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**CAN WE COUNT THEM?**

**DISABLED CHILDREN AND THEIR**

**HOUSEHOLDS**

**Full Project Report to the ESRC**

**Award No: RES-000-22-1725**

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## **BACKGROUND**

The limitations of national data on disabled children and their families are widely recognised (Gordon *et al.* 2000; Office for National Statistics (2004); Prime Minister's Strategy Unit (2005). Currently a number of major policy and legislative developments make it essential to develop more robust local and national data on disabled children and their households. For example, the National Service Framework for Children, Young People and Maternity Services (Department for Education and Skills [DfES] and Department of Health [DH], 2004) set standards for service provision for disabled children and young people of all ages across the next decade; the Children Act 2004 re-organised the way that local services to all children, including those who are disabled, should be delivered; the Disability Discrimination Act (DDA) 2005 introduced the new Disability Equality Duty. These initiatives have implications for disabled children and their families and require strategic planning and service development based on sound evidence.

## **OBJECTIVES**

The objectives were to:

1. Scope existing quantitative national and regional data sets on disabled children.
2. Consider their strengths and limitations with particular reference to prevalence, trends and socio-demographic characteristics of disabled children and their households.
3. Undertake a detailed analysis of data from the Family Resources Survey (FRS) (2004-5) and the Families and Children's Study (FACS) (2004-5) as an exemplar of the wider range of issues in the scoping study and to generate new information on this population.
4. Inform the future development of more robust childhood disability data.

## **DESIGN AND METHODS**

An Advisory Group of nominees from the Department for Work and Pensions, DfES, Disability Rights Commission, DH, Commission for Social Care Inspection, Contact a Family and Council for Disabled Children was convened to provide expert advice on various aspects of the study<sup>1</sup>.

The three elements of the study are described below.

### **1. Consultation exercise**

In addition to the six members of the advisory group, ten key stakeholders participated in a consultation exercise using a structured topic guide. Information from this, with that generated by the Advisory Group and the research team, was used to identify what were considered to be major data sources and key criteria to be used in the review of data.

### **2. Quality assessment of data sources**

Data sets were included if they contained information on disabled children aged 18 or under from the year 2000<sup>2</sup>. The data sources were described and evaluated with reference to:

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<sup>1</sup> A full glossary of terms and abbreviations can be found in Annex 1.

<sup>2</sup> Data from research studies on disabled children and their households were not included in this project.

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- Disability definitions and questions
- Study design
- Population coverage
- Sampling issues
- Social and demographic data
- Appropriateness for identifying childhood as opposed to adult disability

### **3. Secondary data analysis**

Secondary analysis was carried out to:

- Generate prevalence estimates of childhood disability by age, sex and sub-category (function in FRS; body system and medical diagnosis in FACS);
- Describe the social, demographic and economic characteristics of households with disabled children;
- Examine whether disabled children live with disabled adults;
- Examine associations between social, demographic and economic circumstances and childhood disability.

Frequency distributions and cross-tabulations were run to establish prevalence estimates<sup>3</sup>, and describe the circumstances of children. To examine living standards using the FRS data, a deprivation index was constructed from all the items included in Annex 4: Table 8. A score of 1 was given if an item was considered wanted or needed but could not be afforded and the scores summed to give a total score for the number of items lacked.

To examine associations between childhood disability and social and demographic circumstances, logistic regression models were fitted on the dependent variables 'DDA defined disability' in FRS, and LSI in FACS, before and after adjustment for demographic variables. The independent variables consisted of:

- age of child (0-4, 5-11, 12-15, 16-18) – FRS and FACS;
- sex of child – FRS and FACS;
- ethnic group of head of household (white v black/minority ethnic/mixed parentage) – FRS and FACS;
- number of adults in the family unit (1 v 2 or more) – FRS and FACS;
- number of dependent children in the family unit (2 v 3 or more) – FRS and FACS;
- number of adults with a DDA defined disability in FRS and LLSI in FACS in family unit (1 v 2 or more);
- housing tenure (owner occupied v rented/other) – FRS and FACS;
- income in quintiles – FRS and FACS;
- number of items and activities wanted but not afforded (none v 1 or more) – FRS only;
- number of debts (none v 1 or more) – FRS only;
- age respondent left full time education (19+, 17-18, 16 or less) – FACS only;

Bivariate direct logistic regression analyses were used to produce odds ratios with 95% confidence intervals. Housing tenure was chosen for entry into the multivariate

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<sup>3</sup> To establish national and regional prevalence estimates of disability from sample counts, the grossing factors supplied for each survey were used to adjust for non-response and for population estimates for individual countries.

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direct logistic regression analyses for FRS and FACS as it was the social and material variable most strongly associated with the childhood disability in the bivariate analysis. Age respondent left full-time education was also entered into the multivariate model in FACS as the association with childhood disability may be different for education compared with other social and material variables (White et al, 1999). All the remaining demographic factors were entered into multivariate direct logistic regression analyses. The number of dependent children in the family unit was not significant in the bivariate analysis but was included in the multivariate analysis as it has been shown to be an important determinant of poverty in households with children (DWP, 2003). For each factor a baseline odds of 1.0 was set for those in the most advantaged group.

## RESULTS

### 1. Consultation Exercise

Participants identified 16 data sets, of which 15 were included in the quality assessment. Participants' views on strengths and limitations of data informed the quality assessment criteria. There was confirmation among participants of the importance of developing more robust data on disabled children and on the limitations and confusion that currently exists. Access to reliable data was identified as difficult and essential<sup>4</sup>.

### 2. Quality Assessment of Data Sets

In total 37 data sets were identified and 30 were evaluated. Data sets identified but not included are listed in Annex 5. Data sets were reviewed in relation to their capacity both to generate useful prevalence estimates of childhood disability and to capture important characteristics of disabled children's lives. While the collection of data in relation to disabled children and their households is susceptible to all the influences acknowledged to be important in data collection generally, this report focuses on factors that impact specifically on data collection on this population. Although our review included administrative data sets, and we comment where appropriate, we give less attention to these sources as they do not purport to give comprehensive coverage of the whole population of disabled children.

In reviewing data sources we were reminded of the contested assumption that individual impairments are the primary determinant of social and personal restriction. Our reportage of the definitions used in no way implies the research team's acceptance of this. In many instances, the language used reflects that employed in the surveys and their reports.

In this section of the report we provide an overview of the main issues raised by the review. Each data source is described in Annex 3.

#### Disability definitions and questions employed<sup>5</sup>

Prevalence estimates and information on disabled children's characteristics and circumstances vary according to the disability-related definition that is employed.

The review established that the concepts of longstanding and limiting longstanding illness (LSI & LLSI) are frequently used as definitions in government surveys and the Population Census. The LSI question identifies children with a range of illnesses and

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<sup>4</sup> Annex 6 gives details of how to access key data sets.

<sup>5</sup> Annex 2 contains definitions of disability and questions used in major data sources.

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conditions from mild asthma to severe impairment. Its value lies in its inclusiveness and ability to capture a wide range of health problems and impairments. Its limitation however, if used alone, is its inability to identify the degree to which a child's life is seen to be limited as a consequence of living with impairment. Many surveys employ the additional concept of LLSI, which seeks to identify whether a child's activities are limited by their LSI.

Recently, some surveys (FRS and Labour Force Survey [LFS]) have attempted to encompass a definition of disability derived from the DDA (see Annex 2). The FRS is currently the only major data source capable of providing 'DDA-defined' prevalence estimates across the age range 0-15 years while the LFS is capable of providing these and other data on 16-19 year olds.

The major surveys appear to classify limitations and impairments further in two main ways: by function or system. Different systems of sub-classification limit comparison between surveys and frequent changes of disability questions hamper estimates of prevalence trends.

Our review identified that none of the data sets have refined ways of establishing the *extent* of the limitation experienced by the child. Of the main government sponsored surveys, only the GHS collects any information on this by asking respondents to report on whether their children's activities are 'limited' or 'strongly limited' by an illness or disability.

There are a number of other data sources which include large numbers of disabled children but which employ other definitions that reflect the purposes for which the data is routinely collected and the specific population of children concerned. These include data sets relating to schools, local authority children's social services and sentinel conditions. While these sources are not able to provide overall estimates of childhood disability prevalence, they are likely to be valuable for some purposes.

### Study design

Data on disabled children are collected using a number of designs. Of the data sets evaluated, 9 were cross-sectional surveys, 9 panel and cohort studies, 7 administrative databases, 4 sentinel condition databases and 1 was another type. Some data sets are not easy to classify. For example, while it might be appropriate to regard the Family Fund Trust database as an administrative data source, its unique history and characteristics make it almost a stand alone.

Of the government sponsored population surveys (cross-sectional and longitudinal) reviewed none are designed specifically for the purpose of collecting data on childhood disability. As a result, the information they collect on disabled children and their households is limited.

