

# Disabled Children: Numbers, Characteristics and Local Service Provision

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The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Children, Schools and Families.

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## Contents

List of tables and figures .....	4
Executive Summary .....	5
1 Introduction .....	12
1.1 Background .....	12
1.2 Aims.....	15
1.3 Methodology .....	16
1.4 Structure of the report.....	19
2 Numbers of disabled children.....	20
2.1 Numbers of disabled children: survey responses .....	20
2.2 Calculating a figure for disabled children.....	20
2.3 Other sources of data on local prevalence .....	33
2.4 Local authority prevalence estimates .....	34
3 Characteristics of children with disabilities.....	45
3.1 Gender.....	47
3.2 Age .....	48
3.3 Ethnicity .....	48
3.4 Types of disability .....	49
3.5 Summary .....	50
4 Local services provided to disabled children.....	52
4.1 Difficulties in providing information .....	52
4.2 Numbers receiving social care services .....	55
4.3 Numbers receiving services provided by the PCT.....	62
4.4 Summary .....	64
5 Providing information on disabled children .....	65
5.1 Agreement on definitions.....	66
5.2 A single shared database and compatible databases .....	71
5.3 Register for children with disabilities .....	74
5.4 Role of central government .....	75
5.5 Summary .....	76
6 Conclusions.....	77
References.....	80
Appendix A: Survey Questionnaire .....	83
Appendix B: Indicators of children with disabilities, with OPCS and FRS-based estimates .	92
Appendix C: Lower and upper bounds for estimate as number and percentage of age group, and expected numbers from OPCS and FRS prevalences .....	97

## List of tables and figures

Table 1.1: Non-response rates by LA type .....	18
Table 1.2: Non- response rates by region.....	18
Table 2.1: Local authority figure for disabled children .....	20
Table 2.2: Percentage of authorities with a count or estimated figure .....	24
Table 2.3: Sources of data used for figures based on a count .....	24
Table 2.4: Number of sources used for estimated figure based on a count .....	25
Table 2.5: Data source combinations used for calculating a figure for disabled children .....	26
Table 2.6: Confidence in figure for disabled children.....	28
Table 2.7: Confidence in figure based on count or estimate.....	29
Table 2.8: Confidence in figure based on count .....	29
Table 2.9: Categories included in definitions of disability .....	33
Table 2.10: Average local authority numbers on a variety of indicators .....	36
Table 2.11: Average local authority percentages on a variety of indicators.....	36
Table 2.12: Correlations between local authority percentages on a variety of indicators .....	37
Table 2.13: Disabled children in receipt of social care services: TCRU survey and CIN Census.....	39
Table 2.14: Lower and upper bound estimates for the number and percentage of disabled children .....	41
Table 3.1: Data on the characteristics of children with disabilities.....	45
Table 3.2: Sources used for characteristics.....	46
Table 3.3: Combinations of sources used for demographic characteristics.....	46
Table 3.4: Demographic characteristics.....	47
Table 3.5: Number of children by type of disability, per 1,000 children under 18 .....	49
Table 4.1: Disabled children receiving social care services: rate per thousand children aged 0-17 in the local population .....	56
Table 4.2: Disabled children receiving social care services as a percentage of children .....	57
Table 5.1: Factors that would help in calculating a figure for disabled children.....	66

# Executive Summary

## Introduction

There is a lack of data at both national and local level on the numbers and characteristics of disabled children and their use of local service provision. Yet, such data is a prerequisite to the planning and delivery of effective services. The Thomas Coram Research Unit was commissioned to undertake a survey of all Directors of Children's Services in England to collect and analyse data on the numbers and characteristics of disabled children and the services provided to them.

## Key Findings

- The survey achieved a high response rate (77%), and local authority respondents made considerable efforts to collate the data available to them in the time available. Despite this, the survey information did not provide a reliable figure for the number of disabled children for each local authority. This was due to the difficulties local authorities had in identifying and counting disabled children and the different definitions of disability applied.
- Due to the varying sources of data available to local authorities, the lack of a consistent definition of disability, and the different categorisations and interpretations of service provision, it is not possible at the current time to assess accurately the level of health and social care services provided for disabled children and their families, nor the variation in services between local authorities.
- Comparisons have however been drawn using published figures. Analysis of these figures makes it possible to put a lower and upper bound on the number of disabled children in each local authority, based on the number of children with a statement of Special Educational Needs and in receipt of Disability Living Allowance (DLA). On this basis the number of disabled children in England is estimated to be between 288,000 and 513,000. The mean percentage of disabled children in English local authorities is likewise estimated to be between 3.0% and 5.4%.

- Most local authorities experienced difficulties in providing information on disabled children for the survey. Most recognised the need for improved data on disabled children to inform their work and deliver effective services, but many were struggling with the difficulties in collecting and collating this data.
- Without comprehensive and comparable data it is difficult for both local and central government to assess how well the needs of disabled children are being met.
- The need for agreement on definitions of disability, a single database or shared, compatible databases, good communication between agencies, adequate resourcing and more guidance from central government are all important in helping to improve data on disabled children.

## **Background**

With the publication of the report, *Aiming High for Disabled Children: Better Support for Families*<sup>1</sup>, the government has pledged to improve outcomes for disabled children and their families identifying three priority areas: access and empowerment; responsive services and timely support; and improving quality and capacity. In order to plan and deliver effective services, local authorities require good information about the numbers and needs of disabled children, and about the support they receive. Such data are also needed by central government to support policy development and monitor progress in improving outcomes. The limitations of national data such as the General Household Survey (GHS) and Family Resources Survey (FRS) (which provide information on the prevalence and type of disability among children) have been widely recognised. Sources of data at the local level, such as the Children Act Register, the Children in Need (CIN) Census, or data on children with special educational needs (SEN) are also unable to provide comprehensive information on the prevalence of children with a disability.

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<sup>1</sup> HM Treasury and Department for Education and Skills 2007

## **Aims**

The study had three specific aims:

1. to design and administer a survey of all 150 Directors of Children's Services in England likely to achieve a high response rate;
2. to analyse and report on how disability is defined and recorded; the prevalence, and characteristics, of children with disabilities; the services that are provided to them and the robustness of these data; and
3. to critically examine the difficulties that local authorities might encounter in providing these data and what may be done to resolve these difficulties.

## **Methodology**

The study began with an initial scoping phase to inform design of the survey. This involved four local authorities and included exploring with them the range of disability definitions, how information was collected and organised (including what information was available from partner agencies), and the kinds of questions that could feasibly be asked in a survey about the provision and delivery of services.

Following piloting, the survey was sent electronically in January 2008 to all 150 Directors of Children's Services and copied to the person most likely to complete it - usually a manager with responsibility for children with disabilities. Altogether, 115 questionnaires were returned - a response rate of 77%. Follow up telephone calls were made to ten of the 35 non-responding authorities to elicit the reasons why they had been unable to complete a return.

## **Findings**

### ***Estimating the numbers of disabled children***

Given the variation in definitions of, and criteria for, disability the survey could not provide definitive figures for the numbers of disabled children for each local authority. However, comparisons have been drawn based on five different sources of data: the total number of children with SEN statements; the total number of children with SEN (both with and without statements); the 2001 Census figure for the number of children with limiting long-term illness

(LLI); the number of children in receipt of Disability Living Allowance (DLA); and the number of disabled children recorded in the CIN Census; and with figures based on the Office of Population Censuses and Surveys (OPCS), which may now be outdated, and FRS estimates.

Based on our analyses of published figures, we propose that it would be possible to put a lower and upper bound on the number of disabled children in each local authority based on the number of children with a SEN statement and the number of children in receipt of DLA. Since it was widely agreed by local authorities that children in either of these categories would be counted as having a disability, a lower bound could be taken as the larger of these two and an upper bound as the sum of those two. The most likely figure would be somewhere between these two, its exact position depending on the degree of overlap between the two sources. It will also depend on the definition of disability applied. A narrow definition would tend towards the lower bound, whereas a broader definition might produce a figure even above the upper bound, for example including SEN pupils without a statement in the definition would give a much higher figure. Figures for each local authority, and for England as a whole, have been calculated based on this model and are included in an appendix to the report. This provides a figure of between 288,000 and 513,000 disabled children in England, or on average between 3.0% and 5.4 % of all children under 18.

### ***Characteristics of disabled children***

According to our survey of local authorities, boys are twice as likely as girls to be categorised as disabled. This is consistent with the 2005 Children in Need Census and the 2007 SEN statement figures. Compared to the 2001 Census, children under five are less likely to be known to be disabled. This is also consistent with CIN and SEN figures. However, our survey found, on average, equal numbers of disabled young people in the age range 5-11 and the range 12-18: this is consistent with the 2001 Census, but the CIN and SEN figures both show higher numbers in the oldest age group.

Due to a lack of comparable data on numbers of children with different types of disability our findings cannot be regarded as clear indicators of the prevalence of different types of disability. As a number of survey respondents pointed out, categorising by disability is not necessarily the best way of collecting information to inform service planning, and that more useful information could be gathered by asking about function and need for support.

### ***Use of local service provision***

Despite careful piloting and the best efforts of survey respondents, the information we were able to collect within this survey on local service provision for disabled children does not provide a strong basis for making judgements about the overall level of health and social care provision, nor of variation between local authorities in the services available. The widely varying range of figures provided, which were converted into rates per thousand of the local child population and per hundred children served by the disabled children's team, cannot be interpreted as evidence of real differences in levels of service provision for disabled children. Substantial variation may well exist, but this could only be safely concluded on the basis of figures that are comparing like with like. The varying sources of data available to the local authorities responding to our survey, the different categorisations and interpretations of service provision and the lack of a consistent definition of disability, all mean that such comparisons cannot yet usefully be made.

### ***Providing information on disabled children***

Most authorities experienced difficulties in providing information on the numbers and characteristics of disabled children and local service provision. This was because Social Care, Education and Health differed in their definitions and criteria for categorising disability. An agreed definition and a single shared database or databases that were compatible were considered essential for improving data on disabled children. Integrated children's services and joint funding and commissioning may help to drive improvements, but more guidance from central government about what data to collect and protocols for data sharing would be helpful. Adequate resourcing for data collection and management, and good communication between agencies were also considered important. Those local authorities advocating that Children Act Registers had an important role to play suggested that adequate investment in the Register was needed, alongside strengthening its reach for example by providing incentives for parents to register their children or even making registration mandatory.

## **Conclusions**

Planning and improving services for disabled children requires accurate, comprehensive data on numbers of disabled children in the population, together with the characteristics and use of local service provision. Improving services for disabled children will be significantly hindered without these data. The TCRU survey has shown that whilst local authorities recognise the need for such data to inform and improve their work, and whilst some are working towards improving their data systems, most are struggling with the difficulties associated with collecting and managing these data. The survey results indicate that no authority has found all the 'answers' to the difficulties, and authorities are at different stages in the process of improving their data with some further along than others.

### ***Implications for policy***

These findings have a number of implications for policy with regard to developing a strategy to meet the commitment outlined in *Aiming High for Disabled Children* for 'better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing'.

At present, it is impossible to compare local authorities on their numbers of disabled children, because they do not use a consistent definition of disability. Whilst there is no single 'correct' definition of disability, it is important that DCSF provides a common definition for the collection of a comparable dataset. The information currently collected on children with special educational needs is relatively comprehensive because there is a standardised format; local authorities know which data they are required to collect for the annual return and in turn have developed databases that will provide the relevant information. If local authorities knew which data they should be collecting on disabled children, and a similar reporting requirement was introduced, improved data collection and better databases would result.

Without data on disabled children collected by local authorities on a consistent basis, it is impossible to compare the services that are provided, as like is not being compared with like. In order to make any progress on assessing service delivery, a prerequisite is that statistics are collected using a common definition. In developing that definition consideration should be given to categorising disability in ways which best inform service planning.

The survey findings support the need for central government to develop guidance for local authorities and health services to promote better practice in collating robust data. Data sharing and data protection are real issues faced by local authorities and their partners as they move towards a better database, and such guidance could usefully include data sharing protocols.

Providing robust data on disabled children requires investing in the necessary resources to make this happen. The resources that local authorities currently allocate for collecting and collating information about disabled children appear to vary considerably.

It will take time for local authorities and their partners to develop the databases necessary to provide better data on disabled children, but the TCRU survey suggests that local authorities in general are keen to move towards this position, even though the process may be difficult. A step has already been taken to address the need for guidance on how to collect robust and comparable data, with the recent establishment of a joint DH/DCSF working group. This group is considering how effective systems can be developed for data collection and the use of data in the local planning and delivery of services, and what central government can do to remove obstacles that act as a barrier to joint commissioning and joint activities. With a greater commitment to improvement in data collection, it is to be hoped that associated improvements in services for disabled children will be realised.

# 1 Introduction

## 1.1 Background

There have been significant developments in policies and practices concerning children with disabilities in recent years. The Special Educational Needs (SEN) and Disability Act 2001 set out a strengthened entitlement to mainstream education for pupils with SEN and protection from discrimination for disabled pupils in schools, and the new Disability Equality Duty (in force from December 2006) requires all public sector organisations including schools to ensure that disabled people are fairly treated and included in policy development. The National Service Framework for Children, Young People and Maternity Services, in particular Standard 8, sets standards for service provision for disabled children and young people across the next ten years (Department of Health, 2004) and the five year strategy for SEN, *Removing Barriers to Achievement*, identifies action to improve early intervention, embed inclusive practice in schools and early years settings, develop teachers' skills and develop effective partnerships between services and with parents (Department for Education and Skills, 2004).

These initiatives are part of the government's commitment to ensure that services are designed to meet the additional needs of disabled children and their families and to improve outcomes for disabled children. However, there remains much variability in the quality of provision, pupil outcomes and levels of parental satisfaction with provision for children with SEN or disabilities (House of Commons Education and Skills Committee, 2006; Ofsted, 2004; Audit Commission, 2003). As highlighted in *Aiming High for Disabled Children: Better Support for Families*, 'across local authorities, disabled children and families are offered different levels and standards of care; those most in need are not always the most likely to get support, and parents and young people in some areas feel insufficiently empowered, informed, or involved' (HM Treasury and Department for Education and Skills, 2007:14).

As a consequence three priority areas to improve outcomes for disabled children have been identified: access and empowerment; responsive services and timely support; and improving quality and capacity (HM Treasury and Department for Education and Skills, 2007). *Aiming High for Disabled Children* sets out a 'core offer' to disabled children and their families, which will encompass minimum standards in five areas identified by research as playing a significant role in the delivery of responsive services: clear information; transparent eligibility criteria and/or processes for accessing services; accessible feedback and complaints procedures; and participation by parents and children in shaping local policies and services.

Parents' experiences of services for disabled children and the 'core offer' will be assessed through an annual survey, which will provide the basis for one of the national indicators within the government's new performance framework for local authorities (Department of Communities and Local Government, 2007).

### ***Sources of information on disabled children***

In order to plan and deliver effective services for disabled children and their families, local authorities and other agencies require good information about the numbers and needs of disabled children in their area, and about the support that they receive. National government also needs such data, in order to support policy development and to monitor compliance with legislation and delivery targets. There is a range of data at the national level including the General Household Survey (GHS), Family Resource Survey (FRS), and the 2001 Census, which provides information on the prevalence and type of disability among children. Data from such surveys suggest prevalence estimates varying from five to 18 percent of the child population depending on the definition or measure of disability that has been applied. For example, a prevalence rate for disabled children of seven percent of all children under the age of 16, based on the 2002 General Household Survey (Office for National Statistics, 2004), is sometimes quoted (PM's Strategy Unit, 2005). The limitations of such national data, such as population coverage, are widely acknowledged (Read et al., 2007).

Local data also suffer from a range of shortcomings. In an analysis of Children and Young People's Plans it was reported that only five of a sample of 20 Plans had included any analysis of the size and characteristics of their population of disabled children and that there are serious gaps in the data available to local authorities in order to plan effective services (Contact a Family et al., 2006). Although there is a statutory requirement under the Children Act 1989 for each local authority to maintain a register of children with disabilities, because registration is voluntary it is not a good source of data on the prevalence and characteristics of children with disabilities (Mooney et al., 2007). Apart from its voluntary nature, there are other reasons why it is difficult to collate information from Children Act Registers to provide accurate figures on the number and characteristics of disabled children nationally. These include: variation in definitions within and across agencies, different criteria for registration (some are open, others require an assessment to 'prove' disability), and difficulties in collating data across different databases within local authorities and across agencies (Council for Disabled Children, 2002; NEOPHO, 2003; Mooney et al., 2007). Another key difficulty, highlighted by the Council for Disabled Children (1999), is the problem of achieving a consistent definition of 'disability' and 'SEN'.

Other sources of information on disabled children are based on particular populations, for example those in contact with particular services, such as education (SEN data) or local authority social services departments (such as the Children in Need Census). Data on SEN are collected annually by DCSF and come from two sources: data recorded by schools as part of the School Census and data recorded by each LEA on the annual return SEN2. The School Census data includes all children attending the school regardless of where they live; whilst SEN2 data refers only to the children the authority has responsibility for, regardless of where they are educated. The two figures therefore differ. A greater problem in using SEN data to estimate numbers of disabled children is that not all children with special educational needs will have disabilities and, conversely, not all children with a disability will have special educational needs. Although it is assumed the overlap will be high, Porter and colleagues found that almost a third of children meeting the DDA definition of disability did not have special educational needs (Porter et al., 2008).

On the other hand, the Children in Need (CIN) Census, which covers all social service activity in a 'typical week', records only those disabled children in contact with local authority children's social services at the time of the Census. Although these figures can give an indication of relative rates of children with disability between local authorities, they cannot themselves be used to calculate rates, as it is not known what percentage of all disabled children received a service in the Census week: 'Reference data collected through the Children in Need Census is not an indication of prevalence of any factor in the general population, but is only an indication of prevalence amongst the Children in Need population' (Department for Education and Skills, 2006). The most recent CIN Census took place in 2005 and although a new Census is in development, it will not produce results until late 2009.

ContactPoint, the Common Assessment Framework (CAF) and the Integrated Children's System (ICS) are tools that have been developed as part of the *Every Child Matters: Change for Children* process, in order to support integrated working and more effective sharing of information about children (Every Child Matters, 2007). ContactPoint will hold a small amount of core demographic data on every child in England (up to their 18<sup>th</sup> birthday) and contact details for their parents/carers and for practitioners providing services to the child, but will not hold any case or assessment information so will not identify if a child has a disability. The CAF is designed to enable practitioners across all agencies to identify in a consistent way those children who have additional needs that are not being met. Although there are plans to develop a single, national Information Technology (IT) system to support

these common assessments, the 'eCAF' will only hold information about children with consent and for a limited period of time.

