Disabled children and their households
A brief guide to quantitative data

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Introduction

Many people need data on disabled children and their households. It can be difficult however, to find and use reliable quantitative[1] data on this group. This is because there is no single way of identifying disabled children and their households and collecting information about them. As a result, many people find it difficult to estimate the prevalence of childhood disability, explore disabled children's social and material circumstances or identify their needs with any degree of accuracy.

How can this guide help?

We have designed this guide to assist those who need to locate and use information on disabled children and their families. These include policy makers, service planners and providers, organisations representing the disabled children and their families, individuals, students and academics.

This guide aims to help people to:

 *Understand the issues involved in estimating the numbers of disabled children and their households in the UK population and why estimates differ

 *Become familiar with the main currently available quantitative data sources on disabled children
 *Appreciate the main strengths and weaknesses of the key sources of information

 *Identify the most useful source of data for their own particular purposes

How to choose a data source

In choosing a source of data you need one which is 'fit for purpose'. You should:
 *Check the definition of disability
 *Choose the right kind of data source i.e. survey etc
 *Choose the data source which covers the population of children you are most interested in
 *Use a reliable data source that you can access
 *Be aware of the strengths and limitations of your source

Checking the definition of disability

There are different definitions of disability: there is no single definition used by disabled children and their parents, those who collect data or professionals responsible for services. This is because disability means different things to different people.

In addition, the definition adopted needs to reflect the purpose for which the data is collected.

Different definitions of disability identify different groups of disabled children and generate different estimates of childhood disability. In the quantitative data sources, three main definitions are used:

Longstanding illness, disability or infirmity (LSI) This has the potential to identify children with wide variety of health conditions affecting them over a period of time. The range includes mild asthma to impairments seen to be severe. Its value lies in its inclusiveness. If used alone however, it does not indicate the limitations on a child's activities which are related to the impairments.

Limiting longstanding illness, disability or infirmity (LLSI) Many surveys use the concept of limiting longstanding illness, disability or infirmity to identify children with impairments and conditions which are perceived to limit their activities in some way.

Definitions derived from the Disability Discrimination Act (DDA) Recently some surveys are attempting to use a definition derived from the DDA. This definition indicates those children who have legal rights under the DDA. This type of definition can identify children whose impairments and conditions result in *significant difficulties* with normal daily living activities and may also identify those whose impairments and conditions *would* result in significant difficulties with normal daily living activities if they were not taking medication. You should check whether this second group are included in any estimate[2].

Other definitions There are other definitions designed to identify children who experience specific impairments e.g. cerebral palsy, visually impaired children, or those with specific support needs e.g. children with special educational needs; disabled children 'in need' under Section 17 of the Children Act, 1989. While these categories may encompass substantial numbers, they are not intended to identify the whole population of disabled children. Therefore these definitions are less useful for generating global estimates of childhood disability.

Choosing the right kind of data source

Data on disabled children are collected in different ways including: cross-sectional surveys, panel and cohort studies, administrative data sets. In this section we comment on the main features of different types of data sources on disabled children:

The main *cross-sectional surveys* (e.g. Family Resources Survey) collect information, to varying degrees, on disabled children and their circumstances at a particular point in time. They are considered to be the best design for estimating disability prevalence.

The main *panel studies* collect data on a randomly selected sample, usually of households, on two or more occasions. This type of longitudinal design can generate annual prevalence estimates and can track trends over time. In addition, some offer detailed information on child and household circumstances (e.g. Families and Children Study, FACS). Problems can be caused by children and families dropping out of the studies, although some studies compensate by recruiting additional participants to maintain sample size.

Cohort studies also have a longitudinal design. They track over time, groups of children born during a particular period. They have the potential to offer insights into the dynamics and trajectories of disability across the lifecourse. They are less valuable as a source of prevalence estimates because estimates are only available up to the age of the child at the time of the last data collection.

Administrative data sources collect data, often in the form of an annual census, on specific groups of children who come into contact with agencies or organisations which provide services for them and which often have statutory duties towards them (e.g. those with special educational needs, those defined as children in need). They use definitions relevant to the particular administrative category. They are therefore unlikely to be suitable for generating global prevalence estimates of childhood disability.

Choosing a data source which covers the population you are interested in

Data sources cover different populations of children in terms of geographical coverage, age and place of residence. Population coverage is not always immediately clear so users need to check.

*Some sources are UK-wide while others are limited to GB, one of the home nations or a particular region.

*Age coverage varies. Some only provide data on children who are pre-school or of school age while others purport to cover all children. The definition of 'dependent child' used however, can mean that not all children and young people age 0-18 are covered in all data sources. In particular, users need to be alert to the fact that not all 16 to 18 year olds may be covered.

*Many data sets only cover children living in private households. Such data sources may not collect data on some children living elsewhere for some or part of the year.