Cross-sectional designs appear to have the most cost-effective and appropriate design for estimating disability prevalence as they tend to have higher response rates than other designs (Purdon, 2005). As the majority of government sponsored surveys have a repeated cross-sectional design, they are able to provide up-to-date prevalence estimates and allow prevalence trends to be identified. While cross-sectional studies can identify associations, for example of childhood disability with socio-economic circumstances, longitudinal studies are required in order to identify distal factors and causal relationships, as well as to give a lifecourse dimension to the experience of children and families.

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The panel studies (FACS & British Household Panel Study [BHPS]) also enable annual prevalence and trend estimates to be made as well as collecting longitudinal data from which causal inference is possible though these are susceptible to attrition. The reviewed longitudinal cohort studies, tracking children from birth or early childhood, have the potential to provide valuable data, particularly related to the life course influences on childhood disability and the disability trajectory. Their value as sources of disability prevalence estimates across the whole of childhood is limited because estimates are only possible up to the age of the child at the time of last data collection. The strength of the 1958 and 1970 British Cohort Studies lie in their potential to offer insights into the dynamics and trajectories of disability by tracking the life course of disabled children into adulthood.

In addition to the issues identified earlier, our review suggests that some are unsuitable for generating global prevalence estimates. For example, the Children in Need census records only those disabled children in contact with Local Authority Children's Social Services at the time of the census and the published report specifically states that the data should not be used for prevalence estimation (DfES, 2005). The National Registers of Deaf, Hard of Hearing and Sight Impaired are not comprehensive in coverage (DH, 2004, 2006). The UK Cerebral Palsy register, that collects data from 5 UK regions, is likely to be a more reliable source of prevalence estimates of cerebral palsy as carefully monitored systems for case attainment and reporting have been established.

The majority of the data sets collect information on children by proxy from adults: they do not seek information from children themselves. Exceptions are the Health Survey for England (HSE), the Home Office Citizen Survey (HOCS) and the Avon Longitudinal Study of Parents and Children (ALSPAC). However, none of these sources collect information on disability from children.

#### Population coverage

As data sets cover different populations of children, users need to be aware of population coverage in terms of geography, age and place of residence. Some sets collect UK-wide data (for example, FRS, LFS, Population Census, BHPS and the Millennium Cohort Study [MCS]), some are limited to GB (for example, the General Household Survey [GHS]), some are confined to one of the home nations, (e.g. the Continuous Household Survey covers Northern Ireland only), while others are regionally based (e.g. ALSPAC). Most government sponsored survey and administrative sources allow regional prevalence estimates to be generated. The review established that population coverage is not always immediately clear to data users.

Coverage of age range also varies. The review suggested that because of the definition of 'dependent children' used in some surveys, some age groups of children may not be covered. For example, the FRS does not classify as dependent children, 16-18 year olds who are not living at home and not in full time non-advanced education. More accurate estimates of DDA-defined disability and LLSI in this age group are likely to come from the LFS and the BCS. The Population Census however, aims to cover the whole age range of children.

The population coverage for most of the data sets reviewed is confined to children living in private households. The Population Census however, does cover both private and institutional settings. Prevalence estimates derived from sources relating to private households may not collect data on some children living elsewhere, for example in residential establishments. In addition, some who are 'looked after' by the

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local authority and are away from home, may not be appear at all as *disabled* children in the LAC censuses due to the coding system. The complexity of collecting data on all disabled children living away from home for all or part the year is well recognised (DfES 2005).

Some data sets do not cover the whole population of disabled children. The FFT database, for example, only covers children with high support needs from low income families applying for grant aid from the Trust. Although this source is sometimes used to generate prevalence estimates, these are unlikely to be generalisable to the wider population of disabled children. However, the FFT data is a rich source of information on this population of severely disabled children and their circumstances.

### Sample issues

We reviewed the data sets to establish sample size, response rate and weighting as these are established factors influencing sample representativeness, which in turn affects the reliability of prevalence estimates derived from them. There appears to be considerable variation in sample size and response rates. As prevalence of disability among children is low, the sample of children needs to be relatively large in order to generate a sub-sample of disabled children large enough to minimise bias in prevalence estimates. For example, the FRS with 16,000 children, only generates a sub-sample of 1400 children who would be considered disabled under the DDA.

Although some government sponsored surveys have sample sizes adequate for estimating overall prevalence, they are less reliable for generating estimates for sub-groups of disabled children with reference to, for example, specific types of impairment, and minority ethnic status. Some surveys, for example, the HSE 2004, the MCS and the Longitudinal Study of Young People in England, overcome this by over-sampling population sub-groups.

The responses rates in the key surveys reviewed varied from 61% to 97%. Many of the surveys adjust sample counts both for non-response and for population estimates using grossing factors so that national disability prevalence estimates can be generated. The longitudinal cohort studies do not use weighting variables so it can not be assumed that they generate accurate national prevalence estimates.

### Social and demographic data

Most of the data sources are limited in their collection of social and demographic data that enables the circumstances of this population to be described. Of the cross-sectional, panel and longitudinal surveys, the FRS and FACS are richer sources of information on the circumstances of disabled children (see secondary analysis) as they contain detailed data on income, living standards, demographic characteristics and caring circumstances at the household (FRS) and family level (FRS and FACS). Data collection on social and demographic circumstances is much more limited in administrative data sets.

### Child specific questions

Many surveys ask the same questions of both adults and children to ascertain information on illness and disability. As a result they do not take account of the way in which the age and developmental of the child shapes experiences, functioning and abilities. Of the cross-sectional surveys, only the FRS and HSE, take account of the child's developmental stage in the questions asked about LSI and LLSI (by asking respondents to exclude any difficulties a child of that age could be expected to have). The cohort studies more commonly employ child specific questions. The MCS and the Growing Up in Scotland are those currently most sensitive to children's

development as they specifically ask if the disability limits the child 'at play or from joining in any other activity normal for the child's age'(see Annex 2).

### 3. Secondary data analysis

Secondary analyses of the FRS and FACS was undertaken to exemplify some of the issues raised in the quality assessment exercise and to generate up-to-date information on the circumstances of this population. The surveys have the capacity to illuminate issues relating to the estimation of prevalence and the circumstances of disabled children and their households in different ways. Here we report prevalence estimates from both surveys but utilise the FRS to demonstrate how changing definitions of disability and modification to survey questions can shape prevalence estimates. As the FRS has been modified to enable information to be collected on 'DDA-defined disability', it is used to describe the circumstances of children who would be defined as disabled in law, under the DDA 1995 and 2005. Both data sets are used to examine the relationship between child and adult disability and childhood disability and social and material circumstances. Tables and figures can be found in Annex 4.

#### Prevalence estimates

- Estimates for LSI derived from FACS and FRS have remained fairly stable over time (Figure 1). The FACS has consistently identified a higher proportion of children with LSI than the FRS. This is likely to be attributable, at least in part, to differences in the survey design and process.
- In 2004/5, 5.1% of children ages 0-18 were reported as having a limiting longstanding illness (FRS, Table 1).
- In 2003/4, in addition to identifying the proportion of children with a LLSI, the FRS sought to provide a measure of the number of children afforded rights under the DDA. In the 2003/4 survey, a child was categorised as having a 'DDA defined disability' if they had any illness, disability or infirmity which has 'troubled' them over a period of time and resulted in significant difficulties with normal day-to-day activities (see Table 1). For both 2003/4 and 2004/5, the percentage of children with one or more significant difficulties was similar.
- It was made more DDA compliant in the 2004/5 survey by the addition of a further question to establish whether, without medication, the child would have significant difficulties with normal activities. Using this more inclusive measure increases the prevalence estimate by almost two percentage points and 250,000 children in 2004/5 (Table 1). This illustrates how changes to disability definitions can affect prevalence estimates.
- Both the FRS and FACS show that the prevalence of disability is higher among boys than girls, and lowest among children of both sexes age under 5 years of age (Table 2).
- Both FRS and FACS had small sample sizes of disabled children from Black and minority ethnic groups (FRS: n=90; FACS: n=128), hence disability prevalence estimates for individual groups from these sources for these groups should be used with caution. The logistic regression analysis indicated that when demographic and social factors were controlled for, the odds of being disabled was greater for children from 'White' ethnic group/s than those from Black and minority ethnic/other groups (Table 9).



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- The FRS classifies impairments by functional difficulty (with mobility, lifting, communication etc.). Difficulties with memory or ability to concentrate, learn and understand are the most commonly reported impairments. Difficulties more commonly reported in boys than girls include difficulty with manual dexterity; communication; memory, concentration and learning; recognising physical danger; physical coordination (Table 3).
- The FACS adopts primarily an approach based on affected system and identifies that the most commonly reported LSI's are respiratory (chest and breathing problems, asthma and bronchitis) and skin conditions and allergies (Table 4).
- Both surveys are very limited in terms of the measurement of the extent of any limitation or magnitude of any difficulty experienced by the child: the FRS has no measure and FACS asks only about the whether 'problems affect ability to attend school or college regularly'.
- The FRS suggests that the highest prevalence of DDA-defined disability is found among children in Wales (9.8%) and East Midlands (9.0%) and the lowest prevalence in London (5.8%) and the Eastern Region (6.0%) (Table 5).
- FACS show that the highest prevalence of LSI is found among children in Scotland (16.9%) and the South West (16.5%) and the lowest among those in London (11.7) and the East Midlands (13.7%) (Table 5).