The Integrated Children's System (ICS) is a framework for collecting information about children in need, whose health or development would be impaired without the provision of services. Although the ICS is not yet fully implemented by all local authorities (Department for Education and Skills, 2007a), it should eventually provide comprehensive information about disabled children with more complex needs who are in contact with social care services. The move to integrated children's services and the introduction of the ICS has often been a spur for local authorities to re-examine data collection and data management systems (Mooney et al., 2007).

Primary Care Trusts (PCTs) also hold data on disabled children: the Child Health Team within the PCT is responsible for recording information on the child health computer system on all children for whom the PCT is responsible. This includes all children from birth to sixteen years of age and children with special needs to the age of 19. Information held on the computer system covers all aspects of a child's health including immunisations and health promotion checks. Children with special needs / conditions as defined by a clinician are recorded on this system using the International Statistical Classification of Diseases and Related Health Problems (ICD) although the variable use and quality of this module on the system means that reliable estimates across authorities cannot be made (Read et al., 2007).

## **1.2 Aims**

The overall aim of this study was to examine the prevalence of disability among children at the local level. In order to do this, it aimed to collect information from local authorities on the numbers and characteristics of children with disabilities and the services provided to them by the local authority and, where appropriate, their partners. Specific objectives of the study were to:

- Design and administer a survey of all 150 Directors of Children's Services (DCSs) in England in ways that are likely to achieve a high response rate;
- Analyse and report on prevalence and characteristics of children with disabilities, the services that are provided to them and the robustness of these data; and

- Critically examine the difficulties that local authorities may encounter in providing these data and what may be done to resolve these difficulties.

### **1.3 Methodology**

#### ***Scoping, designing and piloting the survey of local authorities***

In order to meet the first objective (to design a relatively straightforward questionnaire that addressed the complexities associated with differences across authorities in definitions, eligibility criteria and data held about disabled children), the first stage of the study involved a scoping exercise to ascertain:

- The range of disability definitions and the feasibility of getting replies from local authorities to survey questions asking them to indicate which definitions they use;
- How information on the numbers and characteristics of disabled children and service use is organised and collated at local authority level, including information about services provided by partner agencies;
- The kinds of questions that could feasibly be asked about the provision and delivery of services.

Four local authorities, selected to represent different types of authority and geographic region, agreed to help with this stage of the project. Issues relating to the survey were explored in telephone interviews with service managers and database co-ordinators. In addition, literature and web searches were undertaken to help inform the survey design. A draft questionnaire, suitable for completion electronically or as a hard copy was piloted with six local authorities and subsequently revised. Unfortunately, the timetable for the study did not allow time for a further round of piloting. A copy of the questionnaire can be found in Appendix A.

#### ***Administering the survey of local authorities***

In January 2008, the questionnaire together with a summary of the project was emailed to each of the 150 Directors of Children's Services in England and copied to the person most likely to take responsibility for completing it. Authorities were given two weeks in which to respond after which two reminders were sent with a seven day interval between them.

DCSF provided a list of local authority contacts who had applied for pathfinder status for the short break scheme, and we had contact details, though often for the co-ordinator of the Children Act Register (CAR) or its equivalent, from authorities responding to our earlier survey for the national disabled children's indicator. To ensure that we had correctly identified the team manager for children with disabilities or another senior manager with responsibility in this area, we telephoned authorities for verification. This proved to be an extremely useful exercise and a number of corrections were made to our database.

Nevertheless, despite these efforts, it was apparent from the survey and in follow-up calls to non-respondents that in some authorities the person who received the questionnaire was not in fact the person who could complete it. Inevitably this led to some delay before it reached the right person. In addition, collecting and collating the data for the questionnaire usually required coordination between departments, which added to the time needed to respond. As explained by one of the 23 authorities who either requested an extension or informed us that there would be a delay:

*The team I manage is responsible for three of the key areas you identify, however even those data sources are held on three separate databases, a fourth key area you identify, PCT's, may be more problematic within your timeframe (Two-tier authority)*

### **Response rate and non-respondents**

Authorities made considerable efforts in the short-time scale to respond to the survey and 115 authorities returned a questionnaire, a highly satisfactory response rate of 77%. In addition, three authorities contacted us to say they were unable to respond due to capacity issues and a further seven authorities emailed or telephoned to say they were intending to respond. Thus, we heard from 122 authorities (81%) in response to the survey.

There were differences in non-response rates by type of authority and region: the proportion of non-respondents was higher among outer London and Unitary authorities and from the East of England and East Midlands (Tables 1.1 and 1.2).

**Table 1.1: Non-response rates by LA type**

Type of authority	Percent
Outer London	35.0
Unitary	31.9
Metropolitan	16.7
Two-Tier	14.7
Inner London	15.4

(n=35)

**Table 1.2: Non- response rates by region**

Region	Percent
East of England	40.0
East Midlands	33.3
West Midlands	28.6
London	27.3
North East	25.0
North West	18.2
South East	15.8
Yorkshire & Humberside	13.3

(n=35)

Follow up calls to ten non-responding authorities, selected to represent different regions and type of authority, sought to explore the reasons why they had been unable to complete a return. The time it would take, staffing problems, restructuring within the authority and the difficulties associated with identifying and counting the number of disabled children were the most frequently mentioned reasons for non-response. A manager from a metropolitan authority, who explained that a Joint Area Review taking place at the time and issues within the authority that affected capacity had led to a decision not to respond, commented that the very time the task would take highlighted the fact that they did not have the systems in place to provide this information. Another manager, this time from an inner London authority, acknowledged the importance and value of the study, but said that during a particularly busy time it could not be given priority. When she was able to look at it she realised how difficult it would be to provide data that would be meaningful, explaining that they had no means by which to identify overlap between the three sources of data - Education, Social Care and the Looked After Children (LAC) team - and come up with one figure.

## **1.4 Structure of the report**

The rest of the report is organised as follows. Chapter 2 reports on the survey findings relating to the number of disabled children, the sources of data upon which local authority respondents based their figures and the confidence they had in these data before considering other sources of published data and how these could be used to provide a model for calculating a more comparable figure. Chapter 3 reports on the characteristics of disabled children and how the survey findings relate to other data in this area. Chapter 4 addresses services provided by the local authority and its partners, specifically the number of disabled children in receipt of services and the type of service they received whilst Chapter 5 discusses the difficulties that local authorities encountered in providing information on disabled children. Chapter 6 presents the conclusions and implications for policy suggested by the survey findings.

## 2 Numbers of disabled children

This chapter addresses part of the second objective - how information on the numbers of disabled children is organised and collated at local authority level. It first presents information about the number of disabled children (however defined) given by local authorities in their response to the TCRU survey, followed by a discussion of the varying sources and criteria used as the basis for these figures. The chapter then considers whether other published sources of data could be used to provide a more comparable figure for numbers of disabled children at local authority level, and suggests which of these might provide the best approximation given the information provided in the survey.

### 2.1 Numbers of disabled children: survey responses

All but five of the 115 authorities (97%) provided a figure or figures in response to the question asking for a best estimate of the number of disabled children in the authority, but the accompanying comments highlighted their difficulties in estimating an overall number (discussed below). Across the authorities, the mean figure for disabled children was 3,542; this equates to a mean rate per thousand children in the local population of 42.3 (Table 2.1). However the rates varied enormously across authorities, from 2.9 per thousand to 179. This range reflects more the different ways in which local authorities produced a figure for the number of disabled children than it does real differences in rates between authorities. This is dealt with in the next section.

**Table 2.1: Local authority figure for disabled children**

	Mean	Standard Deviation
Number	3542	5362
Rate per thousand child population	42.3	37.8

### 2.2 Calculating a figure for disabled children

There was significant variation between local authorities as to which children were included in the figure provided for the local number of disabled children, and how this figure had been calculated. The following comment illustrates the difficulties authorities had with their calculation:

*'Information is gathered and collated individually by all the main agencies. However this is not put together or managed in any agreed way such that the above question about numbers can be answered accurately. Having contacted people across the agencies, the other key factor that was mentioned was that we all employ different definitions of a 'disabled child'. This again serves to skew any attempt at an accurate figure. I did consider contacting the National Census Office for official figures but again this is a subjective figure and based on parent/carer opinion. For your information there are 389 Children on the social care disabled children's database. These young people are currently in contact with the service in some way. There are 115 names on the statutory register. No figure was available from the PCT and Inclusion services offered a figure of 1004 children on full statements'. (Metropolitan authority who gave their figure as 1500)*

This metropolitan authority totalled the figures provided by the three data sources to arrive at their estimated figure, but was unable to take account of any overlap between these sources of data so the same child could appear on more than one database. A unitary authority had likewise totalled the figures from across the same three data sources, but had also included in their total the number of children receiving Disability Living Allowance (DLA) up to the age of 24. They too were unable to take account of any overlap between these different sources.

Another metropolitan authority whose figure of 358 represented the children known to the social care team made the following comment:

*'[The council] has excellent data on children with special needs. These are not included in the above figure, because it is not currently included in the definition of disabilities used by the local authority. [The council] has 781 children attending nine special schools in the city, including 411 with moderate learning difficulties, 170 with severe learning difficulties, 120 with emotional/behavioural difficulties, and 80 with physical disabilities. [The council] has around 1,500 children with a Statement of SEN and 5,500 children at School Action.'*

Whilst these examples show that the figure for disabled children was based on one or more data sources, there were authorities that had estimated their figure for disabled children based on national prevalence figures, such as the ONS estimate of 7% based on the General Household Survey 2002, or by using data for children with limiting long-term illness from the 2001 Census, or records of Disability Living Allowance (DLA) payments (see 2.3 for

further discussion of national estimates). The following comments demonstrate the different ways in which authorities estimated the number of disabled children:

*'This number is based on the ONS estimate that 7% of all children are disabled; there are approximately 39,565 children and young people living in [authority] aged 0-17 which would equate to 2,770 disabled children. We maintain several other sources of information (including our Children Act Register, the children with disabilities team lists, SEN data and the PCT health information system), but no single source would give an accurate estimate of the number of disabled children in the authority, due to differences in definitions, age groups, eligibility for services etc'. (Metropolitan authority)*

*'Using a model which was developed by the Department of Health to assist local authorities in providing information on the numbers of disabled children in their area for their Quality Protects Management Action Plans, the prevalence of disabled children is estimated to be 29 per 1000 children aged 5-16.' (Shire authority)*

*'This figure was estimated ....using projections from GHS and HSE and national prevalence figures applied to [the local population]. This predicts the number of disabled children from 0-19 years in the borough. This is a general estimate only and assumptions are made in the data sources that there will be a similar population with disabilities across all boroughs.' (Outer London authority)*

*'The figure of 1450 disabled children was an estimate used 18 months ago in a report on adaptations etc and was arrived at from extrapolations from figures from the Family Fund database, the 2001 Census and a London Housing Strategy EQIA. The estimate given here is greater to take account of an increase in the population in this age band in this borough.' (Inner London authority)*

A distinction was often drawn between the children known to the authority and an estimate based on national prevalence rates:

*There are approx 1,000 children and young people (aged 0-20th birthday) on the [Children Act Register]. Over 90% of them get DLA and/or have statements of SEN. We also know of a further approx 250 who were registered but haven't updated their registration for over 2 years. In Jan 2007, 1,169 children had statements. In May 2007, 1,320 under 16s got DLA (DWP). The Family Resources Survey G.B. (2002-*

03) and the ONS (2004) "Living in Britain: Results from the 2002 GHS", found 5% and 7% respectively of UK children were disabled. The 2001 Census recorded 52,835 under 20s (41,261 under 16s). If 5-7% are disabled then we expect roughly 2,500 to 3,500 disabled under 20s (2,000 to 3,000 disabled under 16s). (Unitary authority who estimated their figure at 3,000)

Sutton<sup>2</sup>, along with other authorities, sent supporting documentation with their completed questionnaire including their Draft Strategy for Children and Young People with Disabilities (Sutton Children and Young People's Partnership, 2007). The Strategy articulates the different estimates and counts that could be made of the number of disabled children, which are reflected in our survey data, and sets out how the authority should be responsible for meeting their needs depending on which figure is being used:

'Until such time as we have reliable local information to suggest otherwise, we will continue to use the Government's 7% figure to give us a working estimate of 2,800 under 18s who meet the DDA definition of disability. These include our provisional estimate of 1,100 eligible for registration [on Sutton's Register, called I Count]. On these estimates there are some 1,700 children and young people who fall within the scope of the DDA but do not meet the higher threshold required for registration on Sutton's I Count Register. Service providers would be expected to make "reasonable adjustments" for this group, but these children are unlikely to require ongoing support from specialist agencies. The Disability Partnership's role in respect of this group is to monitor their needs and circumstances, ensure they have access to information about rights and benefits, and generally promote their inclusion in universal services' (Sutton Children and Young People's Partnership, 2007:13).

### ***Was the number based on an estimate or a count of disabled children?***

Since it was clear that authorities differed between those who had based their disability figure on a count of actual children and those who had estimated a figure based on a percentage of their population of children, we coded each authority's response according to whether it was a count or an estimate, using the qualitative data supplied in the relevant comments box. Where an authority had provided both a count and an estimate, we took the larger of the two figures, which was usually the estimate. As can be seen from Table 2.2, authorities were more likely to base their figure on a count than an

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<sup>2</sup> The authority agreed to be identified.

estimate. Databases providing SEN data were the most usual source upon which this count was based though it is important to note that there were differences between authorities as to which children with SEN were included: some included only those children with statements whilst others included children both with and without statements (Table 2.3).

**Table 2.2: Percentage of authorities with a count or estimated figure**

	Frequency	Percent
Estimate	32	29
Count	76	69
Not known if estimate or count	2	2
Total	110	100
Not answered	5	

**Table 2.3: Sources of data used for figures based on a count**

	Frequency	Percent
Children Act Register or equivalent	23	30.3
Social care	37	48.7
SEN:	57	75.0
<i>with statement</i>	(27)	(35.5)
<i>with/without statement</i>	(17)	(22.4)
<i>not stated</i>	(13)	(17.1)
PCT	14	18.4
Other sources	12	15.8
Total	76	100.0

Of those authorities basing their figure on a count a half had used only one data source whilst the remainder had used two or more sources (Table 2.4). Table 2.5 in showing the combinations of data sources that were used indicates the numerous ways in which a figure for disabled children based on a count was reached. As can be seen the number of authorities using any one combination is too small to enable an analysis of how different combinations of data sources affect the figure for disabled children.

**Table 2.4: Number of sources used for estimated figure based on a count**

Number of sources	Frequency	Percent
1	38	50.0
2	18	23.7
3	11	14.5
4	9	11.8
Total	76	100.0

**Table 2.5: Data source combinations used for calculating a figure for disabled children**

	Frequency	Percent
Children Act (CA) Register only	7	9.2
Social care only	7	9.2
SEN: with statement only	12	15.8
SEN: with / without statement only	10	13.2
SEN: not stated only	2	2.6
CA Register / Social care	2	2.6
CA Register / SEN: with statement	1	1.3
CA Register / SEN: with / without statement	2	2.6
CA Register / SEN: not stated	1	1.3
Social care / SEN: with statement	3	3.9
Social care / SEN: with/without statement	2	2.6
Social care / SEN: not stated	1	1.3
Social care / PCT	1	1.3
Social care / Other	1	1.3
SEN: with statement / PCT	1	1.3
SEN: with statement / Other	2	2.6
SEN: with / without statement / Other	1	1.3
CA Register / Social care / SEN: with statement	4	5.3
CA Register / Social care / PCT	1	1.3
Social care / SEN: with statement / PCT	1	1.3
Social care / SEN: with statement / Other	1	1.3
Social care / SEN: with / without statement / PCT	1	1.3
Social care / SEN: not stated / PCT	2	2.6
Social care / SEN: not stated / Other	1	1.3
CA Register / Social care / SEN: with statement / Other	2	2.6
CA Register / Social care / SEN: with / without statement / PCT	1	1.3
CA Register / Social care / SEN: not stated / PCT	2	2.6
Social care / SEN: not stated / PCT / Other	4	5.3
<b>Total</b>	<b>76</b>	<b>100.0</b>

### ***Overlap between different data sources: double-counting***

Of the 38 authorities that had used more than one source of data to estimate their figure of disabled children, 29 said they had been able to take account of any overlap between the different data sources. Names, dates of birth and/or postcodes were used as identifiers to prevent double counting and on occasions the process of matching had to be undertaken manually because IT systems were not compatible. Issues of data protection meant that names could often not be used for cross-referencing purposes and using dates of birth and/or postcodes depended on these fields being complete across databases, which was not always the case. Few authorities it seemed had a unique identifier common across all agency databases that enabled matching and eliminated double-counting. The following two authorities were unusual in having unique identifiers:

*'We have a field on LEA EMS [Education Management System] database which gives the start date on the [multi-agency Children Act Register] this field is then used to filter to data held on EMS by the current SEN Casework service so we can see who has a statement that is not on the [Children Act Register] database. Because there are children on [the Register] without statements we need both systems. We have similar sharing of information with the Disabled Children's Team and the Pre-school Special Needs Service, and the Quality Assurance unit in social care'.*

(Metropolitan authority)

*'Within the Children, Learning and Young People's Directorate, the education database (One) contains the child identifier used in the social care database (SURFACS). This enables the two systems to be linked together.'* (Metropolitan authority)

Not being able to address overlap in the data sources contributed to the difficulty in estimating a figure for the number of disabled children and to a low level of confidence in the figure provided as discussed below. Authorities were often well aware of the problems they had with these data, but the survey often served to reinforce the view that further work needed to be undertaken: *'This has been a helpful exercise for us to begin to consider the best way of gaining accurate statistics, and we will be considering how we can ensure there is no overlap'* (Unitary authority).

### ***Level of confidence in the estimated number and the data provided***

Recognising the difficulties authorities were likely to encounter in estimating a figure for disabled children, we asked authorities to indicate on a six-point rating scale how confident they were that their figure was a reasonable estimate of all disabled children in the authority. Of the 109 authorities (95%) answering this question, two in five (41%) had a low level of confidence rating - between one and three (Table 2.6).

**Table 2.6: Confidence in figure for disabled children**

Confidence rating	Frequency	Percent
1 Low	6	5.5
2	13	11.9
3	26	23.9
4	38	34.9
5	23	21.1
6 High	3	2.8
Total	109	100.0

There was little difference in confidence levels between those authorities basing their figure on an estimate and those that based it on a count (Table 2.7). However, the authorities whose count was based on SEN data only (32%) were more likely to have a higher level of confidence in their figure (Table 2.8).