*Some data sets only cover particular groups of children. For example, data from the Family Fund Trust only covers children with high support needs from low income households applying for grant aid from the Trust. Data generated from such sources are not generalisable to the wider population of disabled children but may be a rich source of information on the particular group covered.

Use a reliable data source

Whether the data from any one source is likely to be representative of the wider population of disabled children will depend on a number of factors including the group from which the sample is drawn (see above), the sample size and the response rate.

Even national surveys often only capture small numbers of disabled children. This is because the prevalence of childhood disability in the whole population is relatively low. This means that sub-samples of disabled children, for example, disabled children from black and minority ethnic groups are often very small. As a result, it is important to be cautious about generalising from the data collected on these sub-groups of children.

Is there a 'golden estimate'?

There is no such thing as the perfect estimate or data source on disabled children. All have their strengths and limitations. You need to have a 'horses for courses' approach and choose the best source for the job you need to do.

Which source is best for you?

Use the table below to help you choose the best estimate and data source for you. The list is not comprehensive but we have selected estimates that are likely to be useful to users and that utilise the most reliable data sources. If you need more information on data sources on disabled children, a detailed table is available at:

http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/research/currentfundedres/disabledchildren/res-000-22-1725-5k.pdf

Finding the data you need

I want an estimate of the number of disabled children aged 0-16 covered by the DDA

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
Family Resources Survey (FRS)	DDA disabled 2004/5: 5.4% (weighted to whole population: 704,843) DDA disabled* 2004/5: 7.3% (weighted: 952,741) *DDA disabled definition expanded to include those whose activities would be limited if their medication was discontinued	Currently only survey to comply with DDA definition for children Reasonable sample size for overall prevalence estimates UK wide with data by region Good socio-demographic & benefits data	No child-specific DDA questions (i.e. current questions do not take account of child's developmental stage) Sample size not adequate for studying small sub-groups of the population such as minority ethnic groups Data not available at local authority level Trend data not available as full DDA definition only used in 2004/5 survey No data on children in institutions	The best available estimate of DDA disability in children FRS data available to academics for analysis & research Reports available from DWP – latest 2004-5: but information on childhood disability limited to 0-15 prevalence in table 6.7	Data source: www.data-archive.ac.uk Reports summarising data: www.dwp.gov.uk/asd/frs

I want an estimate of disabled young people 16-18 covered by the DDA

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
Labour Force Survey (LFS)	Not published separately for this age group	Complies with DDA and includes substantial data on this age group Large sample size UK wide with data by region Good socio-demographic & benefits data	Data on this age group not published separately No data on young people in institutions	Data on this age group available in form of raw data to those with permission to access but not readily available otherwise	Data source: www.data-archive.ac.uk

I want an estimate of the number of school children aged 2-18 with Special Educational Needs/SEN statements

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
Special Educational Needs Data	2006 estimate: all children with SEN = 18.6% (2.9% with statements)	Based on SEN2 and Pupil level annual school census - >8 million school children Trend data available but only from 2002 as data collection changed	SEN classification not DDA compliant Only maintained schools covered England only	SEN data available from DfES website	www.dfes.gov.uk/rsgateway/DB/SFR/

Finding the data you need

I want an estimate of the number of children aged 0-18 with cerebral palsy

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
UK Collaborative Cerebral Palsy Register	2/1000	Clinically confirmed diagnoses Most reliable source of data on this major childhood disability	5 Regions of the UK only Limited socio-demographic data	Limited to published papers & to those with authorised access	www.liv.ac.uk/ publichealth/ukcp/ UKCP.html

I want an estimate of the number of school children aged 5-15 with mental health problems

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
DH Mental Health in Children and Young People Survey in GB 1999/ 2004	2004: prevalence of clinically diagnosed mental health problem = 10% No change since 1999	Adequate sample size Standardised data collection methods Trends data –'99 to '04 Good socio-demographic data Different types of mental health problems identified	Limited age range	Full reports downloadable from the web	www.ic.nhs.uk/pubs/ mentalhealth04

I want an estimate of the number of disabled children aged 0-18 in my locality

Data source	Prevalence/ estimate	Strengths	Limitations	Assessment of usability	How to access
2001 Population Census	4.5% Limiting long-standing illness (LLSI)	Whole population Numbers large enough to study small population sub-groups Includes children and young people in institutions Reasonable socio-demographic data including ethnicity Data at locality and small area level	DDA disability not collected No sub-classification of LLSI 10 year period between censuses Under-enumeration in inner city areas	Published reports downloadable but often available only 4-5 years after census complete Data related to a 3% sample of anonymised records (SARs) available to authorised users	SARs data: www.census.data-archive.ac.uk Reports summarising data: www.statistics.gov.uk/

Notes:
[1] While this guide focuses on quantitative data sources, it is important to recognize that there is a large body of qualitative research data on disabled children and their households which offers important insights into their lives and experiences.
[2] Currently, official estimates published from the Family Resources Survey by ONS do not include this second group of children.

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