#### Circumstances of disabled children

In view of word limit constraints, this section offers a brief analysis of key data on the circumstances of disabled children and their households from the FRS. More in-depth analyses will be reported in publications currently in preparation in peer-reviewed journals.

#### *Who do disabled children live with? (Tables 6 and 9)*

- Two thirds (64%) live in families with two parents and one third (34%) live in lone parent families. The proportion living in lone parent families is greater than that for non-disabled children (26%) ( $p < 0.0001$ ).
- On average, disabled children, like their non-disabled counterparts, live in families with a total median number of two children.
- There is an association between childhood disability and living with a disabled adult, regardless of the adult or child measure of disability. The proportion of disabled children living with a disabled adult was approximately twice that of non-disabled children.
- The association between childhood disability and living with a disabled adult remains when other factors were controlled for. For children with a DDA-defined disability, the odds of living with a parent with a DDA-defined disability were three times greater than for non-disabled children (Table 9).

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### *Housing circumstances (Table 6)*

- Almost half (47.4%) of disabled children live in rented accommodation, compared to a third (33.3%) of non-disabled children ( $p < 0.0001$ ).
- On average however, disabled children live in homes with fewer rooms than non-disabled children ( $p < 0.0001$ ).

### *Income (Table 6)*

- The median (unequivallised) total weekly income for a family unit with a disabled child was £475.00. This compared to £543.00 for family units with no disabled children.
- Among families with disabled children, the presence of one or more adults with a DDA-defined disability in the family appeared to lower median income (no disabled adults: £433.00, one or more disabled adults: £513.00;  $z = -4.04$ ,  $p < 0.0001$ ).
- The lowest median income was among lone parent families with disabled children (£300.50).
- Almost a quarter (22.5%), of the income of families with a disabled child/ren was made up of benefits compared one-tenth (11.2%) to those of able bodied children. For lone parent households with disabled children this rose to 55%.

### *Deprivation and debt (Table 7 and 8)*

- On almost every measure parents of disabled children are more likely than those of non-disabled children to report not being able to afford items and activities they want or need, and doing without items most people agree people ought to have (Table 7).
- The median total deprivation score for families with disabled children (2.00) was higher than that for other families (1.00) ( $z = -8.690$ ,  $p < 0.0001$ ) suggesting greater deprivation.
- A greater proportion of families with disabled children than those with non-disabled children reported having one or more debts: 26.7% compared to 16.2% (Table 8). Almost one third (30.6%) of families with both disabled children and disabled adults had debts.
- Being behind with payments for council tax, water rates and telephone bills were the most common source of debt for families with disabled children.

### Relationship between childhood disability and social and material circumstances

The main findings from the logistic regression analyses were as follows and are shown in Table 9:

- Older children and boys had greater odds of having a DDA-defined disability and LSI than children 0-4 and girls. DDA-defined disability appears to be more strongly associated with age and sex than LSI.

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- Black and ethnic minority children had lower odds of being reported to have a DDA-defined disability and LSI than white children.
- Children in lone parent families had greater odds of being reported to have a DDA-defined disability or LSI. However, the associations are reduced in multivariate analysis.
- Number of dependent children is not associated with either measure of childhood disability.
- For children living in households with one or more adults the odds of being reported as having a DDA-defined disability or LSI were two times greater than for those without disabled adults in the family even after adjustment for other variables.
- Children living in more materially disadvantaged families measured by a range of variables had greater odds than other children of having a DDA defined disability or LSI. The association with housing tenure was reduced in multivariate analysis but remained significant in both studies.
- In FACS, education level of the respondent was associated with reported LSI. The association was reduced in the multivariate analysis but remained significant for the lowest education group.

## CONCLUSIONS: KEY POINTS

- Users' access to reliable data was identified as essential but difficult.
- Prevalence estimates vary from 5% to 18% depending on the definition/measure used.
- Users need to choose a measure from a data source that is 'fit for purpose'. By this, we mean an estimate from a source covering the group of children they are interested in and is capable of giving them the particular kind of information they want.
- As a measure of disability, LSI is a poorer measure of disability than LLSI and DDA-related measures.
- Different sub-classifications limit comparison between surveys.
- No data sets have *refined* ways of established the *extent* of restriction experienced by a child.
- Currently, no survey is designed specifically to collect data on the whole population of disabled children.
- Most administrative sets cannot provide reliable or representative prevalence estimates or data on disabled children.
- Many data sources are limited by their population coverage for example, in terms of age, geography, size of sub-groups and place of residence.
- Very few sources collect detailed data on a child's social and demographic circumstances.
- No surveys collect information on disability from children themselves and few take account of how the age and development of children may shape functioning and ability.
- Disabled children and their families currently live in markedly poorer living standards than other children.
- For disabled children, the odds of living with a disabled adult are greater than for non-disabled children.

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## ACTIVITIES

### **National dissemination conference (University of Warwick, 14 March 2007)**

It was attended by 95 key stakeholders and data users from local authorities, NHS Trusts, Central Government Departments (DWP, DH, DfES), organisations representing the interests of disabled children and adults, carers' organisations and universities. See Annex 7 for conference programme.

### **Conference attendances**

- International Conference on Child Cohort Studies, St. Catherine's College, Oxford, September 2006 for networking and to gather information on international data sets;
- Disability Studies Association Conference, University of Lancaster, 18-20 September 2006: to give paper and to recruit participants to the project consultation exercised;
- Nordic Network on Disability Research Conference, Gothenburg, 10-12 May, 2007: to give paper and to make international links ;
- University of Oxford and Oxford Brookes University, Invited International Symposium, Researching children's health: implications of the WHO International Classification of Functioning, Disability and Health, Oxford, July 4-5 2007: invited to share the relevance of research project to WHO's international classifications.

## OUTPUTS

### **Publications**

One paper has already been published (see below). Others will be submitted to peer reviewed international journals as well as publications for practitioners and service providers.

Blackburn, C., Read, J. and Spencer, N. (2006) Can we count them? Scoping data sources on disabled children and their households in the UK. Child: Care, Health and Development: 33, 3, 291-295.

### **Conference papers**

Disability Studies Association International Conference, University of Lancaster, September 18-20 2006: Read, J, Blackburn, C. and Spencer, N.: Data on disabled children and their households: scoping the problem.

Nordic Network for Disability Research International Conference, Gothenburg, 10-12 May 2007: Blackburn, C., Read, J. and Spencer, S: Building better data sources on disabled children.

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## **Web-based user guide**

As stated in the project proposal, a web-based user friendly guide to data sets on disabled children and their households is planned and due to be piloted with a range of users and stakeholders in May/June 2007.

## **IMPACTS**

A number of individual service providers and planners have sought and used our advice on estimating disability prevalence in children in their local areas. We were also consulted by The Treasury as part of its review of services for disabled children. The dissemination conference was attended by a substantial number of service providers and planners responsible for provision for disabled children and their families.

## **FUTURE RESEARCH PRIORITIES**

Further work is planned to:

- Evaluate the approaches taken to the collection of childhood disability data in other countries;
- Explore the meta analysis of prevalence estimates;
- Explore opportunities for secondary analysis of Population Census and GHS;
- Further secondary analysis of the Family Resources Study data on the caring circumstances of families with disabled children.

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## **Annex 1: Glossary of Abbreviations**

ALSPAC – Avon Longitudinal Study of Parents and Children  
ASD – Autistic Spectrum Disorder  
BCS – British Crime Survey  
BHPS – British Household Panel Survey  
BME – Black and minority ethnic  
CSCI – Commission for Social Care Inspection  
CP – Cerebral Palsy  
DCMS – Department for Culture, Media and Sport  
DDA – Disability Discrimination Act  
DfES – Department for Education and Skills  
DFP – Department of Finance and Personnel, Northern Ireland  
DH – Department of Health  
DRC – Disability Rights Commission  
DS – Down’s Syndrome  
DWP – Department of Work and Pensions  
EBD – Emotional and Behavioural Disorders  
EMIS – Egton Medical Information Systems  
ESRC – Economic and Social Research Council  
Eurostat – European Statistics  
FACS – Families and Children’s Study  
FFT – Family Fund Trust  
FRS – Family Resources Survey  
GHS – General Household Survey  
GPRD – General Practice Research Database  
GUS – Growing up in Scotland cohort study  
HOCS – Home Office Citizenship Survey  
HSE - Health Survey for England  
IRC – Inland Revenue and Customs  
ICD10 – International Classification of Disease 10<sup>th</sup> revision  
LFS – Labour Force Survey  
LLSI – Limiting Longstanding Illness  
LSI – Longstanding illness  
LSYPE – Longitudinal Study of Young People in England  
MCS – Millenium Cohort Study  
NCDS – National Child Development Study (1958 British cohort study)  
ODPM – Office of the Deputy Prime Minister  
ONS – Office of National Statistics  
PLASC – Pupil Level Annual Schools Census  
PMSU – Prime Minister’s Strategy Unit  
SEN – Special Educational Needs  
SEH - Survey of English Housing  
SES – Socio-economic Status  
SNHL – Sensori-neural Hearing Loss  
SSNS – Scottish Support Needs System

## **Annex 2: Definitions of disability and questions used in major data sources**

### **Definitions of disability**

#### **Disability Discrimination Act 1995**

Subject to the provisions of Schedule 1, 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.