Many authorities emphasised the caution with which their data should be treated:

*Please note that the data in this document should be treated with the appropriate health warning. Much of the data is estimated, based on prevalence or is based on initial findings of the needs analysis we are currently bringing together (Unitary authority)*

*This is not an accurate snapshot for one second of the number of children with disabilities in the authority and should not be used to compile any real picture of [authority's] children with disabilities. (Inner London authority)*

**Table 2.7: Confidence in figure based on count or estimate**

Rating	Estimate	Count
	(n=31) %	(n=74) %
1 Low	0	8
2	10	12
3	32	22
4	36	34
5	23	20
6 High	0	4

**Table 2.8: Confidence in figure based on count**

	LAs using SEN data only		LAs not solely using SEN data	
	n	%	n	%
1 Low	1	4	3	8
2	3	12	2	5
3	4	16	12	32
4	10	40	9	24
5	6	24	9	24
6 High	1	4	2	5
Total	25*	100	37*	100

\*Not all authorities gave a confidence rating so the total is 62 and not 74.

### ***What criteria of disability are being used?***

Survey respondents were asked about the criteria that they used in estimating their figure for disabled children. Whilst some related this to the figure they had provided, others described the varying criteria applied by different agencies within their authority. Commonly used legislative frameworks were the Disability Discrimination Act (DDA), the SEN Code of Practice and the Children Act 1989, which were typically used by different agencies for different purposes. Children Act criteria were most likely to be used by Children with Disabilities teams within social care (this included authorities describing use of the Framework for the Assessment of Children in Need, or Children in Need client categories). The continuum of criteria specified within the SEN Code of Practice was typically used in an

educational context, although one small unitary authority made a distinction between applying the criteria for eligibility for a SEN statement to provide a figure for the number of disabled children, and actually providing such children with statements:

*'The criteria used are children with learning and/or physical disabilities significant enough to justify a statement of special educational needs. [But] not all such pupils would necessarily have a statement as local policy is for provision to be made according to needs'.*

Use of the DDA criteria was less closely linked to a particular agency, but was often cited in the context of Disabled Children Registers or as an overarching framework within which different service thresholds were applied. Less commonly used criteria were parent/carer definition of disability (those voluntary registers where any parent who wanted their child to go on the register would be registered); diagnosis by a medical professional (the infrequency with which this was mentioned is probably due to many survey respondents being unable to obtain relevant data from health partners within the survey timescale), and criteria that were linked to the level of service received, for example requiring two or more specialist services, support from two or more professionals or receiving services across agencies. A number of authorities referred specifically to adopting as a guiding principle a social model of disability (where disability is seen as caused not by an individual's 'impairment', but by the way society fails to meet their needs and so disables them), although other criteria were also applied by some agencies:

*'The authority as a whole subscribes to a social model criteria and definition of disability, although individual service providers will operate their own threshold and eligibility criterion'.*

Two key themes emerged from analysis of the qualitative information from survey respondents about the criteria of disability used in their authority. The first was the high threshold that applied for accessing support from Children with Disabilities teams within social care services. Respondents used terms such as 'significant', 'substantial', 'severe', 'permanent', 'complex' and 'profound' to describe the criteria for accessing support from such teams.

*'With regard to the Disabled Children's Team, current eligibility criteria for obtaining a service is that the child must have a formally diagnosed profound and/or substantial disability where this impacts severely upon family functioning'.*

This did not necessarily mean that other disabled children were not eligible for support from social care services, since children with less severe or complex needs would often be supported by other teams - but these children would not be captured within the figures provided for children in contact with disability teams. One authority indicated that recent restructuring had significantly tightened the criteria for accessing their specialist team:

*'The children with disability team will only provide a service to the most severely disabled children and those with complex needs:*

- *Chronic and life-limiting conditions*
- *Severe physical or sensory impairment*
- *Severe learning disability, to include severe challenging behaviour*
- *Combined with complex health care needs'*

This authority noted that less severely disabled children would still be supported within other social work teams. Emotional/behavioural difficulties, 'high functioning' autistic spectrum disorders and ADHD (unless associated with another disability) were most likely to be mentioned in our survey as insufficient to bring a child within the remit of the specialist disability team. However, children falling within these categories might be eligible for an assessment from another team, for example within the Safeguarding Division. What was clear, however, is that the number of children in contact with social care disability teams is only a small proportion of those who might be considered disabled (see Section 2.4 below).

A second recurrent theme in the analysis of our data on criteria used to define disability was the extent to which local authorities reported that different criteria and thresholds needed to be applied by different agencies:

*'There is no one definition of disability used across the LA and partner agencies. The various services / agencies have developed criteria according to their own needs'*

*'There are different criteria for the different teams and these are based on different legislation'*

*'Services use definitions of disability which relate to the population they support: e.g. education defines disability by the way it impacts on a child's ability to access education/ learning; the dedicated Children's Disability Service supports the children*

*and young people with the most complex disabilities....other children and young people with different disabling conditions are supported by mainstream social care teams'*

One London borough succinctly summed up the criteria used by different agencies as follows:

*'Children with Disabilities registrations - severe, profound and permanent  
Special Education Needs - relating to learning ability and physical disability  
Health - relating to complex health needs, diagnosis of particular syndromes, ADHD  
and Aspergers.'*

We also asked authorities whether or not particular groups of children were included in the definition of disability applied by the local authority (Table 2.9). These categories were selected based on our scoping work for this study and our earlier work (Mooney et al., 2007), which suggested there was significant variation between authorities as to which groups of children were included in a definition of disability. We are aware, as several respondents pointed out, that these categories are a mix of levels and types of disability and, as we have seen, the decision about which groups might be defined as disabled depended on the criteria and thresholds applied by different agencies. Furthermore, it is the impact of the disability rather than the disability itself which is likely to be more meaningful in terms of meeting needs. Although we cannot be sure whether respondents answered this question with a broad or a more restricted definition of disability in mind, the findings serve to reinforce the significant differences between authorities.

**Table 2.9: Categories included in definitions of disability**

	Yes (%)	No (%)
Autistic Spectrum Disorder (ASD)	88	12
Children with a statement of SEN	70	30
Behaviour / emotional difficulties	58	42
Dyspraxia	55	45
Attention Deficit Disorder (ADHD)	53	47
Dyslexia	49	51
Mental health difficulties	45	55
Children on School Action Plus	41	59
Children with a mild disability	41	59

(n=113)

### **2.3 Other sources of data on local prevalence**

The marked variations in definitions and criteria used by local authorities for children with disabilities has meant that the figures given in the survey cannot be used to provide an estimate of disabled children for each local authority on any consistent basis. However, there are a number of other sources with information about disabled children for each local authority, although none gives a single figure for all children who could potentially be described as disabled. Before turning to these sources, it is worth considering the national estimates used by some local authorities to estimate their number of disabled children. Two figures frequently quoted were that three percent and seven percent of all children could be expected to have a disability. The 3 percent figure comes from the OPCS survey of disability conducted in the late 1980s (Bone and Meltzer, 1989). This was a national survey of private households and communal establishments. From an original sample of 100,000 addresses, they identified 40,000 children. The survey used a detailed interview to assess disability, and estimated 3.2 percent of children to have some level of disability. The results of this survey have been used since that time to estimate the prevalence of disabled children for regions, but did not have enough cases to provide estimates at a local authority level. The results are now also very out of date. The seven percent figure comes from the Family Resources Survey (FRS). A recent study called 'Can We Count Them?' (Read et al., 2007) concluded that this was the best source for estimating national prevalence. The FRS is a national household survey conducted annually for the Department for Work and Pensions, which includes a Disability Discrimination Act (DDA) measure of disability. Using data from the

2004/05 survey, Read et al. estimated the overall rate of children with disability at 7.3 percent, considerably higher than the 3.2 percent estimate of Bone and Meltzer. However, the problem with making a local estimate based on national prevalence is that it eliminates variations between authorities.

## **2.4 Local authority prevalence estimates**

This section will look at a range of sources other than our survey, to see what information they can provide on the prevalence of children with disabilities within local authorities. The sources are the annual SEN figures, 2001 Census figures on limiting long-term illness, Disability Living Allowance payments and the periodic Children in Need Census. As we will see, none of these are exactly what is required.

Figures on children with special educational needs are published annually for DCSF, and give local authority figures for different levels of SEN. Under the Disability Discrimination Act 1995, 'a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities' (Part 1, paragraph 1). Young people with a SEN statement are generally deemed to have an 'impairment which has a substantial and long-term adverse effect', and so should be considered as having a disability under the DDA. However, whether children with a special educational need less severe than that needing a statement, and instead dealt with under school action or school action plus, should also be considered to have a disability under the DDA is less clear, and most authorities did not include them in the overall figures they supplied for our survey (Table 2.3). However, for comparison of prevalence estimates, two SEN figures are used below. One is the total number of children with SEN statements<sup>3</sup> (Department for Education and Skills, 2007b: Table 13); the other is the total number of SEN children<sup>4</sup>, including those with statements, those receiving school action and those receiving school action plus (Department for Education and Skills, 2007b: Tables 14 and 15). Figures for 2007 have been used here.

In addition to these two sources of local data on children with SEN, there are two sources which have data at a local level and which might be used as estimates of local authority prevalence of disabled children. One comes from the 2001 Census and the other comes

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<sup>3</sup> Includes Nursery, Primary, Middle, Secondary, Independent and Special schools, Pupil Referral Units, City Technology Colleges and Academies.

<sup>4</sup> Maintained primary and secondary schools only.

from Department of Work and Pensions (DWP) records of Disability Living Allowance payments. However, each has its limitations.

The 2001 Census figure is the number of children with a limiting long-term illness (LLI) living in private households. That would seem to be a rather broader definition than the DDA definition of disability, so this indicator is likely to be an overestimate of the number of disabled children. As the figure relates to 2001 it is also likely to be somewhat out of date.

The DWP estimate comes from the records of Disability Living Allowance (DLA) payments. The numbers made in each local authority, by age, are published on the DWP web site each quarter. The figures are sourced from the Work and Pensions Longitudinal Study and cover all claimants. A major advantage of the DLA figures is that recipients of the benefit will have had to give evidence of disability, usually from their doctor. In consequence, it is likely that all children in receipt of DLA do have a disability as defined under the DDA, unlike with the 2001 Census LLI figure which is a self-definition with no validity check. On the other hand, an unknown number of disabled children who would be eligible for the allowance may not be claiming it. This figure is therefore likely to be an underestimate, but to what degree is unknown (Kasparova et al., 2007). Below, we have averaged figures on the number of children receiving DLA payments for the two quarters up to May and November 2007.

The Children in Need (CIN) Census also collects data on disabled children. It has been conducted four times by Social Services Departments. As described in the background section to this report (see 1.1) the Census covers all social service activity in a 'typical' week (Department for Education and Skills, 2006). As it is not known what percentage of all disabled children received a service in the reference week, the CIN figures cannot be used to calculate rates though they can give an indication of relative rates of children with disability between local authorities: 'Reference data collected through the Children in Need Census is not an indication of prevalence of any factor in the general population, but is only an indication of prevalence amongst the Children in Need population. For example, the reference data collected through the survey on the number of children with a disability, or with autism, is not a measure of the number of children in the general population who are disabled or autistic, but data on the number of disabled / autistic children in touch with Social Services' (Department for Education and Skills, 2006, p.3). Nevertheless, correlations of the other indicators with CIN figures give an indication of how they might be related. Also included is the number of open cases for disabled children 'on the books' of Social Services even if they did not have any activity in the Census week, These figures are thought to give a better estimate of the total number of disabled children than the lower figure for children

with an activity in the census week: just over half of disabled children known to Social Services had an activity in the census week. However, these figures are not included in the published reports, and have kindly been provided by the DCSF. For the analysis in this report, data have been averaged for the two most recent CIN Censuses, 2003 and 2005 (Department for Education and Skills, 2004; Department for Education and Skills, 2006).

Figures from these five different sources are compared below for the light they might shed on the local prevalence of disability. These are also compared with figures based on the OPCS estimate of 3.2 percent and the FRS estimate of 7.3 percent. Means across the 150 local authorities are shown in Table 2.10, and figures for each local authority are provided in Appendix B.

**Table 2.10: Average local authority numbers on a variety of indicators**

	Mean	Standard Deviation
Total pupils with SEN statements: 2007	1527	1223
All SEN pupils (Primary/Secondary)	9255	7005
Limiting long-term illness: children 0-17: Census 2001	3183	2342
In receipt of Disability Living Allowance aged under 18	1894	1494
Disabled Children in Need: 2003/2005	400	343
OPCS estimate: 3.2%	2346	1817
FRS estimate: 7.3%	5352	4144

Whilst these numbers are useful, it may be easier to compare authorities when data from all the sources are expressed as rates. Table 2.11 shows the same data all expressed as a percentage of the relevant age groups.

**Table 2.11: Average local authority percentages on a variety of indicators**

	Mean	Standard Deviation
Total pupils with statements %: 2007	2.8	.61
SEN pupils % (Primary / Secondary)	19.3	3.54
Limiting long-term illness %: children 0-17: Census 2001	4.4	.74
In receipt of Disability Living Allowance aged under 18: %	2.6	.54
Disabled Children in Need %: 2003/2005	.55	.28

It is clear that the percentage of children with a SEN statement is only a small proportion of the whole SEN population: more than five times as many children with SEN do not have a statement as do have one. The average percentage with a SEN statement (2.8%) is somewhat below the percentage of children in the 2001 Census with a limiting long-term illness (4.4%), but almost the same as the percentage in receipt of Disability Living Allowance (2.6%). Whilst all three are very similar to the OPCS estimate of 3.2 percent and below the FRS estimate of 7.3 percent, there is no way of assessing the degree of overlap between these different indicators.

One way of investigating the overlap is to look at the correlations between the measures. The correlations will not give information about the relative levels of the different indicators, but they will give some indication as to whether the same children are counted between them. These correlations are shown in Table 2.12.

**Table 2.12: Correlations between local authority percentages on a variety of indicators**

	Pupils with SEN statements	All SEN pupils	Limiting long-term illness	Disability Living Allowance	Disabled Children in Need
Pupils with SEN statements	1	.15	.23	.41	-.12
All SEN pupils	.15	1	.43	.24	.08
Limiting long-term illness	.23	.43	1	.78	.03
Disability Living Allowance	.41	.24	.78	1	.06
Disabled Children in Need	-.12	.08	.03	.06	1

It is clear that all the indicators involving SEN have very low correlations with the other indicators. This suggests that the overlap between having a special educational need and having a limiting long-term illness or receiving Disability Living Allowance is fairly small. However the correlation between these latter two indicators is quite high (.78), suggesting that these two have a much higher overlap. It is not that they are the same people, as the Census was in 2001 and the DLA figures are for 2007: it is the overlap in prevalence that is being suggested.

In Tables 2.10 and 2.11 the figures for disabled children recorded as being 'on the books' in the Children in Need Census is much lower than any of the other figures - little more than a fifth of the DLA figure. However, this figure can also be compared to the figure provided by respondents to our survey for the number of disabled children known to be in receipt of

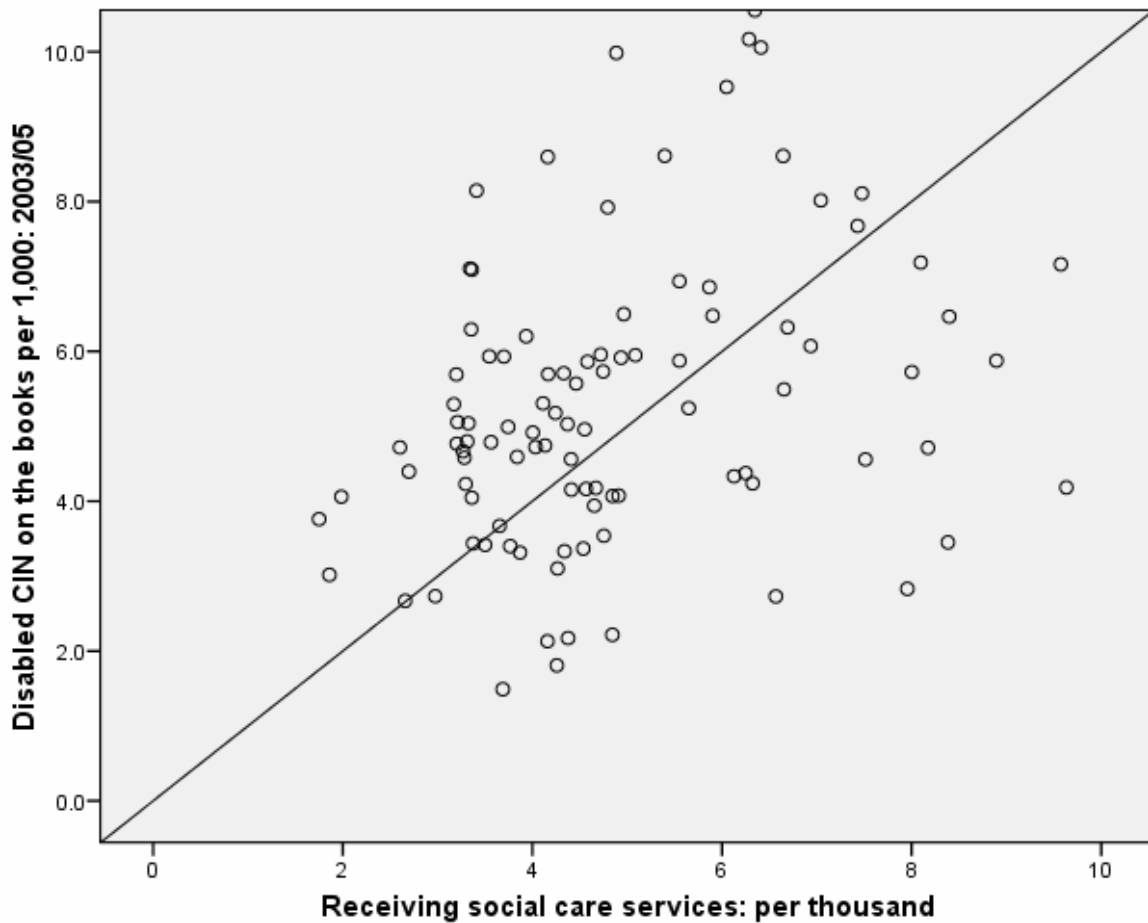
social care services. The number and rate per thousand children is shown in Table 2.13 for the 103 authorities who gave a figure in the TCRU survey. The average number, of 337, is a little lower than the CIN Census figure, of 417. This suggests that the majority of disabled children who are 'on the books' are also currently in receipt of social care services.

Table 2.13: Disabled children in receipt of social care services: TCRU survey and CIN Census

	Number	Per thousand
In receipt of social care services (TCRU survey)	337	4.9
Disabled Children in Need: 2003/2005	417	5.7

Figure 2.1 shows the rates per thousand for these two measures plotted against one another at local authority level. Points above the diagonal are where the local authority reported a lower rate of disabled children in receipt of social care services in the TCRU survey than the rate of disabled children 'on the books' in the CIN Census week. Most authorities are above the line, which confirms that disabled children reported as known to Social Care Services in the TCRU survey were generally only a proportion of those 'on the books' during the CIN Census week, although this was the large majority. Of course, the CIN Census and TCRU survey were conducted at different times, and so would be expected to differ. However, the correlation between the two indicators was low (.26), suggesting that the CIN Census is not a good indicator of relative rates between authorities.

