maintained special schools than in 2003 (90,970): so these schools are, on average, catering for higher pupil numbers.
- Over the same period, the number of non-maintained special schools has fluctuated from year to year, from 72 in 2003 to 69 in 2014⁴⁷. Meanwhile the number of pupils has fallen by 18%, from almost 5000 to just over 4000. Schools in this sector must therefore, on average, have fewer pupils than ten years ago.

⁴⁴ Published online in March 2014, accessed May 2014. <https://www.gov.uk/government/publications/independent-and-non-maintained-special-schools>

⁴⁵ Although we have not focused on children with BESD in the rest of this analysis, it is probable some children with learning difficulties and challenging behaviour are placed in NMISS schools approved for BESD, so these schools are included in this section.

⁴⁶ DfE, Schools, pupils and their characteristics (SFR 15-2014, table 2a). Figures quoted are headcount i.e. not adjusted to reflect dual placements.

⁴⁷ Ibid

Year-on-year trend data on the number of independent schools approved for SEN and independent special schools is not published.⁴⁸ However time series data is available on placements of children with statements in independent schools. Between 2005 and 2013, placements of children with statements in independent schools grew by 55%, up from 7,260 to 11,265⁴⁹. Independent schools now cater for nearly 5% (4.9%) of children with statements. Placements of children in non-maintained special schools fell by 14% over the same period (from 4,740 to 4,085).

2.8 Cost of 'out of authority' and residential placements for children with SEN

Recent, robust data on the cost of 'out of authority' (OOA) and residential placements for children with SEN is lacking. This section provides a brief overview of what little relevant data is available.

Regional Partnerships' survey of 'out of authority' placements, 2008⁵⁰

The Regional Partnerships (initially known as the SEN Regional Partnerships), funded by the Government from 1998 to 2008, developed benchmarking data to enable local authorities in England to compare their spending on 'out of authority' placements (i.e. placements in non-maintained and independent special schools). In January 2008:

- 10,232 placements were made in NMISS schools, 4,778 (47%) of them residential. The total cost of these placements (day and residential) was £613 million.
- Out of authority (OOA) placements most often involved children whose primary need was BESD or ASD, together accounting for over half (56%) of placements and nearly two-thirds (64%) of spending. Primary needs involving a learning difficulty represented 13% of placements and 17% of spending.
- The average cost of a day place (OOA) in January 2008 was £31,696 and the average cost of a residential place was £92,169. Upated to 2012/13 prices⁵¹, day places cost on average £34,320 and boarding places cost £99,798.
- 53% of OOA placements were day, 18% weekly or fortnightly, 15% termly and 12% were 52-week placements. Children with ASD, MLD and PMLD were most likely to be in day placements. Children with SLD were the most likely to be in 52-week placements, followed by children with PMLD.

National cost data

Information on the cost of residential placements is not reported centrally by local authorities (LAs).

National data on LA expenditure on special school placements may best be described as a 'work in progress', following recent reform to the way schools are funded. From 2013, a new system for funding 'high need' pupils and students was introduced.⁵² The new 'place plus' approach is intended to ensure that providers are funded on an equivalent basis, to improve transparency and to encourage flexibility and choice. It involves:

48 A directory of independent and non-maintained schools for children with SEN is published on-line, but this data is not collated and analysed over time. The most recent snapshot is described in the preceding section. See: <https://www.gov.uk/government/publications/independent-and-non-maintained-special-schools>

49 DfE, 2013, Children with SEN: an analysis (SFR 42-2013, data for 2009-2013) and DfE 2009, Children with SEN: an analysis (data for 2005-2009, table 1.1)

50 Regional Partnerships, July 2008, Analysis of out of authority placements (p.9 and tables 4, 11 & 12. Data from 117 LAs, extrapolated to all English LAs).

51 Upated to reflect 2012/13 prices using the Hospital and Community Health Services (HCHS) Pay and Prices Index in Curtis L. (2013) Unit costs of health and social care 2013.

Canterbury: Personal Social Services Research Unit, University of Kent.

52 DfE (2012) School funding reform: arrangements for 2013-14

- Base funding of £10,000 per place provided by LAs or, for non-maintained and independent special schools (NMISS), by the Education Funding Agency (EFA)
- Top-up funding agreed between individual schools and commissioners (LAs) to meet children's assessed needs.