#### **Children Act 1989**

Section 17(11) of the Act defines a disabled child as being:

Blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and in this Part – ‘development’ means physical, intellectual, emotional, social or behavioural development; and ‘health’ means physical or mental health.

### **Questions used in major data sources**

#### **DDA-related disability**

##### FRS, 2004/5

*Does [child's name] have any illness, disability or infirmity? By long-standing I means anything that has troubled [child's name] over a period of time or that is likely to affect him/her over a period of time?*

If yes, the following is asked:

*Does this physical or mental illness or disability limit [child's name] in any way?*

*Does this/these health problem/s or disability/ies mean that [child's name] has significant difficulties with any of these areas of his/her life? Exclude difficulties that you would expect for a child of that age.*

- *Mobility, lifting/carrying, manual dexterity, continence, communication (speech, hearing, eyesight), memory/ability to concentrate or understand, recognise if in physical danger, physical coordination, other problem or disability, none of these*

*Can I just check, does [child's name] take medication without which their health problems (when taken together) would significantly affect their life in the areas we have been discussing?*

##### LFS 2005:

*Do you have any health problems or disabilities that you expect will last for more than a year?*

If yes:

*Do these health problems or disabilities, when taken singly or together, substantially*



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*limit your ability to carry out normal day to day activities? If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment.*

### **Limiting longstanding illness:**

#### **FRS 2004/5**

*Does [child's name] have any illness, disability or infirmity? By long-standing I means anything that has troubled [child's name] over a period of time or that is likely to affect him/her over a period of time?*

If yes, the following is asked:

*Does this physical or mental illness or disability limit [child's name] in any way?*

#### **GHS 2005**

*Does [name] have any longstanding illness, disability or infirmity? By longstanding I mean anything which has troubled [name] over a period of time or that is likely to affect him/her over a period of time?*

If yes:

*What is the matter with [name]? (classified according to symptoms into ICD10 system groups – neoplasm & benign; endocrine & metabolic; mental disorder; nervous system; eye complaints; ear complaints; heart & circulation; respiratory; digestive system; genito-urinary; musculoskeletal; infectious; blood; skin; other complaints)*

*Does this illness or disability limit [name] in any way?*

If yes:

*Now I'd like you to think about the 2 weeks ending yesterday. During this 2 weeks, did [name] have to cut down he/she normally does (at school or in his/her free time) because this/these illness or injury?*

#### **Census 1991**

*Does child have any long term illness, health problems or handicap which limits child's daily activities or work child can do?*

#### **Census 2001**

*Does child have any long term illness, health problems or disability which limits child's daily activities or work child can do?*

#### **GUS 2007**

*Does child have any longstanding illness or disability? By longstanding I mean anything that has troubled child over a period of time or that is likely to affect child over a period of time?*

If yes:

*What is the illness or disability?*

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*Does this (do these) condition(s) or health problem(s) limit child at play or from joining in any other activity normal for a child of his/her age?*

*Does child have any other longstanding illness or disability?*

MCS 2003/5

*Does child have any long-term conditions that have been diagnosed by a health professional? By long-term I mean anything child has had for at least 3 months or is expected to continue for at least the next 3 months.*

If yes:

*What is the condition?*

*Does this limit the child at play or from joining in any other activity normal for a child of his/her age?*

### Annex 3: Key features of data sets reviewed

Data set (latest year) [Sponsor/s]	Disability Definitions & questions used	Child specific questions used	Study design & frequency	Child Population coverage	Sample size	Response rate & weighting	Proxy interviews & data collection mode	Social & demographic data	Estimates	Comments
<b>Cross-sectional surveys</b>										
Family Resources Survey (FRS) (2004/5) [DWP]	DDA-related LLSI by function	Yes	Annual cross-sectional since '93	UK (since '02). Children 0-18 [single living at home & in non-advanced education] Institutions excluded	16,000+ 0-18 in 28,041 households [900+ with LLSI]	62% overall in 2004/5 Weighted	Yes – adult respondent on behalf of children Face-to-face interviews	Child's age, sex, ethnicity, lone parent household + range of SES measures*	2004/5: DDA-related 7.3% LLSI 5.1%	Only major survey with DDA-related data on children 0-18
Population Census (2001) [ONS]	LLSI – not sub-classified	No	Every 10 years – cross-sectional	UK. 0-18. Institutions included	Entire UK population	96% estimated	Yes – main respondent on behalf of children. Self-completion postal return form	Child's age, sex, ethnicity, lone parent household + limited SES measures	LLSI 4.5%	Under-enumeration of residents in inner-city areas
General Household Survey (GHS) (2004/5) [ONS, DH, ODPM, DCMS, DWP, IRC, DfES, Scottish Executive]	LSI and LLSI by affected system (ICD10)	No	Annual cross-sectional since '71	GB. Children 0-18 [single living at home & in full time education] Institutions excluded	4,000+ 0-18 in 8,000+ households [800+ with LSI]	71% in 2002 Weighted	Yes – parent/main carer on behalf of child/ren Household questionnaire Face-to-Face interviews	Child's age, sex, ethnicity, lone parent household + range of SES measures	LSI 18% LLSI 7%	Long-standing serial cross-sectional survey

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Data source (latest year) [Sponsor/s]	Disability Definition questions used	Child specific questions used	Study design & frequency	Child Population coverage	Sample size	Response rate & weighting	Proxy interviews & data collection mode	Social & demographic data	Estimates	Comments
Continuous Household Survey (CHS) (2005/6) [DFP (N. Ireland)]	LSI and LLSI by affected system (ICD10)	No		Annual cross-sectional since '83	1,381 0-15 in 2000+ households [110 with LLSI]	67% in 2005/6 Weighted	Yes – parent/ main carer on behalf of child/ren Household questionnaire Face-to-Face interviews	Child's age, sex, ethnicity, lone parent household + range of SES measures	LLSI 8%	Compatible with GHS
Health Survey for England (HSE) (2004 – focus on Children & Young People in 2002) [DH]	LSI & LLSI by affected system (ICD10)	Only in 2002 survey	Annual cross-sectional since '91	England. Children 0-18 [single 16-18 in full-time education]. Institutions excluded	11,000+ 0-16 in 2002 survey focusing on Children & Young People 4000+ 0-16 in '04	66% in 2004 Weighted	Yes – parent/ main carer on behalf of children <13 Children 13+ - self-reporting. Face-to-face interviews Self-completion Clinical measures	Child's age, sex, ethnicity, lone parent household + range of SES measures	LLSI 8% (2002)	Over-sampling of BME children in 2004
British Crime Survey (BCS) (2005/6) [Home Office]	LSI & LLSI – no sub-classification	Not Applicable	Annual cross-sectional since '01/'02 Biennial '82-'01	England & Wales. 16-19 year olds. Institutions excluded	3800 16-24 in 2005/6	75% Weighted	No Face-to-face	Age, sex, ethnicity, + range of SES measures	Not reported in 16-19 age group	Potential source of disability data on 16-19 year olds

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Data set (latest year) [Sponsor/s]	Disability Definitions & questions used	Child specific questions used	Study design & frequency	Child Population coverage	Sample size	Response rate & weighting	Proxy interviews & data collection mode	Social & demographic data	Estimates	Comments
Labour Force Survey (LFS) (2005/6) [ONS, Department of Finance & Personnel, NI]	Limitations on type & amount of work can do LLSI by affected system DDA-related disability	Not Applicable	New cross-section of households selected each quarter (wave 1) & all adults reinterview in next 4 quarters (waves 2-5)	UK. 16-19 year olds. Institutions excluded	6000+ 16-19 among 80,000 individuals in 60,000 households	70% Weighted	Yes – for those living away from home in boarding schools etc. Face-to-face first interview with telephone interview subsequent waves	Age, sex, ethnicity, + range of SES & work-related measures	Not reported in 16-19 age group	Potential source of disability data on 16-19 year olds
Home Office Citizenship Survey (HOCS) (2005) [Home Office]	LLSI – no sub-classification	N/A	Biennial cross-sectional since '01	England & Wales Adults 16+ Sub-sample of young people 11-15 & children 8-10 Institutions excluded	9,600 adults in core sample & 4,600 in booster BME sample 1600+ 11-15 1000+ 8-10	64% in '03 Weighted	Yes – adult respondent on behalf of all children & those living outside home Adult, young person & child questionnaires	Child's age, sex, ethnicity + range of SES measures	No published estimates identified	Young persons' & children's questionnaires have no disability questions
Survey of English Housing (SEH) (2004/5) [ODPM]	Serious medical condition or disability Need for housing adaptation	No	Annual cross-sectional since '93	England. Children 0-18 [single 16-18 in full-time education]. Institutions excluded	5000+ households with children in 2004/5	67% in 2004/5 Weighted	Yes – main household respondent on behalf of all children Face-to-face	Child's age, sex, ethnicity, lone parent household + range of SES measures	Estimated 57,000 0-15 year olds with medical condition or disability needing adaptation	Source of data on those needing adapted housing & wheelchair users