**Figure 2.1: Disabled children receiving social care: TCRU local authority survey and Children in Need Census: rates per thousand**



## 2.5 A best estimate of disabled children

Estimating the number of disabled children in each local authority will inevitably depend on the definition of disability that is used. However, 70 percent of local authorities in the survey said that they took children with SEN statements as being disabled (Table 2.9), so these should probably be included. Children in receipt of Disability Living Allowance can fairly confidently be assumed to have a disability as defined under the Disability Discrimination Act, because of the assessment children undergo before being granted the allowance. This group would, therefore, also be included in any definition of disabled children. The analysis above suggested that these two measures did not have a great deal of overlap.

Consequently, a best estimate for the number of disabled children in a local authority might have as a lower bound the greater of the number of children with a SEN statement and the number of children in receipt of DLA, and an upper bound as the sum of those two. The median and quartiles for these bounds and their percentage rates are shown in Table 2.14

(and figures for each local authority are provided in Appendix C). The median for the lower bound is a little below the 1989 OPCS estimate of 3.2 percent, but even the median for the upper bound is below the FRS-based estimate of 7.3 percent, which suggests that the latter estimate might have taken too broad a definition of disability.

**Table 2.14: Lower and upper bound estimates for the number and percentage of disabled children**

	Number			Percent		
	Lower Quartile	<b>Median</b>	Upper Quartile	Lower Quartile	<b>Median</b>	Upper Quartile
Lower bound	1034	<b>1424</b>	2298	2.58	<b>2.96</b>	3.32
Upper bound	1833	<b>2617</b>	4156	4.79	<b>5.44</b>	5.97

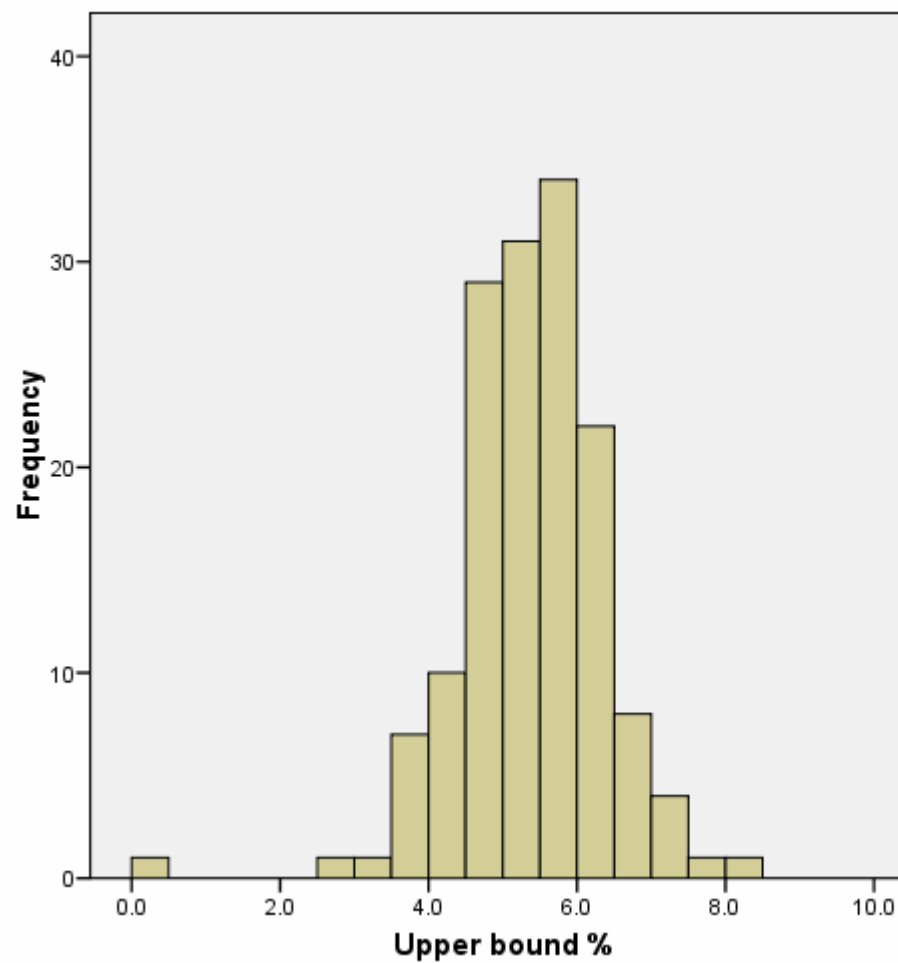
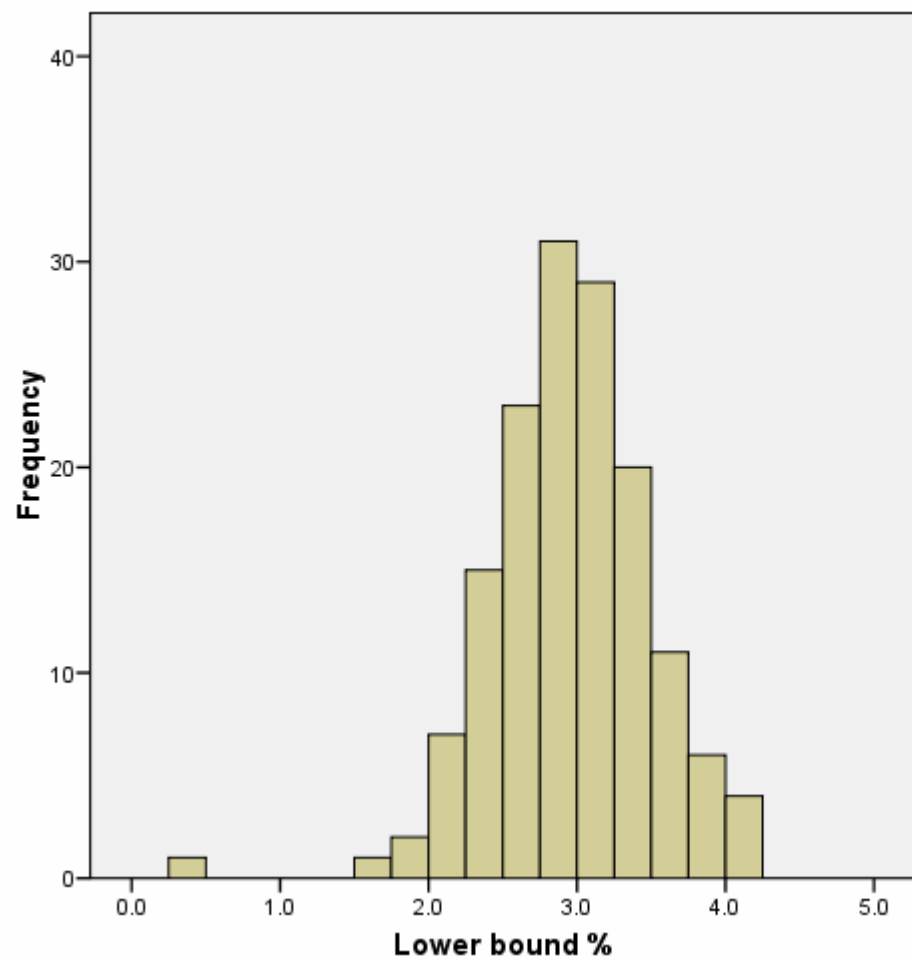
N=150

It is also clear from Table 2.14, that there is a considerable range on both these bounds for the percentage of disabled children. The interquartile range for the lower bound is from 2.58 percent to 3.32 percent; for the upper bound it is from 4.79 percent to 5.97 percent. The full distributions are shown in Figure 2.2. It can be seen that both distributions are somewhat negatively skewed, with a tail of local authorities with low percentages of disabled children. The one outlier, with a very low percentage is the City of London: this very small authority has a child population of under a thousand, none of whom were in receipt of Disability Living Allowance.

So which is the best figure to use? It is clear that neither the lower nor the upper bound is the correct figure. For the lower bound to be correct, either the SEN stated number or the Disability Living Allowance number (whichever is greater) would have to include all disabled children within a local authority, and the overlap between the two measures would have to be total - anyone on the lesser of the two measures would also have to be on the other. For the upper bound to be correct there would need to be no overlap at all between the two sources - so that no child with a SEN statement was also receiving Disability Living Allowance. Both these scenarios are impossible. The correct figure is likely to be somewhere in between: just where depends upon the overlap between the two sources. If the overlap is very large, in other words if most children receiving Disability Living Allowance also have a SEN statement, then the lower bound will be more accurate; if the overlap is quite small then the upper bound will be more accurate. The overlap may vary between local authorities.

The more accurate figure will also depend on the definition of disability: a narrow definition would tend towards the lower bound, whereas a broader definition might produce a figure even above the upper bound: including SEN pupils without a statement in the definition would give a much higher figure, for example.

Figure 2.2: Distribution of lower and upper bounds for estimates of the number of disabled children



## 2.6 Summary

Our aim was to design a relatively straightforward questionnaire to encourage a good response rate, but which as far as possible provided robust data on the numbers and characteristics of disabled children. However, estimating a figure for disabled children was a challenging task due to differences between agencies in their definition of disability and eligibility criteria, incompatible databases, and the timescale allowed for the survey. Authorities varied as to whether they calculated their figure on a count of local disabled children or derived a local figure from national estimates, though more than two-thirds based their figure on a count using one or more data sources. The overlap between these different sources of data was often difficult for survey respondents to address because of a lack of a unique identifier common across databases, and their confidence in the estimated figure was, therefore, not uniformly high.

Given the significant variation in definitions and criteria it is not possible to estimate the number of disabled children for each local authority based on the information provided in our survey. However, comparisons have been drawn based on five different sources of data: the total number of children with SEN statements; the total number of children with SEN (both those with and without statements); the 2001 Census figure for the number of children with limiting long-term illness (LLI); the number of children in receipt of Disability Living Allowance (DLA); and the number of disabled children recorded in the Children in Need (CIN) Census. Comparisons are also made with figures based on the OPCS and FRS estimates. The analyses revealed that the overlap between SEN and having a LLI or receiving DLA is relatively small, though there is a much higher overlap (in prevalence) between LLI and DLA. The analysis also suggested that it is only a small minority of disabled children who are in receipt of social care services and also that the CIN Census underestimates the number of disabled children in receipt of social care services and does not differentiate well between authorities. Based on these analyses, we suggest that if a comparable basis is needed for a best estimate of the number of disabled children in each local authority, this could have as a lower bound the greater of the number of children with a SEN statement and the number of children in receipt of DLA, and an upper bound as the sum of these two. Figures for each local authority have been calculated based on this model, and this information along with prevalence rates at local authority level using other published sources is included in Appendix C at the end of this report.

### 3 Characteristics of children with disabilities

This chapter addresses the second part of objective two - to analyse and report on the characteristics of children with disabilities. The TCRU survey asked authorities if their databases included details of the demographic characteristics of disabled children. Seventy (61%) collected and reported data on all three characteristics: gender, age and ethnic group. Table 3.1 shows that 70 percent of authorities collected each of these demographic characteristics. Only two authorities said they did not collect any of them, but eleven (10%) said that, whilst they collected all three, they could not collate data on any of them so could not provide any statistics.

**Table 3.1: Data on the characteristics of children with disabilities**

	Gender		Age		Ethnic Group	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Available	80	69.6	80	69.6	82	71.3
Not collected	3	2.6	3	2.6	5	4.3
Not collated	14	12.2	16	13.9	20	17.4
Don't know	7	6.1	4	3.5	4	3.5
Not answered	11	9.6	12	10.4	4	3.5
<b>Total</b>	<b>115</b>	<b>100</b>	<b>115</b>	<b>100</b>	<b>115</b>	<b>100</b>

Authorities mostly used the same sources for their demographic figures as for their overall number of disabled children. However, there was a tendency to use fewer sources for the demographic characteristics. On average, authorities gave demographic characteristics for 600 children fewer than their reported overall number of disabled children. Table 3.2 shows the sources used. These were often used in combination, as shown in Table 3.3.

**Table 3.2: Sources used for characteristics**

	Frequency	Percent
Children Act Register or equivalent	30	32.6
Special educational needs database	56	60.9
Social care team lists / databases	39	42.4
PCT database	10	10.9
Other sources	6	6.5
<b>Total</b>	<b>92</b>	<b>100</b>

**Table 3.3: Combinations of sources used for demographic characteristics**

	Frequency	Percent
Children Act Register only	14	12.2
SEN database only	29	25.2
Social care database only	18	15.7
Other sources only	1	.9
Children Act Register / SEN database	3	2.6
Children Act Register / Social care database	1	.9
SEN database / Social care database	4	3.5
SEN database / Other sources	1	.9
Children Act Register/SEN database/Social care database	4	3.5
Children Act Register / SEN database / Other	1	.9
SEN database / Social care database / PCT	4	3.5
SEN database / Social care database / Other	1	.9
Children Act Register / SEN database / Social care database/PCT	4	3.5
Children Act Register / Social care database / PCT / Other	1	.9
SEN database / Social care database / PCT / Other	1	.9
None	28	24.3
<b>Total</b>	<b>115</b>	<b>100</b>

With such a variety of combinations of sources used, and since so few used one single source, it has not been possible to estimate demographic variations by data source. The average percentages for each of the demographic characteristics are shown in Table 3.4, across all the data provided by authorities, from whatever source or sources. Since

no one has tried to measure the demographic characteristics of all disabled children before, there are no directly comparable data against which to check the survey results. However the Children in Need Census for 2005 (Department for Education and Skills, 2006) includes some comparable data as does the annual SEN data (Department for Education and Skills, 2007b). Where these are available they have been included in the table.

**Table 3.4: Demographic characteristics**

	TCRU survey %	CIN Census 2005 %	SEN statements 2007 %	Census 2001: All children %
<b>Gender (n=80)</b>				
Male	69	65	73	51
Female	32	35	27	49
<b>Age (n=77)</b>				
0-4	8	10	4	25
5-11	43	38	36	38
12-18	49	52	61	37
<b>Ethnic Group (n=66)</b>				
White	78	81	84	84
Mixed	4	4	3	4
Asian	8	6	6	7
Black	6	5	4	4
Other	4	1	1	1

**3.1 Gender**

As can be seen, the average percentage of males (69%) amongst disabled children in the TCRU survey was reported to be more than twice that of females (32%). This is considerably above the male percentage in the 2001 Census, indicating that boys are more than twice as likely as girls to be disabled. For the Children in Need Census in 2005, it was reported that of the disabled children receiving a service in the census week, 65 percent were male (Department for Education and Skills, 2006: Table 13), which is quite similar to our results. SEN figures for gender are only reported for pupils in maintained primary and secondary schools (Department for Education and Skills, 2007b: Table 5), and these are shown in Table 3.4. The percentages for children with SEN

statements in 2007 show an even higher percentage for boys, of 73 percent. So our survey percentage for males was between the CIN and SEN figure.

### **3.2 Age**

Only 8 percent of disabled children were reported as being in the age group 0-4, which is lower than would be expected if disability were independent of age: in the 2001 Census 25 percent of children aged 0-18 were aged under 5 years. It may be that some forms of disability develop with age, or only become apparent as children get older; however the low percentage is also likely to reflect a high usage of school SEN data, which may miss many children of preschool age. The 2005 Children in Need Census reported that 10 percent of disabled children who received a service in the census week were aged 0-4; 38 percent were aged 5-11 and 52 percent were aged 12-18 (Department for Education and Skills, 2006: Table 15). These percentages are quite close to those found in our local authority survey. The 2007 SEN statement percentages are slightly different (Department for Education and Skills, 2007b: Table 2): they have an even lower percentage of disabled children aged 0-4 (4%). This is hardly surprising, as only a minority of disabled children are likely to have been assessed for special educational needs before starting compulsory schooling at age five. However, the percentage in the oldest (12-18) group (61%) is much higher than that for the 5-11 age group (36%), which is very different from the TCRU survey.

### **3.3 Ethnicity**

The percentages of disabled children by ethnic group fairly closely match the percentages of children (0-17) in the population by ethnicity at the time of the 2001 Census: these figures are also shown in the table. There is a lower percentage of white children than might be expected on the Census, but the minority ethnic groups are all above what would be expected. This is most marked for the black group: 6.4% of disabled children were reported as being black, but this group only represented 3.8 % of the child population in the 2001 Census (The difference for the 'other' ethnic group is also large, but the small numbers here make this comparison unreliable). The figures are also close to those for disabled children from the 2005 Children in Need Census (DfES, 2006: Table 12). However, the CIN Census found a higher percentage of white children (81%) compared to the TCRU survey (78%), but the differences are quite small. SEN figures for ethnicity are only reported for pupils in maintained primary and secondary

schools (Department for Education and Skills, 2007b: Tables 8a and 8b), and these are shown in Table 3.4. These show a higher percentage of statemented SEN pupils as white (84%) and slightly lower percentages for the minority ethnic groups. Lindsay et al. (2006) looked at the relation between ethnicity and SEN using Pupil Level Annual Schools Census (PLASC) data. They concluded that, after controlling for gender and socio-economic disadvantage, there was very little difference in rates between ethnic groups. However, Hatton et al. (2004) thought that ‘the prevalence of severe learning disabilities amongst UK South Asian communities may be up to three times higher than the general population’ (p i).

### 3.4 Types of disability

The TCRU survey also asked about numbers of children with specific types of disability. As with information on demographic characteristics, there was wide variation between local authorities in the sources of data used which means that the figures in Table 3.5 are far from comprehensive. SEN databases were rarely able to provide information on types of disability for children below or above school age, or for children receiving school action or school action plus.

**Table 3.5: Number of children by type of disability, per 1,000 children under 18**

	N*	Mean	Standard Deviation
Physical disability: per 1000	68	2.7	2.4
Sensory impairment: per 1000	64	1.8	1.6
Interaction and communication: per 1000	63	6.1	4.5
Cognition and learning: per 1000	64	12.3	15.0
Emotional/behavioural: per 1000	50	5.3	4.8
Mental health: per 1000	17	6.5	15.5
Chronic illness: per 1000	25	1.0	1.2
Life limiting illness: per1000	13	4.7	14.8

\* Number of local authorities providing a figure (out of 115)

Information was particularly lacking on some types of disability. Table 3.5 shows fewer than a quarter of authorities responding to the survey could provide a figure for mental health, chronic illness or life limiting illness. These categories tended not to be used in the SEN and social care databases from which most respondents extracted information,

and it was frequently noted that to obtain such data from health colleagues would have involved a great deal of time and effort. Porter and colleagues report that children with mental health difficulties are under-identified and there are children with a disability, including those with health and medical needs as well as children who have conditions such as cancer, who are not known to schools and local authorities (Porter et al., 2008).