New financial reporting arrangements⁵³ were introduced following the funding reforms which do not, at present, provide a clear picture of spending on special school placements, even at an aggregate level. In particular:

- Base funding (or 'planned spending') on special school placements is reported separately and on a different basis from 'top-up funding', with some obvious anomalies in the data⁵⁴
- 'Top-up spending' on special schools is combined with top-up spending on alternative provision⁵⁵ and the number of places purchased is not reported
- A separate budget line is reported for expenditure on independent providers⁵⁶ (including non-maintained schools) but we do not know how many places were purchased or how much base funding was provided by the EFA.⁵⁷

Estimates from the National Association of Non-Maintained and Independent Special Schools

The National Association of Non-Maintained and Independent Special Schools (NASS) commissioned an analysis to compare the costs of NMISS placements (often referred to as 'out of authority' placements) with equivalent local authority packages of support, including maintained special school places. A pilot study was carried out in 2011, followed in 2012 by a wider analysis of cost data supplied by 42 NMISS schools, which was compared to local authority cost data.⁵⁸

Headline figures for average annual fees paid by LAs for residential placements in NMISS in 2011 were:

- £167,268 for 52-week boarding placements
- £105,522 for term-time boarding
- £61,859 for weekly or fortnightly boarding.

Table 7 below reproduces their findings in more detail, including where relevant the estimated additional costs incurred by local authorities in providing a package of support including therapeutic interventions and short breaks, and by families caring for a disabled child.

⁵³ Section 251 budget returns

⁵⁴ See 'budget detailed level: table 2 - high needs and alternative provision' (table 3a) for planned spending or top-up funding.

<https://www.gov.uk/government/publications/section-251-budget-2013-to-2014-data>

⁵⁵ See 'high needs budget' lines 1.2.1-1.2.3 in the 'budget summary level' tables (URL as above)

⁵⁶ Ibid, line 1.2.3

⁵⁷ Internet searches failed to find this information.

⁵⁸ Clifford J., Theobald C. (October 2012) Summary of findings: extension of the 2011 cost comparison methodology to a wider sample, NASS and Baker Tilly

Table 7: Estimated cost of NMISS placements compared to equivalent LA provision, in 2011

	52 week boarding (NMISS)	Term time boarding (NMISS)	Weekly/ fortnightly boarding (NMISS)	Day only (NMISS)	LA-maintained
Fees paid by LAs	£167,268	£105,522	£61,859	£46,252	£26,636
Total adjustments*	n/a	£17,379	£27,480	£47,459	£84,432
Total package cost	£167,268	£122,901**	£89,339	£93,711	£111,068

Notes

* Adjustments include the cost of therapeutic interventions, recurrent equipment costs, short breaks, travel costs, depreciation of facilities, and additional costs to the family of caring for a disabled child.

** Correction made to total in report (£120,901) with agreement of author.

Daily Mail Freedom of Information Request

The most recent data on the cost of 'out of authority' special school placements comes from a Freedom of Information request made to local authorities by the Daily Mail in August 2013. Data shared by the Daily Mail on the 'top-ten' spending LAs provides a snapshot of the cost of placements in non-maintained and independent special schools in 2012/13 [Table 8].

The request did not seek detailed information on type of SEN or type of placement, although it may be presumed that the highest cost placements were residential. Data were not all reported on a consistent basis (see notes in Table 8), so some caution should be attached to these figures.

Key points of interest include:

- The top-ten spending LAs (amongst the largest in England) made between 183 and 580 NMISS placements in 2012/13, costing between £7.9 million and £38 million.
- The estimated per place cost was £28,673 to £78,150 with an average (across all 10 LAs) of £48,259.
- The most expensive placements (likely to be residential) ranged from £132,800 to £298,606, the latter including contributions from social care.