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<b>Panel &amp; longitudinal studies</b>										
Families & Children's Study (FACS) (2004) [DWP]	LSI by system affected (ICD10)	No	Annual Panel since '99 – only representative from '01	GB. Children 0-18 [17-18 in full-time education] Institutions excluded	13,000 0-18 [2000 with LSI]	81% in 2004 Weighted	Yes – parent/main carer on behalf of child Face-to-face interviews Self-completion questionnaire (11-15 years)	Child's age, sex, ethnicity, lone parent household & range of SES measures	LSI 15.0%	Panel study focusing on children & their families. No DDA disability or LSI
British Household Panel Survey (BHPS) (2005) [ESRC ONS Eurostat]	LSI & LLSI by affected system & function – only 16+ For 0-15 year olds, respondent asked if caring for sick or disabled No disability questions in youth q're	No	Annual panel since '91	UK since '02. Children 0-18 [16+ interviewed] Institutions excluded	2400+ 0-15 in '04	87% in '04	Yes – parent/main carer on behalf of children 0-15 Face-to-face Self-completion Youth q're (11-15)	Child's age, sex, ethnicity, lone parent household & range of SES measures	No published estimate identified	Potentially rich data source on 16-18 year olds but limited <15

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Longitudinal Study of Young People in England (LSYPE) (2006) [DfES]	LSI SEN FRS DDA-related question to be added in '07	No	Annual interviews planned to age 25	England – 13-14 year olds sampled in Wave 1 ('04). BME & deprived oversampled	15770 '04 13539 '05 12435 '06	Attrition rate 21% by '06	No Face-to-face	Young person's age, sex, ethnicity & limited SES measures	No published estimate identified	Self-reported disability by young people Over-sampling of BME & deprived
ONS longitudinal study (2001) [ONS]	LLSI (no sub-classification) since '91 census	No	10-yearly census data but linkage to births & deaths between censuses	England & Wales – all births in sample households since '71	>200,000 births since '71	N/A	Yes – see population census Self-completion postal return form	Child's age, sex, ethnicity, lone parent household & limited SES measures	Not reported	Potential for studying longitudinal paths to LLSI in childhood
Avon Longitudinal Study of Parents & Children (ALSPAC) (2006)	Detailed questions on symptoms & development questions based on the Denver Developmental Screening Test on 5 occasions between 6 and 81 months	Yes	20 self completed questionnaires up to age of 12	Avon Region of England – all pregnancies April '91 to December '92	14,541 pregnancies enrolled resulting in 14062 live births	80.9% in '99 (latest figure given on ALSPAC website)	Yes – parent/main carer with additional questionnaires for older children & young people Face-to-face interviews & self-completed questionnaires plus clinical tests	Child's age, sex, ethnicity, lone parent household & range of SES measures	No estimate of overall prevalence of disability available	Source of recent longitudinal data on childhood disability & potential for studying longitudinal paths to disability in childhood

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Data set (latest year) [Sponsor/s]	Disability Definition questions & questions used	Child specific questions used	Study design & frequency	Child Population coverage	Sample size	Response rate & weighting	Proxy interviews & data collection mode	Social & demographic data	Estimates	Comments
Millennium cohort study (MCS) (2003-5) [ESRC DfES DH DWP ONS]	Survey 2 ('03-'05) – LSI/LLSI & specific – conditions/ impairments- vision, hearing, asthma, epilepsy	Yes	Biennial – planned through childhood	UK – 9 month olds enrolled between 1.9.00 & 1.8.01 BME & deprived oversampled	15,511 in '03-'05 18,819 in '01-'03	75% of target in '03-'05 82% of those included in '01-'03	Yes – parent/ main carer interviewed Face-to-face Self-completion	Child's age, sex, ethnicity, lone parent household & range of SES measures	15.6% LSI 3.1% LLSI at 3 years	Potential source of up-to-date disability data and life course data
Growing up in Scotland (GUS) (2005) [Scottish Executive]	LSI & LLSI	Yes	Wave 2 '07	Scotland – 10 month olds born 05.04 – 02.05 & 32 month olds born 05.02-02.03	8,000 (5,000+ infants & 2500+ toddlers) wave 1	80% response	Yes – parent/ main carer interviewed Face-to-face	Child's age, sex, ethnicity, lone parent household & range of SES measures	LSI 13% in 10 month olds 18% in 32 month olds	LLSI question sensitive to child's development
1958 British cohort study (NCDS) (2004/5) [ESRC]	LSI LLSI [cohort member only – not children]	Yes	7 waves from birth: 7, 11, 16, 23, 33, 41-2, 46-7	GB. All births in 1 week in March '58 - wave 7 at 47 years of age	17,634 enrolled at birth. 9,534 in wave 7	71.1 % by wave 6	No – not on health of cohort members' children Telephone interview following up on wave 6	Detailed data on cohort member as a child & data on SES over life course	Not Applicable as cohort members are now adults	Historical cohort – valuable for data on life course of disabled children
1970 British Cohort Study (2004/5) [ESRC]	LSI LLSI [cohort member only – not children]	Yes	6 waves from birth: 5, 10, 16, 26, 30, 34	GB. All births in 1 week in April '70 – last wave at 34	16,284 enrolled at birth	69.9% by wave 5	No – not on health of cohort members' children Telephone interview following up on wave 5	Detailed data on cohort member as a child & data on SES over life course	Not applicable as cohort members are now adults	Historical cohort – valuable for data on life course of disabled children



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<b>Administrative data sources (Health)</b>										
Scottish Support Needs System - 2007 [Scottish Executive]	#Special needs defined as any learning difficulty, impaired language/communication, EBD, physical problems #5 indicator conditions used: ASD;DS;C P; SNHL; Neural Tube defects #Function al disability data (DDA)	Not Applicable	Continuous	10 of 15 Scottish Health Boards. Data on 14,579 children & young people aged 0-19 years requiring support	Not Applicable	Incomplete reporting by Health Boards limits usefulness of data for prevalence estimation	Not applicable - data collected from child health computer system	Child's age, sex & ethnicity. Area-based SES measures could be estimated from postcodes	Wide variation in prevalence estimates by Health Board - Grampian where system used - 2.5% 0-4, 4.5% 5-16, 1.7% 17-19 reported to have support needs	Potential source of disability data but limited value at present due to incomplete reporting & non-use of SNS by 5 Health Boards including Glasgow

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Child Health Computer Systems (continuous) [NHS through local Primary Care Trusts]	Special needs/ conditions module of systems with ICD coded diagnoses	Not Applicable	Continuous from the 1960s in some areas	England & Wales with data on all births	Not Applicable	Variable use and quality of Special Needs/ conditions modules of the systems	Not applicable – data collected from child health computer system	Child's age, sex & ethnicity. Area-based SES measures could be estimated from postcodes	No national estimates available	Potential whole population data but variability in use and quality of Special Needs/ Conditions means that reliable national prevalence estimates cannot be made although reliable local estimates may be reliable where local systems well maintained
General Practice Research Database (continuous) [Medicines & Health Regulatory Agency]	Specific diagnoses and summary statistics for ICD 10 categories	Not Applicable	Continuous from 2001	UK-wide – 3.5 million active patient records from 450 General Practices	Not Applicable	Not Applicable	Not Applicable – data from GP records	Child's age, sex & area-based SES measures	No estimates of overall childhood disability prevalence available	Rich potential source of data on specific conditions in childhood but limited value as a source of overall childhood disability estimates
Qresearch (continuous) [University of Nottingham & EMIS computing]	Specific diagnoses and summary statistics for ICD 10 categories	Not Applicable	Continuous from June '03 with historical records back to '88	UK-wide - 9 million patient records – almost 1 million children's records from 549 General Practices.	Not Applicable	Not Applicable	Not Applicable – data from GP records	Child's age, sex & area-based SES measures	No estimates of overall childhood disability prevalence available	Rich potential source of data on specific conditions in childhood but limited value as a source of overall childhood disability estimates