Further lack of comparability was introduced by differences between authorities in the level of need of children included within a particular category:

*'In many cases the numbers will vary depending on the severity of the child's needs - e.g. for hearing impaired children the numbers are very different if those with mild, or moderate as well as severe impairments are included (the sensory impairment figure [we have given] is for children with moderate or severe impairments)'. (Unitary authority)*

Some authorities included children with mild learning difficulties under the heading of 'cognition and learning', others only those with severe learning difficulties. The categories provided in our questionnaire were deliberately broad, as we hoped this would make it easier for respondents using different typologies to present their figures in a standard format that would allow us to draw comparisons. However, this created its own problems as local authorities re-grouped their data (for example on children with autistic spectrum disorders) in different ways, or simply listed figures in the comments box under their own headings. Children with multiple, often profound, disabilities were particularly difficult to fit into a typology requiring an indication of 'main disability'.

### **3.5 Summary**

According to our survey of local authorities, boys are twice as likely to be recorded disabled as girls. This is consistent with the 2005 Children in Need Census and the 2007 SEN statement figures. Relative to the 2001 Census, children under five are relatively unlikely to be known to be disabled. This is also consistent with CIN and SEN figures. However, relative to these figures, the TCRU survey found, on average, equal numbers of disabled young people in the age range 5-11 and the range 12-18: this is consistent with the 2001 Census, but the CIN and SEN figures both show higher numbers in the oldest age group.

Our findings are also consistent with secondary analysis of the Family Resources Survey (FRS) (2004-5) and the Families and Children's Study (FACS) (2004-5), which shows that prevalence of disability is higher among boys than girls, and lowest among children under five years of age (Read et al., 2007: Table 2). Although the numbers of disabled children from Black and minority ethnic (BME) groups were small in both the FRS and FACS, the chance of being disabled was greater for children from white ethnic groups than those from BME groups (Read et al., 2007: Table 9).

Lack of data and of comparable data on numbers of children with different types of disability mean that our findings cannot be regarded as reliable indicators of the prevalence of different types of disability. It should also be noted, as a number of survey respondents pointed out, that categorising by disability is not necessarily the best way of collecting information to inform service planning, and that more useful information could be gathered by asking about function and need for support:

*'The membership form does not ask for main disability but asks if the child needs support in daily living and to place a tick against the relevant category e.g. mobility, hand function, personal care' (Metropolitan authority)*

## **4 Local services provided to disabled children**

Part two of the TCRU survey asked about the number of children with disabilities receiving services provided by the local authority and its partners, and the type or services they received. It, therefore, addressed objective 2 (to analyse and report on the services that are provided to children with disabilities and the robustness of these data).

The questionnaire included an acknowledgement that this information is not always held in a format that makes analysis straightforward, but stressed that we would like respondents to provide as much information as possible within the timeframe for the survey. Information was requested separately for services likely to be provided by social care and by health in order to encourage those completing the questionnaire, who were mostly located within children's services, to forward the request for information about health services to relevant colleagues. Although many did pass on the request, it was frequently not possible for them to obtain this information in time to complete the survey. Others pointed out that, regardless of the time allowed, it would be difficult or impossible to obtain the information we requested on provision of health services to disabled children (see discussion in Section 4.1 below).

This part of the survey included two questions on overall numbers: number of children with disabilities known to the disabled children's team(s) who were receiving social care services; and number of children with disabilities receiving specialist services provided by the Primary Care Trust (PCT). Each of these questions was followed by a list of different services, including an 'other' category, with space to enter the number receiving that service in the authority or to indicate that the information was not known. Space was also provided for comments on both social care and health services (see Appendix A for a copy of the questionnaire).

### **4.1 Difficulties in providing information**

Much of the following analysis is based on the qualitative information provided in the comments boxes, which provided a rich source of data on the difficulties local authorities had in supplying information on the number of disabled children receiving different types of services, and the way in which such data are currently collected and categorised. The main difficulties and issues are summarised below, in order to provide a context for interpreting the quantitative information which is subsequently presented.

### ***How services are accessed***

Where disabled children made use of mainstream services (especially in the case of afterschool clubs or holiday playschemes), or where parents used direct payments to purchase services, these children were unlikely to be counted by local authorities.

*'Please note that it would be impossible to give some of the information above e.g. parents may obtain holiday and after school provision from the private sector. Adaptations are managed through other sections and often funded by DSG [Disability Schools Grant] not us. We do provide and commission such services but parents do commission their own and use direct payments to facilitate this.'* (Shire authority)

The figures provided for children in receipt of social care services most commonly appeared to relate to those children in contact with disabled children's teams, although some authorities had attempted to draw on information from wider sources. Children with less severe disabilities would often also be eligible for some support, but this would be through other teams, for example family support teams, or through children's centres. A number of respondents commented that they knew the figures they were providing were underestimates because they did not include such children:

*The figures for family support are likely to be an underestimate as many of our children's centres are providing family support to disabled children'*  
(Metropolitan authority)

Others reported that the number using a service was not known (or not available to them in the timescale) because the service was provided by an independent organisation, often through a grant:

*'We commission our sitting service from a parent organisation I haven't the figures available'* (Unitary authority)

*'Holiday and after school provision is provided by voluntary sector and I have no numbers at present'* (Outer London authority)

The sheer range of agencies providing services also made collating information difficult:

*Some of this provision is provided by a number of agencies, especially holiday and after school provision, early years, youth service, extended schools etc., so it's not been possible to get figures.'* (Metropolitan authority)

### **Multiple service use**

Many children in contact with disabled children's teams will receive a complex combination or 'package' of services, and this could lead to many cases of double or triple counting. Some authorities tried to get around this by giving figures only for children receiving a particular service without other types of provision, whilst acknowledging that the number actually receiving this service would be higher if children with complex care packages were included: *'These [sitting service] figures refer to children for whom this is their only service - there are more children who are using this scheme alongside other services'* (Metropolitan authority). As one shire authority noted: *'many care packages are made up of a range of support services and it is difficult to disaggregate this information from the existing databases'*.

### **Information on service use not electronically recorded or collated**

Several respondents commented that the information requested could in principle be obtained, at least for children served by the disabled children's team, but this would require a manual trawl of case files or care plans. *'The requested information could be extracted on a case by case or team basis; however detailed information is not currently held electronically in one system to allow easy extraction'* (Unitary authority).

### **Lack of clarity about the timeframe over which service provision should be counted**

The questionnaire did not specify the timeframe over which information about service provision should be provided, since it was hoped that this would simplify the task for local authorities as they could supply data in the form in which it was held locally. In practice, however, this led to some confusion, especially in relation to the number of children receiving adaptations and specialist equipment. As one authority commented, *'it is difficult to answer [this question] without a timeframe being put around it as this is ongoing'*.

### ***Different ways of categorising services***

In order to obtain hopefully comparable information about the types of services available, the survey included a list of specific services that might be offered to disabled children and their families. These were based on scoping work to identify the main types of provision available, but in practice local authorities categorised their provision in many different ways that did not always map onto those in our survey: *'We have direct service provision and contracts to provide a range of support services that are not easily broken down into the above categories'* (Metropolitan authority). Another factor militating against comparability was that service categories were not necessarily understood in the same way across authorities, for example how residential short breaks were defined (see below). This finding closely mirrors that of another recent study which explored definitions of local authority services for children and discovered a 'myriad different ways in which the services may be named, commissioned, paid for and delivered, even within the same authority' (Gatehouse et al., 2008, p1).

## **4.2 Numbers receiving social care services**

Ninety percent of authorities provided a figure for the number of children with disabilities known to the disabled children's team and receiving social care services. When converted to a rate per thousand children under 18 in the authority, this ranged from 1.8 per 1000 to 9.6 per 1000, with a mean of just under five per thousand (Table 4.1).

Survey respondents were then asked to provide figures against a list of ten different types of social care service. This list was constructed on the basis of our earlier research on information recorded in disabled children registers and other local authority sources of data on disabled children (Mooney et al., 2007). We present the information below in two forms: as a rate per thousand children under 18 (Table 4.1), and as a percentage of the children known to the disabled children team and receiving a service (Table 4.2). The former gives an indication of the scale of provision, the latter of the relative prevalence of different types of support for disabled children in contact with services.

However, it is important to approach these figures with a considerable degree of caution. In the case of some services listed (adaptations and special equipment, support for personal care, sitter service, holiday and after school provision and family support worker) around half or more of authorities were unable to provide a figure. And for the

reasons discussed above, data were often not provided on a comparable basis, or local authorities were aware that the figure given was not necessarily accurate. Our instructions for completing the survey encouraged respondents to provide whatever information they could, since pilot work had revealed the considerable difficulties they were likely to face in supplying figures on local service provision and we wanted to avoid nil returns wherever possible. The lack of robustness in the data from this part of the survey is therefore not surprising. The information below is offered as a starting point for further work on levels of service provision for disabled children, and should not be treated as a definitive analysis. After the tables, we provide some commentary on the figures given for each type of service.

**Table 4.1: Disabled children receiving social care services: rate per thousand children aged 0-17 in the local population**

	N*	Mean	Standard Deviation
Receiving social care services: per 1000	103	4.9	1.8
Allocated social worker: per 1000	102	3.6	1.7
Residential full-time care: per 1000	101	.2	.2
Residential short breaks: per 1000	100	.8	.4
Foster care: per 1000	96	.5	.5
Family support worker: per 1000	66	.8	.7
Holiday and afterschool: per 1000	60	2.4	2.2
Sitter service: per 1000	57	.6	.7
Support for personal care: per 1000	56	.8	1.0
Adaptations or special equipment: per 1000	40	2.1	1.8
Direct payments: per 1000	96	.9	.6
Other social care services: per 1000	26	1.9	3.6

\* Number of local authorities supplying a figure, out of 115

**Table 4.2: Disabled children receiving social care services as a percentage of children receiving services from the children with disabilities team**

	N*	Mean	Standard Deviation
Allocated social worker: %	96	75.0	29.5
Residential full-time care: %	95	4.4	3.5
Residential short breaks: %	93	18.2	11.4
Foster care: %	88	11.8	12.0
Family support worker: %	61	17.0	16.2
Holiday and afterschool: %	61	17.0	16.2
Sitter service: %	55	13.5	17.8
Support for personal care: %	53	16.3	18.4
Adaptations or special equipment: %	39	41.1	37.5
Direct payments: %	91	18.8	12.2
Other social care services: %	26	44.1	87.4

\* Number of local authorities answering the two questions on children receiving any service from Children with Disabilities Teams and children receiving the specific service.

### ***Allocated social worker***

Ninety six authorities (84%) gave a figure for the number of children with disabilities who had an allocated social worker. This averaged just 3.6 per thousand of all children under 18, but was by far the most common kind of service received by children in contact with disabled children’s teams. On average, three quarters had an allocated social worker, although this varied hugely from 11 percent to 165 percent. In many authorities the number of children with an allocated social worker was the same as the number of children receiving a service from the disabled children team, but in other authorities the two figures differed substantially. Analysis of the qualitative data suggested some reasons for this. In authorities where not all the children in contact with the disabled children’s team had a social worker, this could be because they were still being assessed, or because they had an agreed care package which was reviewed annually by a Reviewing Officer, or because social workers were only allocated to those with the most severe/complex needs. A number of authorities noted that other categories of worker could be allocated to disabled children instead of a social worker, such as occupational therapists or family support workers, and some explained that they had counted these as social workers for the purpose of our survey: *‘Please note the above*

*figure is not only for allocated social worker but for just 'allocated worker' because some are assigned to Occupational Therapists and others to Social Work Assistants' (Unitary authority)*

One unitary authority explained why *more* children were reported as having an allocated social worker than were receiving services from the disabled children's team: *'Some children are allocated a social worker although they receive no service provision from social care. The package is provided by Health [for example when] children/young people have palliative care needs'*.

Another explanation for the difference between the number of children with an allocated social worker and the number of children known to the Children with Disabilities Team and receiving social care services was that whilst some authorities included only those cases that were open to the team, others included both open and closed cases in the number of children known to them. Closed cases would not be expected to have an allocated social worker.

### ***Residential full-time care***

Ninety five authorities (83%) gave a figure for the number of children with disabilities who were receiving residential full-time care. As a proportion of the general population this was tiny - two per 10,000 on average, and just 4% of those receiving a service from disabled children's teams (Table 4.2). This is likely to be because some authorities included children attending residential special schools whilst others only included social care provision, making comparisons difficult.

### ***Residential short breaks***

The figures for short breaks need to be interpreted with caution because it was apparent from the comments made by local authorities that information was not always provided on a comparable basis. For example, some counted only overnight breaks whilst others included daytime periods of care too. Some collapsed the category of 'sitter service' with short breaks, and others noted that short break packages were flexible and so it was not possible to fit them into the categories provided. One authority decided to include children attending weekly or termly boarding school in their figure for residential short breaks. There appeared to be some confusion as to whether 'residential' meant overnight or in a residential institution as opposed to a family setting. Finally, 'family link'

type schemes were often commissioned from independent organisations, and some authorities gave this as a reason why figures on service use were less easily obtained.

Within these limitations, 81% of authorities gave a figure for the number of children with disabilities who were receiving residential short breaks, averaging eight per 10,000 of the total child population (Table 4.1) and 18% of those receiving a service from disabled children's teams (Table 4.2).

### ***Foster care***

Just over three quarters of local authorities provided a figure for the number of disabled children receiving foster care, averaging 12% of those receiving a service from the disabled children's team (Table 4.2).

### ***Family support worker***

Around half of authorities gave a figure, averaging 17%, for disabled children who had access to a family support worker (Table 4.2). Differences were apparent in the ways family support workers were defined and counted. One authority, for instance, commented that *'family support worker has been interpreted as numbers of families using the home support service tendered out to [name] home care service'* (Unitary authority) whilst another included workers in an Autism Family Advice Service. A third authority specified that:

*'[The] figure for family support worker relates to our Duty team who deal with new referrals up to 12 weeks, our behavioural workers working with the challenging child or parents under stress, plus our transitional worker dealing with joint assessments and transfer of cases to Adult Services after the age of 17 years'* (Unitary authority)

As mentioned earlier, it was also noted by several respondents that numbers of family support workers were likely to be an underestimate, since many children's centres provide support to disabled children and their families, but were not included in the figures.

### ***Holiday and afterschool***

Just over a half of authorities were able to provide a figure for the number of disabled children in holiday and after-school provision, but there was little confidence in the completeness of this figure since it was noted that many families access such services themselves without the involvement of the local authority. Some authorities only included in their figure places offered on specialist schemes, or in particular services such as a holiday scheme for disabled Asian children or children with Autistic Spectrum Disorders, while others were able to provide a more extensive figure: *'3420 children and young people were included in extended provision in 2006/07'* (large Metropolitan authority). The average was 17% of children receiving a service from the disabled children's team who were reported to have received holiday and / or afterschool provision (Table 4.2).

### ***Sitter service***

As with many of the categories of service provision, 'sitter service' was interpreted in a variety of ways and sometimes included under other headings:

*'Sitter service equals outreach service which is provided into family homes to provide practical support and short breaks'* (Inner London authority)

*'Very few children access a pure 'sitter' service, as the criteria for the home care service is very specialised, most children require personal care and support'*  
(Unitary authority)

Just under half of authorities supplied a figure for children receiving a sitter service, giving an average rate of 13.5% of those children who received support from the disabled children's team (Table 4.2).

### ***Support for personal care***

Many respondents struggled to supply a figure for disabled children provided with support for their personal care needs, although nearly half attempted to do so. Once again, one difficulty was the varying interpretations of 'personal care' resulting in overlap with other categories, so that some authorities said that personal care needs would be covered under direct payments, or under family support worker. Some interpreted support for personal care needs to include receiving help to access community and

leisure activities, others considered this to be a separate category of 'outreach' work which they mentioned under 'other services' (whilst still others counted such outreach as family support work). This could lead to the figure supplied reflecting all children receiving a care package, which often encompassed many of the separately specified services.

*'All cases allocated to the Reviewing Officer with service packages in place'.*

(Unitary authority)

*'Most disabled children in contact with children with disability teams have personal care needs'.* (Unitary authority)

The proportion of children receiving a service from the disabled children's team who received support for personal care was on average 16% among the 53 authorities who responded to this question (Table 4.2).

### ***Adaptations or special equipment***

Little more than a third of authorities attempted to supply a figure for the number of disabled children provided with adaptations or special equipment. Among those who did so, an average of 41% of the children receiving a service from the disabled children's team were said to be provided with aids and equipment - but in at least one authority the rate worked out at over 200%, suggesting the average figure needs to be treated with considerable caution (Table 4.2). Judging from comments added by a number of respondents, the very different rates were most likely to be due to differences in the period of time covered (high rates, for example, could be due to counting all children issued with equipment not just currently open cases), or to an inability to separate out the number of children receiving aids from the number of adults when special equipment stores covered all age ranges.

### ***Direct payments***

Nearly eight in ten authorities could provide a figure for the number of disabled children receiving direct payments. Calculated as a percentage of those served by the disabled children's team the average was 19% (Table 4.2).

### ***Other social care services***

A wide variety of services provided to disabled children were listed by survey respondents under the 'other' category, although sometimes these could have been fitted within the categories provided. The most commonly mentioned were:

- day care provision (such as specialist childminding schemes, places purchased in day nurseries or an opportunity playgroup) for children with SEN or disability;
- domiciliary care / cleaning;
- mentoring / befriending service including one-to-one support to access leisure and other services; and
- children's centres, which often provided outreach support and family support services for disabled children and their families.

Other types of service that were occasionally mentioned included: transport to and from school and / or respite, voucher scheme for private care agencies, Homestart, specialist Learning Difficulties nurse, grants to support groups, sessional workers, Saturday club and transitions support.

### **4.3 Numbers receiving services provided by the PCT**

With hindsight, the wording of this question caused some confusion, since we asked about services 'provided' by the PCT, and as several respondents pointed out PCTs generally commission services rather than provide them directly. But in any case, it was clear that survey respondents had considerable difficulty in obtaining information on the number of disabled children using various types of health provision. Less than a quarter even attempted to provide a figure for the number of children receiving a health service from the PCT, and the source of this figure (where this was indicated in comments boxes) varied considerably. For example, one authority gave a figure based on the caseload of services provided by the Child Development Service. Another calculated a figure based on '*the number of children with severe/complex needs seen by our health Early Years team, our health teams in special schools, and those with complex health needs needing intensive health care in their home*' (Inner London authority).

Of those authorities providing an overall figure for children in receipt of health provided services, even fewer authorities (between 7 and 17%) were able to provide figures for the specific types of service that were asked about: paediatrician, speech / language

therapy, CAMHS, physiotherapy, home nursing, clinical psychology and 'other health service'. Although we analysed these figures, we have not included them in this report since the number of responses was too small (and the caveats about what the figures covered too large) to draw even tentative conclusions.