Table 8: Top-ten spending councils on NMISS placements

	No. of placements	Total spend	Estimated average cost*	Highest cost placement	Notes provided
Surrey	580	£37,969,793	£65,465	£285,500	School year 2012/13. Omits transport costs, includes miscellaneous costs like parent accommodation, meals, therapies provided by school.
Essex	404	£31,572,674 (estimate)	£78,150	£298,606 (joint funded 52 week placement)	School year 2012/13. Includes fees and learning support; also placements where parents paid fees and LA funded learning support; and placements in children's homes with education, joint funded with social care.
Kent	399-450 (termly)	£15,365,068	£36,153	£195,858 (education only)	School year 2012/13. Includes school trips etc.
Lancashire	489	£14,021,000	£28,673	£210,000	
Leicestershire	279	£13,226,081	£47,405	£232,302	School year 2012/13
Bucks	282	£12,621,130	£44,756	£212,780	FY 2012/13
Norfolk	268	£11,343,000	£42,325	£201,853 (residential)	FY 2012/13. Includes fees + additional support like therapies. Transport an additional £785,000.
Warwickshire	283	£10,216,295	£36,100	not given	FY 2012/13. Plus transport costs.
Sutton	183	£7,887,739	£43,102	£132,800	School year 2012/13. Includes school trips etc. Transport was an additional £1,451,419.
Suffolk	185	£8,794,905	£47,540	£214,503	FY 2012/13. Includes fees, therapies, social care contribution. Health contributed an additional £927,456.

Source: Daily Mail Freedom of Information request to local authorities in August 2013, data on the 10 highest spending LAs shared with the Challenging Behaviour Foundation.

Notes: FY = financial year. * Average cost per place estimated by dividing total cost of placements by no. of placements, using the mid-point where a range was provided (by Kent County Council).

3. What do we know from the Learning Disabilities Census?

Summary: What do we know from the Learning Disabilities (LD) Census 2013?

The LD Census provides a snapshot of people with a learning disability, autistic spectrum disorder and/or behaviour that challenges, receiving care in an in-patient setting on 30 September 2013.

- There were 236 in-patients aged 18 or under, representing just over seven per cent of service users. This included 31 children aged 10 or less and 105 aged 11 to 16 years.
- The gender split for 0-17 year olds was 63% male: 37% female.
- Amongst 0-18 year olds, 41% stayed for up to three months and nearly three quarters (74%) for up to one year. There were a small number of long-term in-patients, including 14 who had already stayed for 5 years or more.
- Just over 17% of under-19s lived within 20km of home and 21% lived 20-50km from home. 29% were being treated 100km or more from home.
- Young people under 18 were more likely to be in-patients in mental health wards than other age groups, with 30% in mental health wards and 67% in learning disabilities wards. Young people were also much more likely to be in general non-secure wards than most other age groups.
- Among the under-18s, over two thirds (69% or 127 young people) had been given anti-psychotic medication in the four weeks leading up to Census day, 92% (117) of them on a regular basis.
- Young people were the most likely in-patients to suffer certain types of incident, notably self-harm, hands-on restraint and seclusion. In the three months leading up to the Census:
 - Just over 30% (56 young people) had self-harmed, nearly one third of them eleven times or more.
 - More than four in ten (40.5%, 75 young people) had been physically restrained, over a third of them (28 young people) eleven or more times.
 - Over one in five (22% or 40 young people) had been put in seclusion, one quarter of them eleven times or more.
 - 42 young people (23%) had been involved in accidents, including 6 who had been involved in eleven or more accidents.
 - Just over one in five young people (20.5% or 38 young people) had been subjected to a physical assault, with five who had been assaulted eleven times or more.
- Although young people were more likely to have a discharge plan in place than older in-patients, only 40.5% (75 young people) had a plan or were working towards discharge with an identified place.
- Overall, the 185 children and young people under-18 who are in-patients cost over £46 million per annum, with an average annual cost of £249,319. Just over half of young people (53%) are in placements costing in excess of £4,500 per week.

Please see main body of this chapter for data sources and references. Notes: data quality checks by HSCIC raised some concerns about data reported for this younger age group – please see paragraph 3.1.

3.1 Introduction

The Learning Disabilities (LD) Census was commissioned by the Government as part of a programme of action⁵⁹ agreed following the shocking abuse and neglect uncovered at Winterbourne View Hospital. It provides a snapshot, to be repeated annually, of people with a learning disability, autistic spectrum disorders and/or behaviour that challenges, who were receiving care in an in-patient setting⁶⁰ on 30 September 2013. Data was collected from providers, both NHS and independent, on a wide range of issues.