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<b>Administrative data sources (Education)</b>										
Pupil Level Annual School Census (PLASC) & SEN2 survey (2006) [DfES]	Special Educational Needs & SEN Statements	Not Applicable	Annual census since 1985 – data collection changed in 2002	England – aggregate data on >8 million pupils in maintained schools aged 2-18 years.	Not Applicable	All maintained schools covered by census	Not Applicable – data collected from schools related to individual pupils	Child's age, sex, ethnicity & receipt of free school meals as an SES measure	2.9% (236,700) with SEN statements 15.7% (1,203,300) SEN without statements	Main source of data on prevalence of SEN among school aged children Non-maintained schools not included
<b>Administrative data sources (Local Authority Children's Social Services)</b>										
Children's Disability Registers (continuous) [Local Authority Children's Social Services & DfES]	Disabled children defined according to the 1989 Children Act definition	Not Applicable	Continuous – statutory requirement on local authorities to maintain registers since the 1989 Children Act	England	Not Applicable	Variable maintenance & quality of Registers	Not Applicable	Child's age, sex & ethnicity	No national estimates published	Variable quality of Registers means that reliable national prevalence estimates cannot be made although local estimates may be reliable where local register well maintained
Children in Need including Looked After Children (2005) [DfES]	Disabled children –	Not Applicable	Biannual census of children in contact with social services in a single week (February '05)	England – 0-17 year olds in contact with social services – 34,100 disabled	All 150 local authorities provided data but only on those disabled children in contact with social services	Not clear what percentage of disabled children covered by census	Not Applicable – data supplied by Local Authority Social Service departments	Child's age, sex & ethnicity – no SES measures	34,100 children with disabilities in contact with local social services	DfES report of Children in Need Survey states "the number of disabled children in the survey is not a measure of the number of disabled children in the general population"

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<b>Sentinel condition data sources</b>										
UK Collaborative Cerebral Palsy Registers [supported by NHS in each region (continuous)]	Clinically defined diagnosis of Cerebral Palsy (CP) using a standardised definition & sub-type. Also functional & quality of life measures	Not Applicable	Continuous data collection: Mersey & Cheshire '80; 4 Counties '84; Scotland '90; N. Ireland '91; Northern England '94	Registers in 5 UK regions based on 185,000 births/year – data on over 6,000 children with CP	Not Applicable	Not clear what percentage of children with CP covered by registers	Not Applicable – data provided by paediatricians in each of the regions	Child's age, sex, birthweight, gestational age & area-based SES measures	Estimated rate of 2.0/1000 for birth years '86-'96	Most reliable source of data on this group of children with disabilities
Mental Health of Children and Young People Surveys (2004) [DH]	Mental health disorders as defined by ICD 10	Yes – survey used standard instruments designed for identifying child mental health problems	Two cross-sectional surveys in '99 & '04	GB. 5-15 ('99) & 5-16 ('04) living at home	10,438 in '99 7,977 in '04	76% in '04	Yes – parent/main carer Face-to-face	Child's age, sex, ethnicity, lone parent household & range of SES measures	9.6% in '04 - 7.7% in 5-10 year olds & 11.5% in 11-16 year olds	Most reliable source of data on child mental health problems
Register for Deaf and Hard of Hearing (2004) [DH]	Definitions of deaf and hard of hearing based on function & audiological diagnosis	Not Applicable	Triennial census of continuously collected data since '81/'82	England – 0-17 reported from local registers maintained by Local Authority Councils with Social Services-Responsibilities	7100 (4,100 deaf & 3000 hard of hearing) 0-17 registered in 2004	Registration is voluntary so unlikely to include all deaf children	Not Applicable – data compiled from local registers	Not reported in census publication	4100 in 2004 (no rate given in DH publication)	Useful source of trend data but as the DH report states "these figures will not provide a complete picture of the number of deaf/hard of hearing people in England"

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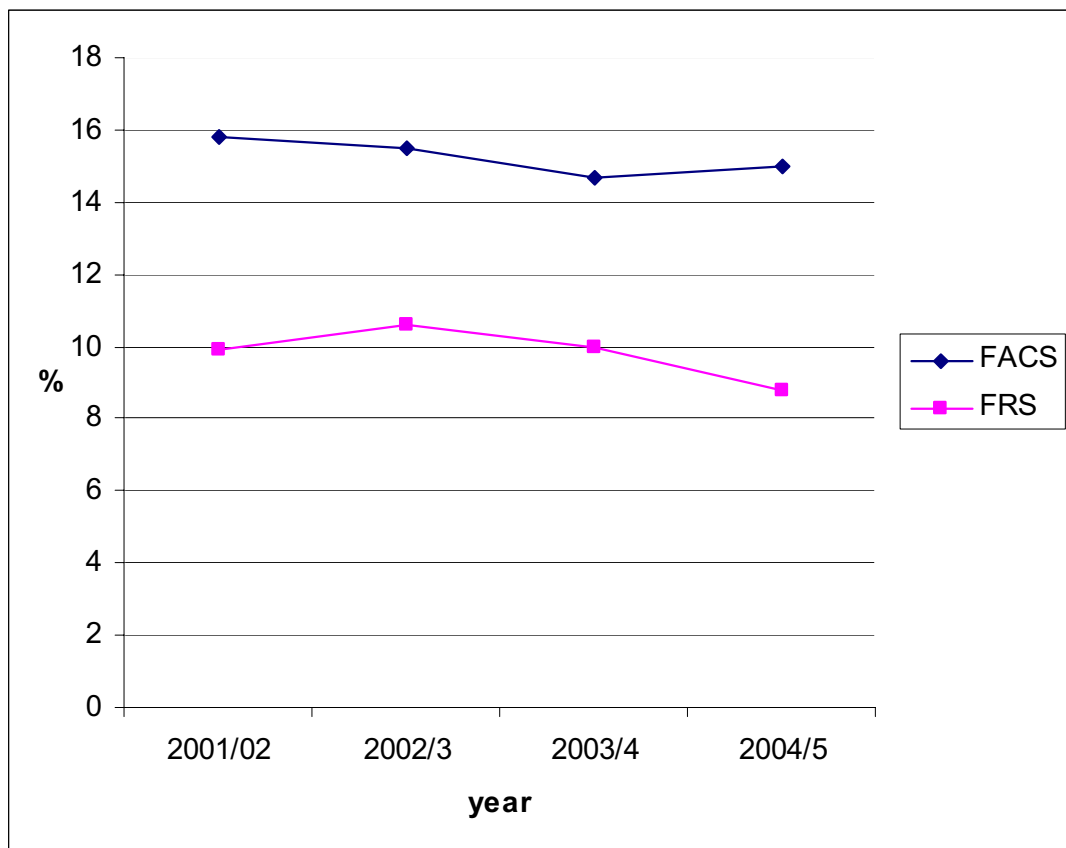
Data set (latest year) [Sponsor/s]	Disability Definitions & questions used	Child specific questions used	Study design & frequency	Child Population coverage	Sample size	Response rate & weighting	Proxy interviews & data collection mode	Social & demographic data	Estimates	Comments
<b>Other data sources</b>										
Family Fund Trust (FFT) [Joseph Rowntree Foundation] (continuous)	Children with severe disabilities classified by diagnosis made by professional information from DLA or child's education assessment	Not Applicable	Continuous	UK 0-16	Data on 165,000 children from low-income households that have applied for funding	Estimated between 50-70% of eligible families apply to the Fund	Not applicable - data based on applications by families for support from the Fund	Child's age, sex, ethnicity, lone parent household & a range of SES measures	8 per 10,000 in 2000	Most extensive data base of severely disabled children. Sample not representative as based on low income households & those applying for assistance through the Fund

\*The term SES measures incorporates a wide range of measures including social class, income, housing tenure and other measures of material circumstances

## Annex 4: Secondary Analysis Tables and Figures

**Figure 1**

**Estimates of limiting longstanding illness, FRS and FACS, 2001/2-2004/5**



**Table 1**

**FRS: Childhood disability prevalence estimates for LSI, LLSI and DDA defined disability, 2003/4 and 2004/5**

	FRS				FACS <sup>1</sup>			
	2003/4		2004/5		2003/4		2004/5	
	n	%	n	%	n	%	n	%
Longstanding illness, disability or impairment	1,295,619	10.0	1,130,405	8.7		14.7	1,884,724	15.0
Limiting longstanding illness, disability or impairment	662,627	5.1	660,270	5.1	--	--	--	--
DDA-defined disability 2003/4 <sup>2</sup>	700,646	5.4	704,843	5.4	--	--	--	--
DDA-defined disability 2004/5 <sup>3</sup>	--	--	952,741	7.3	--	--	--	--

<sup>1</sup>FACS does not collect data on limiting longstanding illness or DDA defined disability

<sup>2</sup> In 2003/4 a DDA-defined disability was defined as having 1 or more substantial difficulties with daily activities

<sup>3</sup>In 2004/5 a DDA-defined disability was defined as 1 or more substantial difficulties plus or would have difficulty/s if medication not taken. A figure for 2003/4 is not available for this measure.