Some local authorities responding to our survey believed that they would have been able to obtain information on the number of disabled children using health services given more time, especially when they had good links with their health colleagues. Others, however, noted that the way in which information was collected by the PCT made it difficult to obtain this information, in particular the fact that disabled and non-disabled children were not distinguished:

*'There is no way of disaggregating the disabled and non-disabled patients. For example, a child may be receiving physiotherapy following a road traffic accident but would not be classed as disabled because the impairment is not likely to last more than a year'* (Metropolitan authority)

*'These numbers will include children who have 'additional needs' rather than disabilities, again depending on how disability is defined'* (Outer London authority)

The different basis used by the PCT for counting service use was mentioned by another authority:

*'In the past, information from the PCT has been provided in terms of 'face-to-face' contacts rather than numbers of children. Where figures were given, they were for all children, not just those with disabilities'*. (Metropolitan authority)

As discussed earlier in this report, the problem of how disability was defined was a recurrent theme in the survey responses, and this included responses to questions about service use. As one respondent explained, *'the issue of a common definition was raised in almost every case where I was able to gain a direct contact with the above services'* (Metropolitan authority). Respondents were unsure about what should or shouldn't be included as use of services by disabled children: for example one queried whether all children receiving a service from Children and Adolescent Mental Health Services (CAMHS) should be defined as disabled, *'as by definition they all have mental health problems'* (Metropolitan authority). Another survey respondent had decided that the

relevant figure for CAMHS use would be the subset of children who were receiving specialist provision from the CAMH service for children and adolescents with neuro-developmental disorders.

In a number of cases, those completing the questionnaire had made considerable efforts to provide the best estimate that they could, balancing out different factors that might affect the figure they gave as in this example relating to number of disabled children supported by a paediatrician:

*'The figure includes all the children referred to our Community Development Team chaired by a paediatrician in 2007, plus the numbers of disabled children in our special schools, who are all under a paediatrician. It does not include those children out of borough or in mainstream schools which offsets the fact that not all of the children referred to the Community Development Team will be disabled children' (Outer London authority)*

#### **4.4 Summary**

Despite careful piloting and the best efforts of survey respondents, the information we were able to collect within this survey on local service provision for disabled children does not provide a strong basis for making judgements about the overall level of health and social care provision, nor of variation between local authorities in the services available. The widely varying range of figures provided, which we converted into rates per thousand of the local child population and per hundred children served by the disabled children's team, cannot be interpreted as evidence of real differences in levels of service provision for disabled children. Substantial variation may well exist, but this could only be safely concluded on the basis of figures that are comparing like with like. The varying sources of data available to the local authorities responding to our survey, the different categorisations and interpretations of service provision and the lack of a consistent definition of disability, all mean that such comparisons cannot currently be made.

## 5 Providing information on disabled children

The third and final objective of the survey was to provide information about the difficulties authorities may have in providing information on disabled children and to consider what might be the distinguishing characteristics of those who experienced little if any difficulty in supplying the data requested. In practice, very few authorities (11%) said that they had not had any problems in supplying this information. Of these 12 authorities, two were very small with fewer than ten disabled children, and five had used only one data source in providing the information. In terms of authority type, they were predominately London or Metropolitan authorities with only one Unitary authority and no Two-Tier authorities in this small group.

The survey included two questions specifically addressing the difficulties in providing information on children with disabilities: one asked what would help authorities to calculate a figure for disabled children in the authority and included both a quantitative and qualitative response and the other asked specifically about the difficulties in providing information generally on children with disabilities and how they might be resolved.

The analysis revealed, as might be expected, that the difficulties authorities described centred predominately on issues to do with definitions and the way in which data are collected and managed as encapsulated in the following comments:

*'I found that either information was not gathered in the way that you have asked for it, or that there was an issue of how information is stored, sorted and collated or that the definitions of disability were unclear and not shared. Although each of the organisations held some sort of database, all of these held different information based on different criteria. In addition, the various systems are not at this time able to either interrogate or provide information to each other.'*

(Metropolitan authority)

*'There is a clear understanding from all agencies and service providers of the need to identify the number of disabled children living within [the authority] and the issues they face. Additionally each service area utilises excellent IT systems however it is recognised that the value of this is minimised by a lack of co-ordination of information and electronic systems.'* (Unitary authority)

It is therefore unsurprising that in response to a question asking about what would help in calculating a figure for disabled children, the most frequently occurring responses were shared or compatible databases and reaching agreement on definitions (Table 5.1).

**Table 5.1: Factors that would help in calculating a figure for disabled children**

	Count	Percent
Shared or compatible databases between agencies	102	91
Reaching agreement on definitions/criteria	96	86
Sufficient resourcing for maintaining database(s)	86	77
Good communication between agencies	86	77
Importance of this information recognised	83	74
Good IT systems	81	72
Active, well-maintained Children Act Register	66	59
Other (e.g. more guidance from central government; data protection protocols)	23	21
Total	112	100

**5.1 Agreement on definitions**

We have already discussed (see Section 2.2 above) how different definitions, criteria and thresholds are applied by different agencies according to their particular needs. Yet, to enable a calculation of the number of disabled children in an authority to be made, to collate information drawn from across different databases, and for benchmarking purposes, many respondents considered it imperative that there was some consensus on the definition of disability across the different agencies and across local authorities. Some thought that authorities and their partners should apply the DDA definition whilst others felt that this definition was open to interpretation or was too broad to be useful for planning purposes. This was articulated in terms of the tension *‘between the need to map all need and have an inclusive definition of disability and the need to target services at those children with the greatest need’* (Shire authority). One suggestion as discussed earlier (2.2) was that authorities adopt the DDA definition as an overarching one *‘even though individual services / agencies may then need their own criteria for eligibility/entitlement’* (Metropolitan authority). Another authority whilst advocating the need for an agreed definition highlighted the importance of *‘not only capturing the numbers and categories of disability, but also capturing information on needs/ unmet*

*needs and barriers experienced by disabled children and their families. This will assist in planning and designing services matched to needs and ensuring children are better supported in the context of their family and home environment'* (Metropolitan authority).

Few authorities appeared to have developed a shared definition of disability across agencies although some were clearly working towards doing so (see text boxes) and there were examples where a common definition had been agreed for the purposes of a multi-agency disabled children's register (Children Act Register) although individual agencies still had their own criteria and thresholds for service provision.

## **Devon County Council<sup>5</sup>**

The Children with Special Needs Record, developed from the Children Act Register, is voluntary and parents consent to registration of their child's details. There are approximately 2400 children on the Record and this represents most children with severe and profound disabilities. Health, Education and Social Care all contribute to the Record, but it is held and maintained by the PCT. A common classification system is used by Health, Social Care and Education to identify children's special needs according to the type and severity of difficulty. A child with at least one area of difficulty at the level of moderate or above may be included.

However, due to the voluntary nature of the Record and the criteria for registration, not all children with a disability are recorded. For example, children with a statement of SEN, but no other services and whose families have not required additional services are not captured on the Record. Although Devon has some of their data on a central system, other data is held in separate systems. Social care and Education for example maintain their own databases, though there is considerable overlap with the Record.

Devon is planning to commission a single data system that will have the functionality to capture all the information required from Education, Health and Social Care. As a Children's Trust Partnership they are moving towards a common shared demographic dataset, which combines the PCT public health data with data from the Local Authority and other partners. Joint commissioning is helping all agencies to reach agreement for the common dataset baseline and overcoming problems to do with each having different views about data collection.

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<sup>5</sup> Authorities have agreed to being named.

## **Medway Council**

The multi-agency Children's Disability Review group has contributed to the considerable groundwork that has taken place in this authority in moving towards agreement on definitions and eligibility criteria. Good communication and links between the different professionals working within Health, Education and Social Care has facilitated this work as the authority moves towards Children's Trust status. The NSF working group, Children's Disability Review group and Transitional Practitioners' forum are actively working towards increased and effective sharing of information and statistics and towards establishing shared databases in the future.

Although a common understanding or agreement on definitions was considered to be a key factor in providing better information on disabled children, there was a view expressed by some authorities that the inevitable difficulties in achieving agreement may detract from meeting the needs of disabled children:

*'The debate around the definition of disability and criteria/threshold for services etc is a really difficult one to resolve. Each agency uses different language and is governed by different legislation and priorities. I really don't think we should get 'too hung up' on definitions. It would seem the DDA one is clear but has the potential to be interpreted differently by the various professionals who come into a disabled child's life. The most important thing is for professionals to assess the impact of the child's disability on them and their family. Other children who don't 'fit in' to this criteria/assessment should not in theory fall through the net as they should be picked up by Children in Need services or CAMHS etc. The danger of endlessly debating definitions is that we become immobilised and don't develop or deliver services' (Outer London authority)*

*'Not all my colleagues agree, but my own view is that trying to reach agreement on definitions/criteria between different services within a single area is a fruitless exercise. Different services have developed different criteria because they have different functions for different needs groups. However, sharing definitions across similar services in different areas is immensely helpful, as we have found in sharing criteria for Children Act Registers with a number of other south London authorities'. (Outer London authority)*

## ***Integrated children's services***

An emerging theme was how the move towards integrated children's services and integrated working would help in reaching a shared understanding and clarifying many of the discrepancies in this area. ContactPoint, the Common Assessment Framework (CAF) and the Integrated Children's System (ICS), discussed in the introduction to this report, were systems that some thought would lead to improvements in the collection and sharing of information though as one respondent pointed out '*they would need to record disability*'. Joint funding and joint commissioning would it was thought also act as drivers for improvement. Although authorities were at different stages in their development of integrated children's services, several authorities had or were commissioning joint agency reviews of services for disabled children and young people including a review of databases and information sharing. These reviews were often led by a multi-agency strategy group for children with disabilities which a number of authorities had established:

*'The multi-agency Integrated Services for Children and Young People with Disabilities (ISDC) group, comprising of the local authority, PCT and voluntary agencies, are currently carrying out an audit of all services for children with disabilities against good practice guidance set out in Aiming High for Disabled Children'. (Metropolitan authority)*

*'A review of services for disabled children and young people is about to begin in [authority]. Part of its scope is to review existing databases/registers in order to improve shared information sources. This will help with planning and contribute to better multi agency working'. (Metropolitan authority)*

As this and the following comment illustrate, integrated working can both facilitate and be aided by good communication between agencies, which three-quarters of survey respondents considered to be important (Table 5.1).

*'There is general recognition now that truly integrated working requires good communication and this is being put into effect in, for example, a multi-agency working group on prevalence of and provision for children / young people with ASD.'*  
(Outer London authority)

## **5.2 A single shared database and compatible databases**

When data were not held in one place, but had to be retrieved from different databases all with different recording systems held by different departments, it was often not possible for local authorities to collect and collate the data, particularly within the unavoidably short timeframe for our survey: *'The lack of compatible databases and differences in methods and purpose of data collection across the LA and its partners make it difficult to compare/aggregate data about disabled children'* (Metropolitan authority). Furthermore, as discussed earlier the lack of compatible data from these various sources often meant that there was no means by which to address double counting (see 2.2). For some authorities, manual counting was necessary due to inadequate or incompatible IT systems:

*'The information given was provided through searching a number of different sources - this is time consuming and has to be done manually, e.g. budget information to identify residential placements, LAC numbers, team lists. Of the two Child Disability Teams only one is currently on the electronic database which is being rolled out across the county. When complete and if it functions ok, this will address some of the problems e.g. gender, ethnicity, types of disability. However, this still only captures those children known to Social Care.'* (Shire authority)

A single, shared database or databases that were compatible and could communicate with one another were seen as the means to overcome these difficulties and improve the data on disabled children. Indeed some authorities were already working towards this end and looking at how data on disabled children could be managed more effectively as exemplified by the examples provided in the text boxes. Building on an education database, as in the case of South Tyneside, or on a health data set, as in the case of Devon, were two approaches to developing one database. A number of issues had to be addressed as one authority explained in describing how they had been trying for some time to achieve a shared database: *'resources and technical difficulties are the main*

*issues though some information sharing issues are also present.* (Outer London authority)

Retrieving information from other agencies/departments could take considerable time, and difficulties arose due to data sharing and data protection issues. These difficulties included ensuring that parents/carers had given consent to sharing information on their children for planning purposes, the need to overcome a reluctance in some teams to share information and the *'cultural obstacles to sharing information between agencies'*. Some authorities reported that they had to allay fears about how combined data may be used. This led some to emphasise the importance of developing protocols for information sharing which were agreed between agencies: *'easier establishment of data sharing agreements and the facilitation of smoother / quicker transfer of data between agencies although this won't be necessary if we're using one system'* (Metropolitan authority).

It was not always clear to survey respondents what information on disabled children was held by other agencies / departments and which person to approach for it. This, coupled with the fact that in many cases there was no administrative support for collating these data, led some to suggest that there should be a designated department or officer who took responsibility for collating this information. Even authorities with data support staff emphasised that they often did not have sufficient time to respond to data queries such as ours. Adequate resourcing for the effective management of data on disabled children was therefore a high priority for more than three-quarters of the sample (Table 5.1). As several respondents explained, for these data to be useful in planning and meeting the needs of children with disabilities, they have to be accurate and kept up-to-date:

*'Statistical data that is not kept up to date and relevant causes a reluctance to input resources. It is a catch 22 situation as without the extra commitment from resources the data cannot be obtained or managed sufficiently yet it could be an invaluable tool for future planning if agencies worked together.'* (Metropolitan authority)

*'The extent to which some data is readily available is determined by the level of staff resource which is also currently being addressed.'* (Shire authority)

*'Not enough complete data and no investment in building this up'* (Shire authority)

### **South Tyneside Council**

The Active Network (Children Act Disability Register) has 320 children registered, both service users and non-users. Parents who register are provided with free entry to leisure facilities (e.g. sports facilities, museums) and receive regular newsletters and information.

It is estimated that there are approximately 1170 disabled children in the authority calculated using Education and Social Care databases. These databases tend to be robust for children aged 5-16, but there are gaps for the pre-school and 16-18 years age range. Active Network is therefore thought to represent under a third of all disabled children in the authority.

With the different data sets, the authority's initial approach was to bring names from different data sets into a new data set. However, rather than have a single but separate database of disabled children, the authority has decided to build on the Education database and flag up vulnerable children including those with disabilities. This it is felt will provide more accurate data and will be firmly based within operational services whose staff will input the data. However, the authority is aware that the PCT is not yet part of this process, although it needs to be if the new database is to be comprehensive.

### **London Borough of Hammersmith and Fulham**

Recognising the limitation of local registers, such as the Children Act Register of children with disabilities that tend to be partial in their coverage, Hammersmith and Fulham are compiling a 'super register'. This register brings together information from the Children Act Register, the local authority disability register (1948 statute), the SEN list and social services database. Initial work on this new register has demonstrated the relative lack of overlap. For example only 107 of 242 children on the local authority disability register have a statement of SEN. Because national and regional figures are based on estimates from partial data or on variable definitions of disability, as well as the 'super-register' project the authority is looking at estimates from other sources, such as the RNIB and NDCS, about specific disability groups and exploring how these have been calculated.

### 5.3 Register for children with disabilities

Most local authorities have a register of disabled children as required under the Children Act 1989 although not all these registers are active and up to date (Mooney et al., 2007). When asked what would be most helpful in enabling an authority to calculate the number of disabled children, however, a well-maintained register of this kind was relatively low on the list (Table 5.1). Voluntary registration in particular, but also for some authorities the lack of investment in its maintenance and lack of incentives for parents to register, inhibited its usefulness as a data source:

*'We do not feel that a well resourced Children Act Register is fit for purpose given that registration is entirely voluntary - all it can ever do is give us a snapshot, and then not a particularly reliable one.'* (Unitary authority)

This led some authorities to suggest a strengthening of the role and importance of this Register for example through better resourcing, providing incentives for parents to register their children and even making registration mandatory as illustrated by the following comments:

*'[It needs] a commitment from all agencies in the promotion and continued development of the Children's Disability Register including sufficient resources and to planning services for the future'.* (Metropolitan authority)

*'We are also considering how to 'market' the disabled children's register and are looking at schemes which other LAs have used to increase uptake. This is a logical way to give more muscle to the original rationale for this database.'* (Outer London authority)

*'If Government were to make entry onto this mandatory, then agencies would have to work together to populate it and we could make some real inroads into counting the number of disabled children on a multi-agency basis.'* (Shire authority)

## 5.4 Role of central government

In analysing the qualitative response asking what the difficulties were and how they could be overcome, several respondents thought there was a need for a stronger lead from central government. This was expressed in terms of wanting to see clear guidance to local authorities and PCTs either about definitions, the range of data they should be collecting or the protocols for sharing such data. That sometimes there was inconsistency between central government departments in their categories did not go unnoticed: *'ICS and CAF do not use the same precise definitions, yet one should logically follow on from the other'* (Metropolitan authority). Some went as far as to suggest that there should be a mandatory requirement to collect and share statistical data on children with disabilities, with one authority highlighting the fact that because there had been *'no national performance imperative to collect this data in children's social care and health, the systems have not been set up to collect, analyse and use it'* (Unitary authority)

*'There is poor central guidance about what all the agencies should collect and what definitions apply, e.g. Aiming High suggests the DDA definition for planning short-break services, whereas social care uses the 1989 [Children] Act definition if only for legal reasons, and education use educational definitions. There are similar issues for the PCT's and Trusts. This contributes to problems of data management which are then seen as getting in the way by service users who want to know what services am I entitled to and when?'*  
(Shire authority)

As this quotation suggests, the different legislative frameworks that apply to Social Care, Health and Education were seen as adding to the problems associated with collating data on disabled children, and one authority suggested that what was needed was a *'unified social care, health and education framework of legislation in which support for children and families with additional needs is assessed and provided'* (Shire authority).

## **5.5 Summary**

Most authorities experienced difficulties in providing information on the numbers and characteristics of disabled children and local service provision. Reaching agreement across agencies on definitions and criteria for disability and having one single database or compatible database were considered essential for improving data on disabled children. Integrated children's services and joint funding and commissioning may help to drive improvements, but more guidance from central government about what data to collect and protocols for data sharing would be helpful. Adequate resourcing for data collection and management, and good communication between agencies were also considered important. Those who advocated Children Act Registers as having an important role to play in data collection and management suggested that there should be adequate investment in the Register and a strengthening of its reach by, for example, providing incentives for parents to register their children or even making registration mandatory.