Data on children and young people

The LD Census report⁶¹ presents data banded by age, with children and young people grouped into a single under-18s (i.e. 0-17 years) age band. We requested data for 0-18 year olds inclusive, seeking a breakdown by age, length of stay and distance from home. Some caution must be attached to these figures as data quality checks by HSCIC raised concerns about the reporting of date of birth information, particularly for this younger age group, which could affect service user numbers.⁶²

We have not tested the statistical significance of the figures presented, but data concerns are highlighted, where known (as above).

3.2 Individual characteristics

Age

There were 236 in-patients aged 18 or under, representing just over seven per cent of service users [Table 9]. Young people are much less likely to be in this type of provision than any other age group, except for the over-65s.⁶³

Table 9: Service users aged under 19 by age

Age (years)	No. of service users
0-10	31
11-16	105
17-18	100
Total under 19	236

Source: Learning Disabilities Census 2013, special data request. Data provided by HSCIC.

⁵⁹ DH (December 2012), DH Winterbourne View Review, Concordat: Programme of action.

⁶⁰ In-patient environments in the Census included: High, medium and low secure forensic wards; acute admission beds within specialised learning disability units; acute admission beds within generic mental health settings; forensic rehabilitation beds; complex continuing care and rehabilitation beds; other beds including for specialist neuropsychiatric conditions.

⁶¹ HSCIC (September 2013) Learning Disabilities Census Report - hereafter referred to as 'the Census report'

⁶² Analysis of the quality of submitted date of birth information suggested that this was inaccurate for 205 of the 3,250 valid records in the Census (45 records could not be traced). After taking into account 'movement' between age bands, the net difference between the published figures and those held centrally by the NHS for the service users in the LD Census was a decrease of 30 in the under 18 age band.

⁶³ The Census Report notes that around one in twenty (5.7% or 185 people) service users were aged under 18, much lower than the comparable proportion of England's general population (21.4%).

Gender

Among the under-18s, 63% of in-patients are male compared to 37% female. This gender split is less pronounced than for most other age groups (approximately 75% male: 25% female) except for the over-65s.

Legal status

Just over 42% of young people (78) were admitted to hospital informally, compared to just 22% of all in-patients. This is consistent with the fact that young people were more likely to be in general non-secure wards (see 3.3 below).

A slightly higher proportion (49% or 91 young people) were detained under Part II of the Mental Health Act 1983 and related legislation, which provides for assessment and treatment (which can be compulsory), generally for up to 28 days. Young people aged 18-34 were the most likely to be detained under these sections.

A small proportion - just over 8% or 15 young people - were detained under Part III, which provides for compulsory treatment, initially for 6 months. This is much lower than for any other age group, reflecting that the fact that young people are more likely to have their needs assessed for the first time. Overall, 32% of all in-patients were detained under Part III for compulsory treatment.

3.3 Nature of provision made

Type of ward

Young people under 18 were more likely to be in mental health wards than other age groups, with 30% in mental health wards and 67% in learning disabilities wards. This may in part reflect the availability of suitable provision (the LD Census report notes that ward type varied by region)⁶⁴ as well as the nature of young people's needs.

Young people were much more likely to be in general non-secure wards than other age groups, except for the over 65s. 67% were in non-secure wards compared to 45% of service users overall. Among in-patients of all ages, distance from home was greater, the higher the level of ward security.⁶⁵

Distance from home

The Government's response to the Winterbourne View Hospital scandal reiterated the desirability of providing treatment locally wherever possible, so that in-patients can be in familiar surroundings, close to family and friends.⁶⁶

We requested a breakdown of distance from home for in-patients aged 18 or under [Table 10]. Just over 17% were being treated within 20km of home and 21% were 20-50km from home. Of more concern, 29% were being treated 100km or more from home and for 16% (38 young people), a valid postcode was not available.