**Table 2**

**FRS: Childhood disability population prevalence estimates for DDA defined disability, by sex, age and ethnic group, 2004/5**

	FRS		FACS	
	n	%	n	%
<b>Children with a DDA defined disability</b>				
<i>Sex</i>				
Boys	583,278	8.8	1,081,765	16.6
Girls	369,463	5.8	802,959	13.3
<i>Age</i>				
0-4 years	129,074	3.7	433,437	11.6
5-11 years	409,862	8.2	786,355	16.7
12-15 years	302,485	9.5	446,311	16.8
16-18 years	111,320	8.5	218,611	15.3
<i>Ethnicity* (FRS only)</i>				
White	870,603	7.6	--	--
Mixed parentage	12,186	9.5		
Indian	7,947	2.7		
Pakistani and Bangladeshi	24,097	5.7		
Black or Black British	26,610	7.0		
Other ethnic group	11,298	3.6		
<i>Ethnicity* (FACS only)</i>				
White	--	--	1,749,606	15.2
Black: Caribbean, African, other			35,646	12.8
Asian: Indian, Pakistani, Bangladeshi			57,965	12.2
Other			38,130	13.4

\* FRS and FACS use different classifications of ethnicity



**Table 3**

**Population estimates for proportions of children with a DDA-defined disability with particular difficulties/problems by sex of child  
 FRS, 2004/5**

Difficulty/problem experienced	% of population		% of children with DDA defined disability			
	All		Male		Female	
	n	%	n	%	n	%
Mobility	193,950	1.5	119,282	20.5	74,668	20.2
Lifting and carrying	84,759	0.7	50,482	8.7	34,277	9.3
Manual dexterity	107,798	0.8	76,293	13.1	31,505	8.5
Continence	88,748	0.7	54,264	9.3	34,484	9.3
Communication	255,534	2.0	170,783	29.3	84,751	22.9
Memory, concentration, learning	288,203	2.2	211,743	36.3	76,460	20.7
Recognising physical danger	171,352	1.3	126,622	21.7	44,730	12.1
Physical coordination	167,585	1.3	116,841	30.0	50,744	13.7
Other	268,427	2.1	166,668	28.6	101,759	27.5

**Table 4**

**Population estimates for proportions of children with LSI with particular difficulties/problems by sex of child  
 FACS, 2004/5**

Difficulty/problem experienced	% of population		% of children with LSI			
	All		Male		Female	
	n	%	n	%	n	%
Problems with arms, legs, feet, back or neck	132,582	1.0	68,868	1.0	63,714	1.0
Difficulty in seeing	73,349	0.6	43,434	0.7	29,911	0.5
Difficulty in hearing	104,863	0.8	67,091	1.0	37,773	0.6
Skin conditions, allergies	320,365	2.5	183,558	2.8	136,807	2.3
Chest, breathing, asthma, bronchitis	850,898	6.7	497,079	7.6	353,819	5.8
Heart, blood pressure, circulation problems	65,905	0.5	29,243	0.4	36,663	0.5
Stomach, liver, kidneys, digestive problems	120,517	1.0	58,863	0.9	61,654	1.0
Diabetes	23,549	0.2	10,927	0.2	12,623	0.2
Depression, bad nerves	20,898	0.2	9,233	0.1	11,666	0.2
Mental illness, phobias, panic and other nervous	53,257	0.4	34,801	0.5	18,456	0.3
Learning difficulties	236,019	1.9	187,158	2.8	48,861	0.8
Epilepsy	68,656	0.5	34,865	0.5	33,790	0.6
Congenital conditions	46,332	0.4	25,868	0.4	20,464	0.3
Other health problems	254,524	2.0	146,431	2.2	108,093	1.8

**Table 5**

**Prevalence estimates from FRS and FACS by Government Office Region  
 for proportion of children with a DDA defined disability, 2004/5**

<b>Region</b>	<b>FRS</b>		<b>FACS</b>	
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>
North East	42,462	7.8	97,801	16.0
North West and Merseyside	123,086	8.1	224,918	15.0
Yorkshire and Humberside	95,422	8.6	164,237	15.7
East Midlands	82,942	9.0	134,440	13.7
West Midlands	77,245	6.5	167,487	14.8
Eastern	71,670	6.0	202,473	16.3
London	93,291	5.8	177,460	11.7
South East	119,673	6.8	268,673	14.6
South West	70,047	6.7	175,456	16.5
Wales	62,691	9.8	100,757	15.6
Scotland	86,479	8.5	171,024	16.9
Northern Ireland*	27,733	6.4	--	--

\* FACS does not cover Northern Ireland

**Table 6**

**Living circumstances of disabled children compared to non-disabled children, FRS, 2004/5**

	Child has DDA-disabled		No DDA disability		<i>p</i>
	<i>N</i>	%	<i>n</i>	%	
Lone parent family	406	34.1	3797	25.6	<0.0001
Two adult family	783	65.9	11026	74.4	
Median number of children in household	2.00	--	2.00	--	NS
1 or more adults with DDA disability in household	560	47.1	3214	27.1	<0.0001
1 or more adults with DDA disability in family unit	543	45.7	2877	20.1	<0.0001
Housing tenure					
Rented/other	563	47.4	4935	33.3	<0.001
Owner-occupied	626	52.6	9888	66.9	
Median number rooms house	5.00	--	6.00	--	<0.0001
Live in flat	109	9.2	1298	8.8	NS
Live in detached house	223	18.8	3706	25.0	<0.0001
Median unequivalised total weekly income	£475	--	543	--	<0.0001

**Table 7**

**Social and material deprivation: items perceived as needed or wanted but which can't afford, FRS, 2004/5**

	Children with DDA disability		Non-disabled children		p
	n	%	N	%	
Item parent perceived as needed or wanted but which can't afford					
<b>Child specific deprivation</b>					
Family holiday away from home for 1 week a year	461	38.9	4741	32.1	<0.0001
Enough bedrooms for every child of 10 or over of different sex to have own bedroom*	49	22	476	18.5	NS
Leisure equipment such as bicycle	135	11.4	1219	8.3	<0.0001
Celebrations on special occasions – birthdays, Christmas or other religious festivals	71	6	680	4.6	0.036
Go swimming at least once a month	161	13.6	1522	10.3	<0.0001
Do a hobby or leisure activity	114	9.6	1042	7.1	0.001
Have friend round for tea or snack once a fortnight	143	12.1	1224	8.3	<0.0001
Go to toddler group/nursery/playgroup at least once a week	26	7.6	402	6.7	NS
Go on school trips	96	8.6	812	6.5	0.006
Have an outdoor space or facilities nearby where can play	269	22.7	2342	15.9	<0.0001
<b>Household deprivation</b>					
Enough money to keep home in decent decoration	305	25.8	2759	18.7	<0.0001
Enough money for household contents insurance	293	24.8	2683	18.2	<0.0001
Enough money for regular savings of £10 per money	611	51.6	6013	40.7	<0.0001
Enough money for 2 pairs of shoes for each child	209	17.7	1516	10.3	<0.0001
Enough money to replace worn out furniture	452	38.2	4591	31.1	<0.0001
Enough money to replace or repair major electrical goods	302	25.5	3350	22.7	0.028

\* asked if two or more children aged 10 or over of opposite sex in household

**Table 8**

**Proportions in families who report falling behind with payments, FRS,  
 2004/5**

<b>Areas where behind with payments</b>	<b>Children with DDA disability</b>		<b>Non-disabled children</b>		<b>p</b>
	<b>n</b>	<b>%</b>	<b>N</b>	<b>%</b>	
Electricity payments	84	7.1	571	3.9	<0.0001
Gas payments	89	7.5	551	3.7	<0.0001
Other fuel payment	8	0.7	114	0.8	NS
Council tax	125	10.6	957	6.5	<0.0001
Insurance policies	7	0.6	47	0.3	NS
Telephone bill	105	8.9	731	5.0	<0.0001
TV/video payments	24	2.0	1.2	177	0.020
Other HP payments	58	4.9	342	2.3	<0.0001
Water rates	116	9.8	815	5.5	<0.0001
1 or more debts	313	26.5	2393	16.2	<0.0001

**Table 9**

**Logistic regression analyses for FRS and FACS, 2004/5**

	FRS		FACS	
	DDA disability		Longstanding illness	
	<i>Bivariate Odds Ratio (95%CI)</i>	<i>Multivariate Odds Ratio (95% CI)</i>	<i>Bivariate Odds Ratio (95%CI)</i>	<i>Multivariate Odds Ratio (95% CI)</i>
<b>Age of child (years)</b>				
0-4	1.00		1.00	
5-11	2.15 (1.80,2.57)	2.07 (1.72,2.48)	1.31 (1.11,1.55)	1.34 (1.13,1.60)
12-15	2.65 (2.20,3.20)	2.39 (1.97,2.89)	1.51 (1.31,1.73)	1.48 (1.28,1.71)
16-18	2.21 (1.74,2.80)	2.07 (1.62,2.65)	1.49 (1.30,1.68)	1.48 (1.30,1.68)
<b>Sex of child</b>				
Girl	1.00		1.00	
Boy	1.58 (1.40,1.78)	1.59 (1.40,1.80)	1.29 (1.17,1.42)	1.33 (1.20,1.47)
<b>Ethnic group</b>				
Black/ethnic minority/other	1.00		1.00	
White	1.43 (1.15,1.78)	1.48 (1.17,1.84)	1.21 (1.00,1.59)	1.27 (1.04,1.55)
<b>No. of adults in family</b>				
2 adults	1.00		1.00	
1 adult	1.51 (1.33,1.71)	1.26 (1.09, 1.54)	1.43 (1.29,1.59)	1.14 (1.01,1.28)
<b>No. of dependent children in family</b>				
2 or less	1.00		1.00	
3 or more	1.10 (0.97,1.25)*	0.93 (0.81,1.08)*	1.07 (0.97,1.19)*	0.99 (0.89,1.10)*
<b>No. of adults with DDA disability/LLSI</b>				
None	1.00		1.00	
1 or more	3.36 (2.96,3.76)	3.04 (2.68,3.45)	2.26 (1.99,2.57)	2.04 (1.78,2.33)
<b>Housing tenure</b>				
Owner occupied	1.00		1.00	
Rented/other	1.80 (1.60,2.03)	1.49 (1.30,1.71)	1.55 (1.41,1.71)	1.35 (1.20,1.52)
<b>Age respondent left full-time education</b>				
19+	Not available	Not available	1.00	
17-18			1.26 (1.10,1.43)	1.05 (0.92,1.20)
16 or less			1.73 (1.44,2.08)	1.27 (1.04,1.54)