## 6 Conclusions

The study set out to survey all 150 local authorities in England and report on the prevalence and characteristics of disabled children and their use of local service provision. Such data has been lacking at both the national and local level, and is necessary in order to provide a baseline for assessing any impact of the *Aiming High for Disabled Children* programme and the 'core offer' to disabled children and their families. The survey achieved a high response rate, and many local authority respondents made considerable efforts to collate the data available to them in the time available. Despite this, it was not possible for the survey information to provide a reliable figure for the number of disabled children in each local authority, due to the difficulties local authorities had in identifying and counting such children. Providing data on the characteristics of children with disabilities and the use of services provided by social care and health also presented difficulties. The different sources of data available to local authorities responding to the survey, the different definitions of disability used across agencies and between local authorities, the different categorisations and interpretations of service provision, all contributed to this situation.

This report does however provide comparisons for each local authority using different sources of data: the total number of children with SEN statements; the total number of children with SEN (including those with and without statements); the 2001 Census figure for the number of children with limiting long-term illness (LLI); the number of children in receipt of Disability Living Allowance (DLA); the number of disabled children recorded in the 2005 Children in Need (CIN) Census; and figures based on OPCS and FRS estimates. From our analyses of published figures, we propose that it would be possible to put a lower and upper bound on the number of disabled children in each local authority based on the number of children with a SEN statement and the number of children in receipt of DLA. Since it was widely agreed by local authorities that children in either of these categories would be counted as having a disability, a lower bound could be taken as the larger of these two and an upper bound as the sum of the two. The most likely figure would be somewhere between the upper and lower bounds; its exact position depending on the degree of overlap between the two sources. Figures for each local authority, and for England as a whole, have been calculated based on this model. This results in a lower bound of 288,000 and an upper bound of 513,000 disabled children in England, or on average between 3.0 and 5.4 percent of children under 18 years.

Planning and improving services for disabled children requires accurate, comprehensive data on numbers, characteristics and use of local service provision. Improving services for disabled children will be significantly hindered without these data. The National Service Framework for Children, Young People and Maternity Services expects local authorities, Primary Care Trusts and NHS Trusts to ensure that there are 'arrangements to encourage multi-agency strategic planning of services for disabled children...which allow for the development and implementation of a locally based multi-agency database containing core data on disabled children, based on shared and agreed definitions'. (Department for Education and Skills and Department of Health, 2004:39).

The TCRU survey has shown that whilst local authorities recognise the need for such data to inform and improve their work, and whilst some are working towards improving their data systems, most are struggling with the difficulties associated with collecting and managing these data. The survey results indicate that no authority had found all the 'answers' to the difficulties, and that authorities are at different stages in the process of improving the accuracy of their data with some further along than others.

### ***Implications for policy***

These findings have a number of implications for policy with regard to developing a strategy to meet the commitment outlined in *Aiming High for Disabled Children* for 'better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing' (HM Treasury and Department for Education and Skills, 2007: paragraph 3.31).

- At the present, it is impossible to compare local authorities on their numbers of disabled children, because they do not use a consistent definition of disability. Whilst there is no single 'correct' definition of disability, it is important that DCSF provides a common definition for the collection of a comparable dataset. The information currently collected on children with special educational needs is relatively comprehensive because there is a standardised format; local authorities know which data they are required to collect for the annual return and in turn have developed databases that will provide the relevant information. If local authorities knew which data they should be collecting on disabled children, and a similar reporting requirement was introduced, improved data collection and better databases would result.

- Without data on disabled children collected by local authorities on a consistent basis, it is impossible to compare the service that is provided, as we cannot compare like with like. In order to make any progress on assessing service delivery, a prerequisite is that statistics are collected using a common definition.
- The survey findings support the need for central government to develop guidance for local authorities to promote better practice in collating robust data. Data sharing and data protection are real issues faced by local authorities and their partners as they move towards a better database and such guidance could usefully include data sharing protocols.
- Providing robust data on disabled children requires investing in the necessary resources to make this happen. The resources that local authorities currently allocate for collecting and collating data on disabled children appear to vary considerably.

It has to be accepted that it will take time for local authorities and their partners to develop the databases necessary to provide better data on disabled children, but the TCRU survey suggests that local authorities in general are keen to move towards this position, even though the process may be difficult: *'We've all developed different categories for counting disabled children and the services they use. Getting consistency across the country would be painful for those of us who will have to adapt our systems, but ultimately would be most helpful'* (Outer London authority).

A step has already been taken to address the need for guidance on how to collect robust and comparable data with the recent establishment of a joint DH / DCSF working group. This group is considering how effective systems can be developed for data collection and the use of data in the planning and delivery of services, and what central government can do to remove obstacles that act as a barrier to joint commissioning and joint activities. With a greater commitment to improving data collection than there may have been in the past, it is to be hoped that associated improvements in services for disabled children will be realised. This would help to take forward the *Aiming High for Disabled Children: Better Support for Families* agenda.

## References

Audit Commission (2003) *A Review of Services for Disabled Children and Their Families. A Public Sector Briefing*. London: Audit commission.

Bone, M. and Meltzer, H. (1989) *The Prevalence of Disability Among Children*. London: HMSO.

Contact a Family, Council for Disabled Children, Mencap and Special Educational Consortium (2006) *Off the Radar: How Local Authority Plans Fail Disabled Children* [http://www.edcm.org.uk/pdfs/edcm\\_offtheradar\\_fullreport.pdf](http://www.edcm.org.uk/pdfs/edcm_offtheradar_fullreport.pdf)

Council for Disabled Children (1999) *Quality Protects: First Analysis of Management Action Plans with Reference to Disabled Children and their Families*, London: Department of Health.

Council for Disabled Children (2002) *Registering Effectiveness. A Review of Issues in the Development of Registers for Disabled Children*. London: Council for Disabled Children.

Department for Education and Skills (2004) *Removing Barriers to Achievement*. London: Department for Education and Skills.

Department for Education and Skills (2006) *Children in Need in England: Results of a survey of activity and expenditure as reported by Local Authority Social Services' Children and Families Teams for a survey week in February 2005: Local Authority tables and further national analysis (Internet only)* (Vweb02/2006). London: Department for Education and Skills.

Department for Education and Skills (2007a) Children's Social Services Local Authority Circular LAC (SCYPG07\_10): [http://www.everychildmatters.gov.uk/files/SCYPG07\\_10\\_June\\_2007.pdf](http://www.everychildmatters.gov.uk/files/SCYPG07_10_June_2007.pdf)

Department for Education and Skills (2007b) *Special Educational Needs in England: January 2007* (SFR20/2007). London: Department for Education and Skills.

Department for Education and Skills and Department of Health (2004) *Disabled Children Standard, National Service Framework for Children, Young People and Maternity Services*. London: Department of Health.

Department of Communities and Local Government (2007) *The New Performance Framework for Local Authorities and Local Authority Partnerships: Single Set of National Indicators*. London: DCLG.

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*. London: Department of Health.

Every Child Matters (2007) *ICS, CAF and ContactPoint – An Overview*. November 2007. [www.everychildmatters.gov.uk/](http://www.everychildmatters.gov.uk/)

Gatehouse, M., Ward, H. and Holmes, L. (2008) *Developing Definitions of Local Authority Services and Guidance for Future Development of the Children in Need Census*. (RBW033). London: Department for Children, Schools and Families. <http://www.dfes.gov.uk/research/data/uploadfiles/DCSF-RBW033.pdf>

Hatton, C., Akram, Y., Shah, R., Robertson, J. and Emerson, E. (2004) *Supporting South Asian Families with a Child with Severe Disabilities*. London: Jessica Kingsley.

HM Treasury and Department for Education and Skills, (2007) *Aiming High for Disabled Children: Better Support for Families*. [http://www.hm-treasury.gov.uk/media/C/2/cyp\\_disabledchildren180507.pdf](http://www.hm-treasury.gov.uk/media/C/2/cyp_disabledchildren180507.pdf)

House of Commons Education and Skills Committee (2006) *Special Educational Needs: Third Report of Session 2005-06, Volume 1*. London: The Stationery Office.

Kasparova, D., Marsh, A. and Wilkinson, D. (2007) *The Take-Up Rate of Disability Living Allowance and Attendance Allowance: Feasibility Study* (Research Report No 442). London: Department for Work and Pensions.

Lindsay, G., Pather, S. and Strand, S. (2006) *Special Educational Needs and Ethnicity: Issues of Over- and Under-Representation* (RR 757). London: Department for Children, Schools and Families.

Mooney, A., Owen, C. and Statham, J. (2007) *A National Disabled Children's Indicator – Using a Survey of Parents: A Feasibility Study*. Report to Department for Children, Schools and Families.

North East Public Health Observatory (NEPHO) (2003) *Children with long term disability in the former Northern and Yorkshire NHS region*. Stockton on Tees: NEPHO.

Office for National Statistics (2004) *Living in Britain: Results from the 2002 General Household Survey*. London: HMSO.

Ofsted (2004) *Special Educational Needs and Disability: Towards Inclusive Schools*. London: Ofsted.

PM's Strategy Unit (2005) *Improving the Life Chances of Disabled Children*  
[http://www.cabinetoffice.gov.uk/strategy/work\\_areas/disability/~/\\_media/assets/www.cabinetoffice.gov.uk/strategy/disability%20pdf.ashx](http://www.cabinetoffice.gov.uk/strategy/work_areas/disability/~/_media/assets/www.cabinetoffice.gov.uk/strategy/disability%20pdf.ashx)

Porter, J., Georgeson, J., Daniels, H., Hacker, J. and Gallpop, V. (2008) *Disability Data Collection for Children's Services*. London: Department for Children, Schools and Families

Read, J., Spencer, N. and Blackburn, C. (2007), *Can We Count Them? Disabled Children and Their Households*. Full Project Report to the ESRC. Swindon: ESRC.

## Appendix A: Survey Questionnaire

**THOMAS CORAM RESEARCH UNIT**  
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### Disabled Children: Numbers, Characteristics and Local Service Provision

We are conducting a survey of all Directors of Children's Services on behalf of DCSF to collect information on the numbers and characteristics of children with disabilities and the services provided to them by the local authority and their partner agencies. We have attached a summary of the study with this questionnaire.

In August 2007 we emailed each local authority some questions about the Children Act Disability Register. It may seem that we are asking for the same information again. However, we are now interested in all children with disabilities, not just those on the Children Act Register.

From our earlier work we know that there are significant differences between and within authorities in terms of definitions, disability eligibility criteria and the way in which information is collected and managed. In this questionnaire we have tried to take account of these differences wherever possible. We are also aware that authorities may have difficulty in providing detailed figures: but please try to complete as much as possible.

The questionnaire can be completed in Word - just click on the box and start typing for open-ended responses, or to put a cross in the box for ticked responses. If you want to remove a cross, click again on the box. **NB:** Boxes for open-ended questions do not expand as you type - you only have the space provided. You can add further comments at the end of the questionnaire. Only the research team will have access to the information you give, and your responses will not be attributed to your local authority unless you give permission.

The questionnaire can be returned by email - [disabledchildrensurvey@ioe.ac.uk](mailto:disabledchildrensurvey@ioe.ac.uk) - though remember to save it first before sending. If you prefer to print the questionnaire and complete it by hand, please return it to: Michelle Cage, Thomas Coram Research Unit, 27/28 Woburn Square, London, WC1H 0AA.

<b>Please return the questionnaire by 1<sup>st</sup> February 2008</b>
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If you have any queries please contact Michelle Cage on 020 7612 6962 or email [disabledchildrensurvey@ioe.ac.uk](mailto:disabledchildrensurvey@ioe.ac.uk).

## Part 1: Numbers and Characteristics of Children with Disabilities

1. Which local authority do you represent?

2. Using whatever data available what is your authority's best estimate of the number of children with disabilities in your authority? *(Please use text box to add comments)*

Number: \_\_\_\_\_

Comments:

3. On a scale from 1 to 6, what degree of confidence is there that this figure is a reasonable estimate of all disabled children in the authority? *(Please mark one box)*

1 Low     2     3     4     5     6 High

4. Which of the following sources of information is included to estimate this figure? *(Please mark all that apply)*

Children Act Register or its equivalent	<input type="checkbox"/>
The children with disabilities team lists / databases	<input type="checkbox"/>
Special Educational Needs data	<input type="checkbox"/>
Data held by the PCT	<input type="checkbox"/>
Children-in-need register	<input type="checkbox"/>
Number of DLA claimants	<input type="checkbox"/>
Census or OPCS data	<input type="checkbox"/>
Other sources	<input type="checkbox"/> <i>(please specify)</i>

Other sources / comments:

5. What age range does this estimated figure cover? \_\_\_\_\_

6. What criteria of disability are being used?

7. Which of the following categories are included in the definition of disability applied by your authority? *(Please mark all that apply)*

- Attention Deficit Disorder (ADHD)
- Autistic Spectrum Disorder (ASD)
- Behaviour / emotional difficulties
- Mental health difficulties
- Dyslexia
- Dyspraxia
- Children with a statement of SEN
- Children on school action plus
- Children with a mild disability

Comments:

8. What are the factors that help/would help in calculating an estimated figure in your authority for the number of children with disabilities? *(Mark all that apply and please add any comments)*

- Reaching agreement on definitions / criteria
- Shared or compatible databases between agencies
- An active, well maintained CA register or equivalent
- Sufficient resourcing for maintaining database(s)
- Good IT systems
- Good communication between agencies
- Importance of this information recognised
- Other  (please *specify*)

Other factors / comments:

9. Does your estimate take account of any overlap between different databases providing information about disabled children?

- Yes
- No
- Don't know

What steps have you taken to address this overlap?

*We realise that providing information on characteristics of children with disabilities will depend on the databases available and the relative ease of collating data within and/or across databases. For the following questions, we would appreciate whatever data, however limited, you can provide within our time frame.*

10. Can the authority provide by gender the number of disabled children known to them?  
*(Please provide the figures or mark the appropriate box)*

Male \_\_\_\_\_  
 Female \_\_\_\_\_  
 Don't Know   
 No data collected on gender   
 Unable to collate this data

11. Can the authority provide by age the number of disabled children known to them?  
*(Please provide the figures or mark the appropriate box)*

0-4 years \_\_\_\_\_  
 5-11 years \_\_\_\_\_  
 12-18 years \_\_\_\_\_  
 Don't Know   
 No data collected on age   
 Unable to collate this data

12. Can the authority provide by ethnicity the number of disabled children known to them?  
*(Please mark one box)*

Yes   
 No   
 Don't Know   
 No data collected on ethnicity   
 Unable to collate data

12a. If yes, how many children are in each of the following ethnic groups?

Census ethnic group	Number
White	
Mixed	
Asian	
Black	
Other ethnic group	

13. There are different ways of categorising types of disability, but can you say how many children are in each of the following categories where this is the main disability?  
**We know there is likely to be double counting**

	Number	Cannot say	Excluded from our definition
Physical disability.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensory impairment.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interaction and communication.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognition and learning.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional / behavioural.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chronic illness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Life limiting illness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

14. Which sources provide information on characteristics of disabled children? (*Please mark all that apply*)

- Children Act Register or equivalent
- Special Educational Needs database
- Social care team lists /databases
- PCT database
- Other sources of data on characteristics  (*Please specify*)

Other sources/Comments:



18. How many children with disabilities receive the following services provided by the PCT? (Please provide number or mark box if not known)

	Number	Don't Know
Physiotherapy.....		<input type="checkbox"/>
Speech / language therapy.....		<input type="checkbox"/>
Paediatrician.....		<input type="checkbox"/>
Clinical Psychology.....		<input type="checkbox"/>
Home nursing.....		<input type="checkbox"/>
CAMHS.....		<input type="checkbox"/>
Other health service (please specify).....		<input type="checkbox"/>

Other health services:

### Part 3: Challenges and further comments

19. Did you have any difficulty in providing information on numbers and characteristics of disabled children and their use of services?

Yes   
No

Please tell us what the difficulties were and how these could be overcome



Who should we contact if we want to talk to someone about this survey?

Name

Position

Tel:

Email:

**THANK YOU FOR YOUR HELP**

Please use the space below to make any comments about the survey and/or about collecting and collating data on disabled children.

## Appendix B: Indicators of children with disabilities, with OPCS and FRS-based estimates

Local Authority	Total pupils with statements: 2007 (PLASC)	SEN pupils (Primary/Secondary)	Limiting long-term illness: children 0-17: Census 2001	In receipt of Disability Living Allowance aged under 18	Disabled Children in Need: 2003/2005	OPCS estimate: 3.2%	FRS estimate: 7.3%
Barking and Dagenham	812	5401	2292	1230	179	1402	3197
Barnet	1316	8732	2685	1585	352	2378	5424
Barnsley	990	6208	2480	1345	140	1565	3570
Bath & North East Somerset	797	3631	1266	710	207	1107	2526
Bedfordshire	2050	10451	3431	2185	542	2938	6701
Bexley	1302	7510	1981	1315	239	1635	3730
Birmingham	6525	35461	13652	8295	1273	8054	18374
Blackburn with Darwen	662	5641	1874	1035	197	1242	2832
Blackpool	558	4091	1466	905	172	960	2190
Bolton	1285	9187	2893	1770	318	1994	4548
Bournemouth	445	3800	1204	650	121	925	2110
Bracknell Forest	494	2817	871	535	111	861	1964
Bradford	2134	18924	6104	3475	1787	4010	9147
Brent	1205	9178	2419	1135	199	1827	4168
Brighton & Hove	1169	6484	2269	1510	254	1478	3373
Bristol	1644	8318	4117	2485	844	2522	5752
Bromley	1557	7466	2382	1645	207	2138	4876
Buckinghamshire	2376	10861	3648	2120	169	3635	8293
Bury	896	4664	1974	1115	346	1363	3110
Calderdale	1025	5641	1898	1130	821	1453	3314
Cambridgeshire	2651	13570	4501	3065	593	3949	9008
Camden	894	4815	1675	840	384	1258	2869
Cheshire	3441	13635	5534	3190	1167	4672	10658
City of London	7	63	24	0	4	26	58
Cornwall	2021	13056	4954	2865	1434	3350	7643
Coventry	1443	10066	3312	2150	229	2166	4942
Croydon	1294	10142	3383	1810	485	2538	5789
Cumbria	2470	13223	4279	2480	541	3238	7388
Darlington	472	2659	1013	640	93	707	1613
Derby	1224	6501	2188	1315	298	1693	3862