The need for long distance placements is likely to reflect a range of factors, not least the patchy availability of specialist services. The Census report notes 'substantial regional imbalances' in the provision of in-patient

⁶⁴ Ibid, p.11

⁶⁵ Ibid, p.19

⁶⁶ Department of Health (2013), Transforming care: a national response to Winterbourne View Hospital

services and at local authority level.⁶⁷

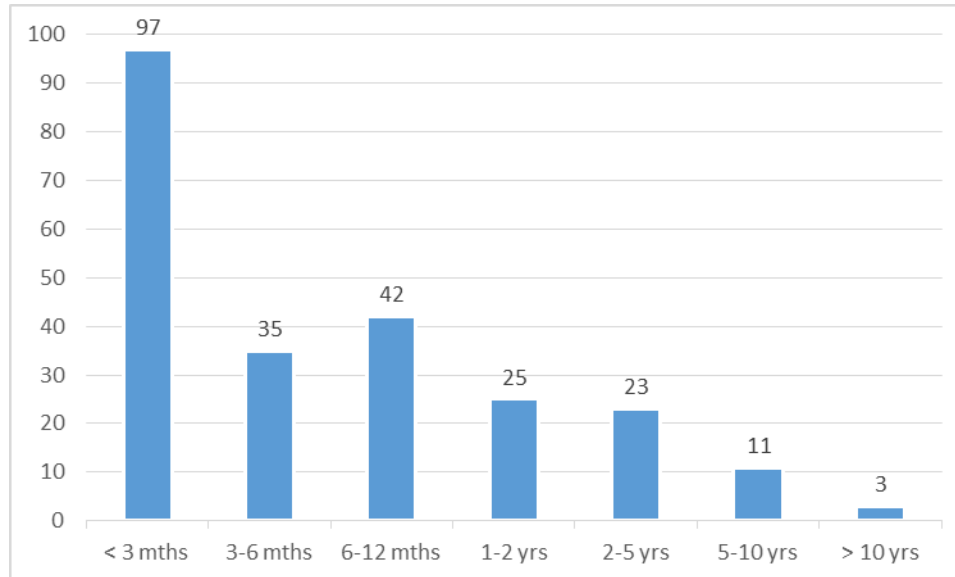
Table 10: Service users aged under 19 by distance from residence

Distance from home	Number of service users	% of service users
Up to 10km	22	9.3%
10 to < 20km	19	8.1%
20 to < 50km	50	21.2%
50 to < 100km	38	16.1%
100km or more	69	29.2%
Same postcode for residence and ward stay or 'unknown'	38	16.1%
Total service users aged under 19	236	100.0%

Source: Learning Disabilities Census 2013, special data request. Data provided by HSCIC.

Length of Stay

Young people are less likely to stay long-term in this type of provision compared with older age groups.⁶⁸ Amongst 0-18 year olds, 41% stayed for up to three months and nearly three quarters (74%) for up to one year. There were a small number of long-term in-patients, including 14 who had already stayed for 5 years or more [see Figure 4].⁶⁹



Source: Learning Disabilities Census 2013, special data request. Data provided by HSCIC.

Figure 4: Young people (aged 0-18 years) by length of stay

⁶⁷ LD Census Report (Sept 2013) p.15

⁶⁸ LD Census Report, p.11: "Length of stay varied with age, with service users aged under 18 proportionally more likely to have been inpatients for three months or less (45.4%) than service users overall (18.5%)."

⁶⁹ Learning Disabilities Census 2013, special data request.

Care planning

Although young people were more likely to have a discharge plan in place than older in-patients, at the time of the Census, only 40.5% (75 young people) had a plan or were working towards discharge with an identified place. This compares to just under 30% of all in-patients. Those who did not have a discharge plan included:

- Just over 30% of young people (56) who were receiving active treatment
- Just over 23% (43) considered 'currently not dischargeable because of mental illness' - the highest proportion of any age group
- 8 (4.3%) who had a delayed transfer of care because no onward placement had been found
- A small number who were thought to require indefinite treatment because of their physical or behavioural needs (1.1%, 2 young people).

3.4 Anti-psychotic medication and incidents of concern

Use of anti-psychotic medication (tranquilisers)

The Census asked about the use of major tranquiliser class drugs (anti-psychotic medication) in the 28 days leading up to the Census. This showed high levels of medication being used routinely, in spite of concerns about the efficacy and appropriateness of such treatment, particularly for patients with learning disabilities.⁷⁰

Among the under-18s, over two thirds (68.6% or 127 young people) had been given medication leading up to Census day, 92% (117) of them on a regular basis. These proportions are similar to other age groups.

Incidents

Data was gathered on reported incidents in the three months leading up the Census, including self-harm, accidents, physical assaults, hands-on restraint and the use of seclusion. Young people were the most likely in-patients to experience self-harm, hands-on restraint and seclusion.