\* Not significant at 0.05 level

## Annex 5: Excluded data sets

Data sources	Reason for exclusion
OPCS disability surveys 1985-88	No recent data – last survey in 1988
North of England Public Health Observatory report 'Children with long-term disability in the former Northern & Yorkshire regions' [ <a href="http://www.nepho.nhs.uk">www.nepho.nhs.uk</a> ]	This is a report that draws on other data sources & has valuable information on childhood disability but is not an active data source
Hospital Episodes Statistics [ <a href="http://www.dh.gov.uk">www.dh.gov.uk</a> ]	These statistics represent finished consultant episodes (FCEs) and give information on hospital activity related to specific conditions and diagnostic groups but do not provide statistics on individual children
West Sussex Child Health Computer dataset	An example of a child health computer system with a well-maintained Special Conditions register. For the purposes of this review, it is located within the Child Health Computer data source and not considered alone.
Child Health Mapping [ <a href="http://www.childhealthmapping.org.uk">www.childhealthmapping.org.uk</a> ]	Department of Health organised annual censuses of Child and Mental Health services (since 2002) and Child Health and Maternity Services (since 2005) - data relate to services for disabled children and provide no data on individual children or childhood disability prevalence
Epicure Studies [ <a href="http://www.nottingham.ac.uk/human-development/Epicure/">www.nottingham.ac.uk/human-development/Epicure/</a> ]	Two studies on all births up to 25 weeks and 6 days gestation in all neonatal units in UK & Ireland, the first in 1995 and the second in 2006. Although these extremely premature births are associated with high risk of disability among survivors, they do not fall within our definition of sentinel conditions
UK Longitudinal Household Study [ <a href="http://www.esrc.ac.uk">www.esrc.ac.uk</a> ]	Planned as an eventual replacement for the BHPS, data collection will start in 2008 with a target sample size of 40,000 households. Likely to be a major source of childhood disability data but not currently available



## Annex 6: Access to data sources

Data Source	Access to data	Access to reports/information
<b>Cross-sectional:</b> FRS Population Census GHS CHS HSE LFS BCS HOCS SEH	<a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.census.data-archive.ac.uk">www.census.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a>	<a href="http://www.dwp.gov.uk/asd/">www.dwp.gov.uk/asd/</a> <a href="http://www.statistics.gov.uk/">www.statistics.gov.uk/</a> <a href="http://www.statistics.gov.uk/">www.statistics.gov.uk/</a> <a href="http://www.csu.nisra.gov.uk/">www.csu.nisra.gov.uk/</a> <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a> <a href="http://www.statistics.gov.uk/">www.statistics.gov.uk/</a> <a href="http://www.statistics.gov.uk/">www.statistics.gov.uk/</a> <a href="http://www.homeoffice.gov.uk/rds/citizenurvey.html">www.homeoffice.gov.uk/rds/citizenurvey.html</a> <a href="http://www.statistics.gov.uk/">www.statistics.gov.uk/</a>
<b>Panel and Longitudinal:</b> FACS BPHS MCS LSYPE ONS LS ALSPAC[data access limited by cost] GUS [no indication on site if data available for analysis] 1958 cohort (NCDS) 1970 cohort	<a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.celsius.lshtm.ac.uk">www.celsius.lshtm.ac.uk</a> <a href="http://www.alspac.bris.ac.uk">www.alspac.bris.ac.uk</a>  <a href="http://www.natcen.ac.uk/gus/">www.natcen.ac.uk/gus/</a>  <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a> <a href="http://www.data-archive.ac.uk">www.data-archive.ac.uk</a>	<a href="http://www.dwp.gov.uk/asd/">www.dwp.gov.uk/asd/</a> <a href="http://www.esds.ac.uk/">www.esds.ac.uk/</a> <a href="http://www.cls.ioe.ac.uk/">www.cls.ioe.ac.uk/</a> <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a> <a href="http://www.celsius.lshtm.ac.uk">www.celsius.lshtm.ac.uk</a> <a href="http://www.alspac.bris.ac.uk">www.alspac.bris.ac.uk</a>  <a href="http://www.natcen.ac.uk/gus/">www.natcen.ac.uk/gus/</a>  <a href="http://www.esds.ac.uk/">www.esds.ac.uk/</a> <a href="http://www.esds.ac.uk/">www.esds.ac.uk/</a>
<b>Administrative:</b> Scottish Support Needs System [no indication on site if data available for analysis] Child Health Computer Systems England & Wales [data availability for analysis limited to PCT personnel] GPRD [data access limited by cost] Qresearch  PLASC[no indication on site if data available for analysis] Children's Disability Registers [data availability for analysis limited to LA personnel] Children in Need census	<a href="http://www.isdsscotland.org/">www.isdsscotland.org/</a>  <a href="http://www.chiconsortium.org.uk">www.chiconsortium.org.uk</a>   <a href="http://www.gprd.com">www.gprd.com</a>  <a href="http://www.nottingham.ac.uk/~mczqres/index">www.nottingham.ac.uk/~mczqres/index</a> <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>  <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>   <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>	<a href="http://www.isdsscotland.org/">www.isdsscotland.org/</a>  <a href="http://www.chiconsortium.org.uk">www.chiconsortium.org.uk</a>   <a href="http://www.gprd.com">www.gprd.com</a>  <a href="http://www.nottingham.ac.uk/~mczqres/index">www.nottingham.ac.uk/~mczqres/index</a> <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>  <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>   <a href="http://www.dfes.gov.uk/">www.dfes.gov.uk/</a>
<b>Sentinel condition data bases:</b> UK Collaborative Cerebral Palsy Registers Mental Health of Children and Young People Surveys Register for Deaf and Hard of Hearing Register for Sight Impaired	<a href="http://www.liv.ac.uk/publichealth/ukcp/UKCP.html">www.liv.ac.uk/publichealth/ukcp/UKCP.html</a> <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>  <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>  <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>	<a href="http://www.liv.ac.uk/publichealth/ukcp/UKCP.html">www.liv.ac.uk/publichealth/ukcp/UKCP.html</a> <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>  <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>  <a href="http://www.dh.gov.uk/">www.dh.gov.uk/</a>
<b>Other data sources:</b> FFT	<a href="http://www.familyfund.org.uk">www.familyfund.org.uk</a>	<a href="http://www.familyfund.org.uk">www.familyfund.org.uk</a>

## Annex 7: National Dissemination Conference Programme



### CAN WE COUNT THEM: DISABLED CHILDREN AND THEIR HOUSEHOLDS

#### ONE DAY CONFERENCE

14 MARCH 2007

Chancellors Suite, Panorama, Rootes Social Building,  
UNIVERSITY OF WARWICK

#### Programme

10.00	Registration and coffee
10.30	Welcome: <b>Dr Janet Read</b> , University of Warwick
10.35	<b><i>The National Data Strategy: Relevance for Childhood Disability Data</i></b> <b>Professor Peter Elias</b> , ESRC and University of Warwick
11.00	<b><i>Can We Count Them? Disabled Children and Their Households Project</i></b> <b>The Project in Context and its Findings</b> <b>Dr Janet Read, Professor Emeritus Nick Spencer and Dr Clare Blackburn</b> , University of Warwick
11.40	Questions and Discussion
11.50	<b><i>Perspectives of Disabled Children and Young People</i></b> <b>Dr Sonali Shah</b> , University of Leeds
12.30	Buffet lunch
1.30	<b><i>Future challenges for data collection on disabled children and their households: A perspective from the Office for Disability Issues</i></b> <b>Grahame Whitfield</b> , Principal Research Officer, Office for Disability Issues, Department for Work and Pensions
2.15	Concurrent workshops:
a.	<b><i>What can ethnographic work with children contribute?</i></b> Chairs - <b>Professor Alan Prout</b> and <b>Professor Pia Christensen</b> , University of Warwick
b.	<b><i>Issues of definition and question design:</i></b> Chairs - <b>Professor Dave Gordon</b> , University of Bristol and <b>Professor Nick Spencer</b> , University of Warwick
c.	<b><i>Sampling and data sets</i></b> Chair – <b>Dr Susan Purdon</b> , Quantitative Methods Advisor, NatCen
d.	<b><i>How can perspectives from the Disability Rights Movement shape data collection on disabled children?</i></b> Chair: <b>Dr Chih Hoong Sin</b> , Head of Information and Research, Disability Rights Commission
3.30	Tea and close of conference