Local Authority	Total pupils with statements: 2007 (PLASC)	SEN pupils (Primary/Secondary)	Limiting long-term illness: children 0-17: Census 2001	In receipt of Disability Living Allowance aged under 18	Disabled Children in Need: 2003/2005	OPCS estimate: 3.2%	FRS estimate: 7.3%
Derbyshire	2951	18171	6530	3940	823	5136	11717
Devon	3377	17380	6049	3780	396	4643	10592
Doncaster	1356	7353	3127	1595	294	2067	4716
Dorset	1609	10516	3185	1825	577	2598	5928
Dudley	1378	9271	2872	1820	368	2134	4869
Durham	2358	16160	5547	3195	429	3267	7453
Ealing	1261	8434	2782	1350	532	2064	4709
East Riding of Yorkshire	1289	7454	2482	1420	273	2128	4855
East Sussex	2388	12314	4592	2695	517	3341	7621
Enfield	1262	11257	2634	1390	378	2144	4891
Essex	5350	31127	11827	6850	1347	9472	21608
Gateshead	812	5070	2028	1010	210	1267	2891
Gloucestershire	2305	14217	4496	2395	597	3978	9074
Greenwich	1376	9044	2531	1540	240	1658	3781
Hackney	921	6422	2817	1205	357	1642	3745
Halton	780	4153	1367	775	90	890	2029
Hammersmith and Fulham	755	4005	1356	605	190	976	2227
Hampshire	4611	32839	10746	6585	1364	8867	20228
Haringey	1154	7357	2240	1130	515	1568	3577
Harrow	869	6096	1726	1030	241	1546	3526
Hartlepool	354	2953	1191	615	90	678	1548
Havering	875	4822	1921	1200	269	1587	3621
Herefordshire	768	4814	1494	880	108	1174	2679
Hertfordshire	4219	26152	8385	5600	1375	7744	17666
Hillingdon	1294	7938	2266	1455	216	1846	4212
Hounslow	1181	7674	1932	1170	237	1533	3497
Isle of Wight Council	587	2907	1398	835	276	874	1993
Isles of Scilly	5	32	3	5	.	13	29
Islington	722	5830	1884	985	245	1082	2467
Kensington and Chelsea	333	1731	975	380	251	963	2197

Local Authority	Total pupils with statements: 2007 (PLASC)	SEN pupils (Primary/Secondary)	Limiting long-term illness: children 0-17: Census 2001	In receipt of Disability Living Allowance aged under 18	Disabled Children in Need: 2003/2005	OPCS estimate: 3.2%	FRS estimate: 7.3%
Kent	6575	48165	12941	9260	1480	9923	22637
Kingston upon Hull	1212	7441	2921	1515	360	1779	4059
Kingston upon Thames	579	3111	1034	575	255	1014	2314
Kirklees	1977	11173	4080	2275	257	2989	6818
Knowsley	834	6106	2263	1085	179	1155	2635
Lambeth	1062	7286	2633	1425	74	1731	3949
Lancashire	6939	26573	11351	6465	1613	8109	18498
Leeds	2364	17893	6941	3420	1184	4906	11191
Leicester	1450	9720	3522	1965	269	2166	4942
Leicestershire	2812	13676	4869	2830	298	4291	9789
Lewisham	1158	7614	2819	1640	335	1805	4117
Lincolnshire	3905	19262	5955	4220	665	4499	10264
Liverpool	1729	15737	5981	3110	394	2861	6526
Luton	753	6783	2280	1280	277	1494	3409
Manchester	2144	13927	4968	3330	542	3011	6869
Medway	1299	11178	2913	2125	208	1920	4380
Merton	957	4003	1489	805	73	1293	2949
Middlesbrough	939	3264	2356	1325	177	1027	2343
Milton Keynes	1130	5934	2174	1110	120	1744	3979
Newcastle upon Tyne	981	7356	2983	1825	292	1677	3825
Newham	629	10235	3475	1655	486	2102	4796
Norfolk	3740	22936	7017	4775	770	5197	11855
North East Lincolnshire	929	6638	1791	1115	156	1168	2665
North Lincolnshire	897	5535	1477	920	207	1107	2526
North Somerset	599	4484	1482	890	291	1338	3051
North Tyneside	1058	5172	1867	1070	140	1286	2935
North Yorkshire	1909	11906	4470	2365	500	3974	9067
Northamptonshire	3382	22173	5679	3740	1308	4890	11154
Northumberland	1568	7488	2761	1770	458	2000	4563
Nottingham	611	9640	3234	2085	436	1786	4073

Local Authority	Total pupils with statements: 2007 (PLASC)	SEN pupils (Primary/Secondary)	Limiting long-term illness: children 0-17: Census 2001	In receipt of Disability Living Allowance aged under 18	Disabled Children in Need: 2003/2005	OPCS estimate: 3.2%	FRS estimate: 7.3%
Nottinghamshire	1314	19086	6761	4350	822	5171	11797
Oldham	808	7043	2446	1425	187	1763	4022
Oxfordshire	2503	14328	4779	2635	766	4342	9906
Peterborough	1172	6361	1820	1170	176	1235	2818
Plymouth	1263	7379	2870	1980	440	1619	3694
Poole	488	3503	1209	635	196	899	2051
Portsmouth	788	6156	1886	1015	236	1235	2818
Reading	495	2758	1286	730	280	931	2124
Redbridge	1266	6566	2241	1220	452	1942	4431
Redcar and Cleveland	715	5119	2060	1090	203	976	2227
Richmond upon Thames	653	3045	1107	585	264	1226	2796
Rochdale	1106	6242	2405	1360	282	1606	3665
Rotherham	1219	8626	2952	1985	303	1824	4161
Rutland	154	756	250	130	19	294	672
Salford	876	4948	2418	1615	201	1488	3395
Sandwell	1058	10391	3493	1655	183	2166	4942
Sefton	1028	7377	2998	1610	251	1904	4344
Sheffield	2088	15417	5402	3500	566	3408	7775
Shropshire	1315	7147	2295	1375	258	1949	4446
Slough	644	4506	1154	660	294	922	2102
Solihull	999	5396	1679	1135	107	1466	3343
Somerset	1366	10888	4251	2410	1073	3578	8161
South Gloucestershire	1028	5981	2002	1280	288	1808	4125
South Tyneside	775	3815	1647	875	160	1014	2314
Southampton	573	7479	2206	1215	241	1366	3117
Southend-on-Sea	785	4093	1591	1000	148	1114	2540
Southwark	1442	7881	2639	1545	229	1738	3964
St Helens	721	4227	1990	945	88	1258	2869
Staffordshire	4212	17151	7402	4435	587	5539	12636
Stockport	1593	7043	2654	1730	371	1955	4460

Local Authority	Total pupils with statements: 2007 (PLASC)	SEN pupils (Primary/Secondary)	Limiting long-term illness: children 0-17: Census 2001	In receipt of Disability Living Allowance aged under 18	Disabled Children in Need: 2003/2005	OPCS estimate: 3.2%	FRS estimate: 7.3%
Stockton-on-Tees	955	4514	2505	1440	93	1370	3124
Stoke-on-Trent	1254	8952	2716	1445	313	1661	3789
Suffolk	2989	17677	6249	4445	549	4816	10987
Sunderland	1244	8705	3211	1725	216	1885	4300
Surrey	5492	25494	7605	4885	806	7597	17330
Sutton	1029	5034	1637	1060	245	1331	3037
Swindon	856	5326	1670	980	245	1341	3059
Tameside	841	5468	2341	1320	229	1558	3555
Telford and the Wrekin	1069	5022	1812	1280	160	1238	2825
Thurrock	873	5208	1469	970	252	1146	2613
Torbay	838	3405	1337	930	171	838	1913
Tower Hamlets	1249	7548	2594	1345	291	1568	3577
Trafford	889	5422	1776	1065	163	1517	3460
Wakefield	1320	8870	3575	2095	215	2237	5103
Walsall	1145	7252	3079	1515	264	1933	4409
Waltham Forest	1411	9751	2475	1205	320	1670	3811
Wandsworth	1423	7636	2143	1225	344	1504	3431
Warrington	1245	5254	1675	970	151	1389	3168
Warwickshire	2181	14818	4083	2525	526	3571	8147
West Berkshire	1142	4242	1110	735	108	1133	2584
West Sussex	3668	20604	6155	3820	715	5219	11906
Westminster	631	3857	1062	630	757	1066	2431
Wigan	1566	8537	3090	1830	223	2147	4898
Wiltshire	1737	10720	3443	2220	481	3251	7417
Windsor and Maidenhead	698	3255	832	485	168	1040	2373
Wirral	1862	9052	4058	2570	463	2211	5044
Wokingham	904	3224	1045	620	199	1123	2562
Wolverhampton	1299	6262	2782	1690	230	1699	3876
Worcestershire	2619	14562	4836	3410	543	3773	8607
York	453	3798	1341	670	236	1120	2555
<b>Total</b>	<b>229109</b>	<b>1388275</b>	<b>477477</b>	<b>284160</b>	<b>59629</b>	<b>351894</b>	<b>802759</b>

**Appendix C: Lower and upper bounds for estimate as number and percentage of age group, and expected numbers from OPCS and FRS prevalences**

Local Authority	Lower bound	Lower bound %	Upper bound	Upper bound %	OPCS estimate: 3.2%	FRS estimate: 7.3%
Barking and Dagenham	1230	2.8	2042	5.4	1402	3197
Barnet	1585	2.4	2901	4.6	2378	5424
Barnsley	1345	2.9	2335	5.6	1565	3570
Bath & North East Somerset	797	2.7	1507	4.8	1107	2526
Bedfordshire	2185	2.9	4235	5.3	2938	6701
Bexley	1315	3.1	2617	5.7	1635	3730
Birmingham	8295	3.5	14820	6.8	8054	18374
Blackburn with Darwen	1035	2.7	1697	5.0	1242	2832
Blackpool	905	3.0	1463	5.6	960	2190
Bolton	1770	2.8	3055	5.5	1994	4548
Bournemouth	650	2.2	1095	4.2	925	2110
Bracknell Forest	535	2.8	1029	4.7	861	1964
Bradford	3475	2.8	5609	5.1	4010	9147
Brent	1205	2.8	2340	4.7	1827	4168
Brighton & Hove	1510	3.3	2679	6.6	1478	3373
Bristol	2485	3.1	4129	6.1	2522	5752
Bromley	1645	3.1	3202	5.5	2138	4876
Buckinghamshire	2376	2.8	4496	4.7	3635	8293
Bury	1115	2.9	2011	5.5	1363	3110
Calderdale	1130	2.9	2155	5.4	1453	3314
Cambridgeshire	3065	3.1	5716	5.5	3949	9008
Camden	894	3.1	1734	5.2	1258	2869
Cheshire	3441	3.1	6631	5.3	4672	10658
City of London	7	.3	7	.3	26	58
Cornwall	2865	2.7	4886	5.4	3350	7643
Coventry	2150	3.1	3593	5.9	2166	4942
Croydon	1810	2.3	3104	4.5	2538	5789
Cumbria	2480	3.1	4950	5.6	3238	7388
Darlington	640	2.9	1112	5.8	707	1613
Derby	1315	3.0	2539	5.5	1693	3862

Local Authority	Lower bound	Lower bound %	Upper bound	Upper bound %	OPCS estimate: 3.2%	FRS estimate: 7.3%
Derbyshire	3940	2.5	6891	5.0	5136	11717
Devon	3780	3.2	7157	5.8	4643	10592
Doncaster	1595	2.8	2951	5.2	2067	4716
Dorset	1825	2.7	3434	4.9	2598	5928
Dudley	1820	2.8	3198	5.5	2134	4869
Durham	3195	3.1	5553	6.1	3267	7453
Ealing	1350	2.6	2611	4.6	2064	4709
East Riding of Yorkshire	1420	2.5	2709	4.6	2128	4855
East Sussex	2695	3.3	5083	5.9	3341	7621
Enfield	1390	2.4	2652	4.5	2144	4891
Essex	6850	2.5	12200	4.9	9472	21608
Gateshead	1010	2.7	1822	5.2	1267	2891
Gloucestershire	2395	2.5	4700	4.4	3978	9074
Greenwich	1540	3.4	2916	6.4	1658	3781
Hackney	1205	2.9	2126	5.2	1642	3745
Halton	780	4.2	1555	6.9	890	2029
Hammersmith and Fulham	755	3.3	1360	5.2	976	2227
Hampshire	6585	2.5	11196	4.8	8867	20228
Haringey	1154	3.1	2284	5.3	1568	3577
Harrow	1030	2.6	1899	4.7	1546	3526
Hartlepool	615	2.9	969	5.1	678	1548
Havering	1200	2.4	2075	4.8	1587	3621
Herefordshire	880	3.1	1648	5.4	1174	2679
Hertfordshire	5600	2.3	9819	4.5	7744	17666
Hillingdon	1455	2.7	2749	5.3	1846	4212
Hounslow	1181	3.2	2351	5.6	1533	3497
Isle of Wight Council	835	3.0	1422	6.0	874	1993
Isles of Scilly	5	1.9	10	3.3	13	29
Islington	985	3.1	1707	5.9	1082	2467
Kensington and Chelsea	380	1.5	713	2.7	963	2197

Local Authority	Lower bound	Lower bound %	Upper bound	Upper bound %	OPCS estimate: 3.2%	FRS estimate: 7.3%
Kent	9260	3.0	15835	5.8	9923	22637
Kingston upon Hull	1515	3.1	2727	5.8	1779	4059
Kingston upon Thames	579	2.3	1154	4.1	1014	2314
Kirklees	2275	3.0	4252	5.5	2989	6818
Knowsley	1085	3.4	1919	6.3	1155	2635
Lambeth	1425	3.3	2487	5.9	1731	3949
Lancashire	6939	3.9	13404	6.5	8109	18498
Leeds	3420	2.2	5784	4.3	4906	11191
Leicester	1965	2.9	3415	5.8	2166	4942
Leicestershire	2830	2.8	5642	4.9	4291	9789
Lewisham	1640	3.1	2798	6.0	1805	4117
Lincolnshire	4220	3.6	8125	6.6	4499	10264
Liverpool	3110	3.4	4839	5.7	2861	6526
Luton	1280	2.7	2033	5.0	1494	3409
Manchester	3330	3.5	5474	6.5	3011	6869
Medway	2125	3.5	3424	6.4	1920	4380
Merton	957	3.5	1762	5.5	1293	2949
Middlesbrough	1325	4.1	2264	8.1	1027	2343
Milton Keynes	1130	2.9	2240	5.0	1744	3979
Newcastle upon Tyne	1825	3.4	2806	5.7	1677	3825
Newham	1655	2.5	2284	3.7	2102	4796
Norfolk	4775	3.2	8515	6.1	5197	11855
North East Lincolnshire	1115	3.7	2044	6.7	1168	2665
North Lincolnshire	920	3.6	1817	6.3	1107	2526
North Somerset	890	2.2	1489	4.2	1338	3051
North Tyneside	1070	3.4	2128	6.0	1286	2935
North Yorkshire	2365	2.1	4274	4.0	3974	9067
Northamptonshire	3740	3.0	7122	5.5	4890	11154
Northumberland	1770	3.1	3338	5.9	2000	4563
Nottingham	2085	3.7	2696	5.1	1786	4073

Local Authority	Lower bound	Lower bound %	Upper bound	Upper bound %	OPCS estimate: 3.2%	FRS estimate: 7.3%
Nottinghamshire	4350	2.7	5664	3.7	5171	11797
Oldham	1425	2.6	2233	4.5	1763	4022
Oxfordshire	2635	2.5	5138	4.4	4342	9906
Peterborough	1172	4.0	2342	7.0	1235	2818
Plymouth	1980	3.9	3243	7.1	1619	3694
Poole	635	2.4	1123	4.7	899	2051
Portsmouth	1015	2.9	1803	5.5	1235	2818
Reading	730	2.5	1225	5.0	931	2124
Redbridge	1266	2.5	2486	4.6	1942	4431
Redcar and Cleveland	1090	3.5	1805	6.6	976	2227
Richmond upon Thames	653	2.2	1238	3.8	1226	2796
Rochdale	1360	3.2	2466	5.9	1606	3665
Rotherham	1985	3.5	3204	6.2	1824	4161
Rutland	154	2.2	284	3.7	294	672
Salford	1615	3.4	2491	6.0	1488	3395
Sandwell	1655	2.4	2713	4.5	2166	4942
Sefton	1610	2.6	2638	4.8	1904	4344
Sheffield	3500	3.3	5588	6.0	3408	7775
Shropshire	1375	2.9	2690	5.2	1949	4446
Slough	660	2.8	1304	5.1	922	2102
Solihull	1135	2.6	2134	5.0	1466	3343
Somerset	2410	2.2	3776	3.9	3578	8161
South Gloucestershire	1280	2.5	2308	4.8	1808	4125
South Tyneside	875	3.4	1650	6.1	1014	2314
Southampton	1215	2.8	1788	4.8	1366	3117
Southend-on-Sea	1000	2.9	1785	5.6	1114	2540
Southwark	1545	3.4	2987	6.3	1738	3964
St Helens	945	2.6	1666	5.0	1258	2869
Staffordshire	4435	3.2	8647	5.8	5539	12636
Stockport	1730	3.6	3323	6.4	1955	4460

Local Authority	Lower bound	Lower bound %	Upper bound	Upper bound %	OPCS estimate: 3.2%	FRS estimate: 7.3%
Stockton-on-Tees	1440	3.4	2395	6.4	1370	3124
Stoke-on-Trent	1445	3.5	2699	6.2	1661	3789
Suffolk	4445	3.0	7434	5.7	4816	10987
Sunderland	1725	2.9	2969	5.6	1885	4300
Surrey	5492	3.1	10377	5.1	7597	17330
Sutton	1060	3.1	2089	5.7	1331	3037
Swindon	980	3.0	1836	5.3	1341	3059
Tameside	1320	2.7	2161	5.0	1558	3555
Telford and the Wrekin	1280	3.8	2349	7.1	1238	2825
Thurrock	970	3.8	1843	6.5	1146	2613
Torbay	930	4.2	1768	7.8	838	1913
Tower Hamlets	1345	3.2	2594	5.9	1568	3577
Trafford	1065	2.4	1954	4.6	1517	3460
Wakefield	2095	3.0	3415	5.4	2237	5103
Walsall	1515	2.5	2660	4.8	1933	4409
Waltham Forest	1411	3.7	2616	6.0	1670	3811
Wandsworth	1423	3.7	2648	6.3	1504	3431
Warrington	1245	3.9	2215	6.1	1389	3168
Warwickshire	2525	2.6	4706	4.9	3571	8147
West Berkshire	1142	4.0	1877	6.1	1133	2584
West Sussex	3820	3.2	7488	5.5	5219	11906
Westminster	631	2.3	1261	4.1	1066	2431
Wigan	1830	3.3	3396	6.0	2147	4898
Wiltshire	2220	2.4	3957	4.6	3251	7417
Windsor and Maidenhead	698	2.8	1183	4.3	1040	2373
Wirral	2570	3.7	4432	7.2	2211	5044
Wokingham	904	3.4	1524	5.2	1123	2562
Wolverhampton	1690	3.1	2989	6.2	1699	3876
Worcestershire	3410	3.0	6029	5.9	3773	8607
York	670	1.9	1123	3.6	1120	2555
Sum	288056		513269		351894	802759
Mean		3.0		5.4		

\* Lower bound = the greater of two figures: the number of children with a SEN statement or the number of children in receipt of DLA  
Upper bound = the sum of these two figures (see p39)

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