- **Self-harm.** Just over 30% (56 young people) of under-18s had self-harmed, nearly one third of them (18 young people) 11 times or more. Rates of self-harm were highest for young people, peaking between the ages of 18-24 years.
- **Hands-on restraint.** More than four in ten (40.5%, 75 young people) had been physically restrained during this period, over a third of them (28 young people) 11 or more times. Young people were more likely to be restrained than older in-patients, with the highest rate of multiple restraints (15% of under-18s).
- **Seclusion.** Seclusion is defined as '*supervised confinement of a patient in a room which may be locked, to protect others from significant harm*'.⁷¹ This is another incident type to which young people were most likely to be subjected, with over one in five (21.6% or 40 young people) being put in seclusion in the three months leading up to the LD Census, one quarter of them 11 times or more. Seclusion rates decline with age.
- **Accidents.** 42 young people (23%) had been involved in accidents, including 6 who had been involved in 11 or more accidents. Accidents were more common for older in-patients, aged 55 years

⁷⁰ HSCIC (April 2014), LD Census Report - Further Analysis. See commentary on p.13-17.

⁷¹ Care Quality Commission (April 2011) 'Count Me In' Census

or more.

- **Physical assault.** Just over one in five young people (20.5% or 38 young people) had been subjected to a physical assault in the three months prior to the Census, with five young people assaulted 11 times or more.

3.5 Progress towards Winterbourne View Concordat commitments

One of the key commitments made in the Winterbourne View Concordat was to “review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible.”⁷² Progress is being monitored through regular surveys of providers.⁷³

We requested a breakdown of these statistics in relation to children and young people. This showed that at June 2014, 147 children and young people remained in in-patient provision:

- Only 43 (29%) had an agreed transfer date. 104 still had no transfer date. For the great majority of these young people (87), this was due to a clinical decision, but 15 of the reasons given reflected a lack of agreed funding or local provision [Table 11]
- For 94 (64%) of them, the local authority was aware that they would be transferring to their local area, for just over one third of them (53 young people), it was not
- Nearly all (142) had a care co-ordinator and access to an independent advocate (139).

Table 11: Reasons given for lack of transfer date for young people under-18

Type of reason	Frequency
Lack of agreed health care funding	2
Lack of agreed social care funding	3
Lack of local health service provision	2
Lack of local social care support	5
Lack of suitable housing provision	3
Clinical decision	87
Other	16
No reason supplied	5
Total no. without a transfer date	104

Source: *Assuring transformation data collection*, June 2014 (special request, data provided by NHS England).

Note: As more than one reason could be given, the total does not equal the sum of the parts.

3.6 Cost of in-patient provision

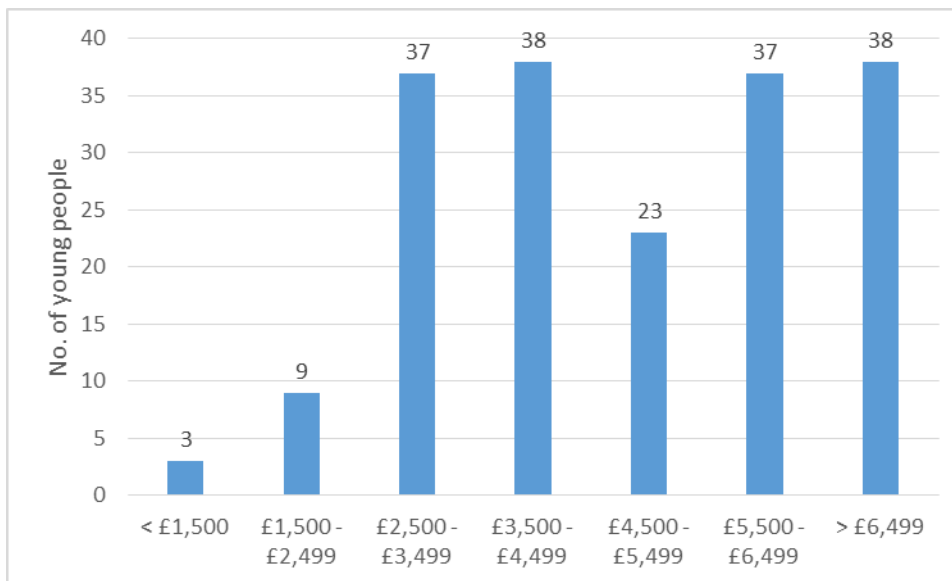
The LD Census asked about the weekly cost of placements. Overall, the 185 children and young people under-18 who are in-patients cost over £46 million per annum (an estimated £46,124,000) with an average annual cost of £249,319.⁷⁴ Young people were the most likely of any age group to be in placements costing in excess of £4,500 per week - which the majority (53%) of their placements cost - with only a small number

⁷² DH (December 2012), DH Winterbourne View Review, Concordat: Programme of action.

⁷³ <http://www.england.nhs.uk/2014/06/27/assuring-transformation/>

⁷⁴ Estimate reached as follows: (no. of service users for each cost band) x (mid-point in weekly charges) x 52 weeks. For placements >£6499, a charge of £7000 was assumed. For placements <£1500, a charge of £1000 was assumed.

(12) in placements costing less than £2,500 per week [Figure 5]. These higher costs may reflect a range of factors including higher staff ratios needed for young people and the higher costs of assessment and acute interventions.



Source: HSCIC (April 2014), *LD Census Report - Further Analysis*. Table 6A.

Figure 5: Weekly cost of in-patient care for under-18's

4. Conclusions and recommendations for improving national data

4.1 Residential placements

National policy has for more than two decades advocated a reduction in the use of residential placements, in favour of investing locally in specialist provision and improved 'early intervention' to support children with more complex needs and their families, from the earliest years onwards. This was reiterated in the Government's response to the abuse and neglect of in-patients at Winterbourne View hospital:

*"The norm should always be that children, young people and adults live in their own homes with the support they need for independent living within a safe environment. People with challenging behaviour benefit from personalised care, not large congregate settings."*⁷⁵

The 2014 SEND Code of Practice similarly expects local authorities and clinical commissioning groups to: "work together to consider how they will reduce out-of-area placements". If a residential placement is needed, then: "so far as reasonably practicable, those placing the child or young person should try to secure a placement that is near to the child's home."⁷⁶

In spite of this long-standing policy direction, nationally-published SEN statistics tell us very little⁷⁷ about the number or nature of residential placements for children with SEN, even though relevant information is collected through the School Census.⁷⁸

A special request was required to reveal the year-on-year 'headline trend' in residential placements of children with statements: showing a fall of 24% since 2007⁷⁹, although this excludes children placed in independent schools, leaving an important gap in the picture. In 2008 (latest available data⁸⁰), an estimated 38% of children with statements who were boarding were in independent schools.

Recommendation: To enable a clearer policy focus on children in residential placements and better data to underpin improvements in local and regional commissioning, we recommend that the '*Children with SEN*' bulletin⁸¹ published annually by the Secretary of State for Education should include a section on children in residential placements, with analysis of:

- Number of residential placements in other local authority areas
- Distance from home
- Length of stay (e.g. 52 week, 38 week (termly), weekly or bi-weekly boarding)

75 DH (2012) 'Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report'

76 DfE and DH, 2014, SEND Code of Practice. See paras. 3.69 and 10.29

77 Residential placements are not mentioned in the two key statistical bulletins on SEN: the annual statistical first release 'SEN in England' or the annual 'Children with SEN' bulletin.

78 The School Census includes a code to show if a child is boarding, so much more data on children with SEN in residential placements in maintained and non-maintained schools could be made available.

79 Source: School Census, Jan. 2007-Jan 2014. Special request.

80 Data on residential placements in non-maintained and independent schools was last collected by the (SEN) Regional Partnerships in 2008 (see section 2.8). Estimate based on this data, School Census data on placements in non-maintained and independent special schools (DfE, 2009, *Children with SEN: an analysis*, table 1.1) and School Census data on residential placements (special request, see table 6 in section 2.6), all Jan. 2008.

81 The Special Educational Needs (Information) Act 2008 required the Secretary of State to publish information about pupils in England with special educational needs every calendar year, fulfilled through the annual Children with SEN bulletin.

- Breakdown of residential placements by primary need
- Breakdown of residential placements by sector (independent, non-maintained, local authority, other).

This would require changes to data-reporting in the School Census and potentially to the SEN2 survey returned by local authorities, including:

- New categories for length of stay in the school census (replacing '6 nights a week or less' and '7 nights a week or less')
- New bands for recording distance from home, as used in the Learning Disabilities Census (in addition to postcodes), to make it easier to extract data and analyse such placements.

4.2 Independent schools

Placements of children with statements in independent schools (independent special schools and independent schools approved for SEN pupils) have increased in recent years. Between 2005 and 2013, placements of children with statements in independent schools grew by 55%, from 7,260 to 11,265. In 2013, nearly one in twenty children with statements were placed in independent schools.⁸²

We have no way of knowing how many children with learning disabilities and behaviour that challenges are in independent schools, or how many of them are in residential placements. This represents a major gap in this analysis.

It is an anomaly⁸³ that non-maintained special schools (NMSS) provide detailed data on all their pupils through the School Census, while independent schools catering principally for children with SEN and funded on the same basis as NMSS (i.e. mainly by places purchased by local authorities) provide only school level data.⁸⁴

This matters because when commissioners, policy makers or researchers examine national data on children with SEN – for example, to plan services or to review the effectiveness of policies – placements in independent schools, involving some of those children with the most complex needs, in the most expensive placements, are often excluded from the statistics.⁸⁵

Recommendation: To inform improved planning and commissioning of specialist provision for children with SEN and better monitoring of outcomes, we recommend that:

- Independent schools catering primarily for children with SEN should be required to participate in the School Census
- The annual 'Children with SEN' bulletin⁸⁶ should include an analysis of the number and profile of children with SEN placed 'out of authority' in independent and non-maintained schools.

⁸² DfE (2013), Children with SEN: an analysis (SFR 42-2013, data for 2009-2013) and DfE 2009, Children with SEN: an analysis (data for 2005-2009, table 1.1)

⁸³ As noted almost a decade ago in Pinney A. (2005), Disabled Children in Residential Placements, DCSF, which made a similar recommendation.

⁸⁴ All maintained schools and non-maintained special schools are required to provide information on individual pupils and on the school itself, through the School Census. Independent schools return only school level information, through 'SLASC': the school level annual school census.

⁸⁵ School and LA-level data on the number children with SEN in independent schools is published, but because these schools do not provide pupil-level data, data tables on e.g. age, gender, free school meal eligibility, looked after status, type of SEN, first language, ethnicity, attainment, exclusions and absences of children with SEN, exclude children in independent schools.

⁸⁶ See footnote 79 (Children with SEN bulletin).

4.3 Cost data

There has been major reform to the way schools are funded, including for high cost placements for children with SEN. New arrangements for reporting spending are likely to require some adjustments, as the new system 'beds down'.

Recommendation: We recommend that in future, LA reporting requirements provide a clearer picture of, both at an aggregate and a per-place basis (including both 'base' and 'top-up' funding):

- Spending on maintained special school placements
- Spending on placements in non-maintained and independent schools.

The Regional Partnerships (initially the SEN Regional Partnerships), funded by the Government between 1998 to 2008, developed benchmarking data to enable local authorities to compare their spending on 'out of authority' placements, to help them plan and manage their budgets more effectively. We recommend that consideration be given as to how meaningful cost comparisons could again be generated – perhaps through a local authority-led initiative or by commissioning regular independent surveys.

Glossary of abbreviations used in this report

ASD	Autistic spectrum disorders
BESD / SEBD	Behavioural, emotional and social difficulties
CBF	Challenging Behaviour Foundation
DCSF	Department for Children, Schools and Families (now DfE)
DfE	Department for Education
DH	Department of Health
EFA	Education Funding Agency
FY	Financial year
HSCIC	Health and Social Care Information Centre
LA	Local authority
LAC	Looked after child/children
LD	Learning disabilities
MLD	Moderate learning difficulties
NASS	National Association of Non-Maintained and Independent Special Schools
NMSS	Non-maintained special school
NMISS	Non-maintained and independent special schools
NPD	National pupil database
OOA	Out of authority placement
PMLD	Profound and multiple learning difficulties
SAP	School action plus
SEN	Special educational needs
SEND	Special educational needs and disabilities
SFR	Statistical first release
SLD	Severe learning difficulties