

Evaluating the  
Impact of  
Valuing People

**Report of Phase 1:  
A Review of  
Existing National  
Datasets**

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# **Evaluating the Impact of *Valuing People***

## **Report of Phase 1: A review of existing national datasets**

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# Executive Summary

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## The Project

In March 2001, the Department of Health published the White Paper “*Valuing People*”, designed to establish a framework for the delivery of health and personal social services for children and adults with learning disabilities in England (Department of Health, 2001). The four basic principles of *Valuing People*; rights, independence, choice and inclusion; are also at the heart of Government strategic thinking concerning all disabled people in Britain; with a recent Government report setting the following vision “By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society” (Prime Minister’s Strategy Unit, 2005).

To provide clear guidance concerning the desired direction of services for people with learning disabilities, *Valuing People* includes a comprehensive set of 11 overall objectives to be reached for people with learning disabilities, with specific sub-objectives for each overall objective.

The Government and other organizations collect a substantial amount of information relevant to services for people with learning disabilities at a national level. However, it is unclear how useful this information is for evaluating the objectives and sub-objectives of *Valuing People*. This report outlines the findings of the first phase of a research project commissioned as part of the Department of Health’s Learning Disability Research Initiative. The research project has the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level. The first phase of this research project has the objective of locating and mapping existing national data sources relevant to people with learning disabilities.

We used several methods to identify national data sources potentially relevant to people with learning disabilities, including:

- Reviewing information on data sources compiled by the Department of Health;
- Contacting the statistics divisions of Government departments and other relevant agencies, including the Office for National Statistics;
- Reviewing national statistics database internet sites and publications;
- Conducting secondary data analyses of national survey data to ascertain whether information was available concerning people with learning disabilities.

For all potential data sources available from statistical returns, we collected the following information using a standardised form:

- Name of data source and agency responsible for the dataset;
- The type of information collected and what the information is used for;
- The frequency of data collection and the earliest and latest dates for which information was available at the time of contact;
- Who the information is obtained from, how it is collected, and an assessment of the quality of the information obtained;
- The geographical area and groups of people covered by the information;
- Potential relevance to specific *Valuing People* objectives;
- Contact details and details of how to access the dataset.

This report:

- Describes the information publicly available from national statistical returns to Government departments and other agencies relevant to people with learning disabilities.
- Discusses national surveys potentially relevant to people with learning disabilities, with a description of each survey and its strengths and limitations concerning people with learning disabilities.
- Draws some conclusions about the potential relevance of current datasets for evaluating the objectives of *Valuing People*.
- Makes recommendations for improvements.

## Conclusions

It is clear that collecting regular statistical information on a national basis is crucial for the Government (and others) to evaluate progress in supporting people with learning disabilities. Collecting information on this basis can:

- Provide comprehensive information for the whole of England.
- Provide detailed information on trends over time.
- Provide information on specific local authorities or NHS services.
- Provide information on the coverage of services for people with learning disabilities.
- Provide information on the resources allocated to services for people with learning disabilities.

However, statistical returns collected on a national basis have several limitations.

First, information collected in statistical returns often lags behind current policy priorities:

- To analyse trends over time, the information collected needs to be consistent over time, meaning that the information collected in statistical returns often lags behind current policy priorities.
- Information is collected using the information systems of local agencies (typically local authorities or NHS services). Changing the information required involves considerable lead-in times to enable them to change their information systems.
- New policy priorities often do not come with clearly specified objectives that can be easily evaluated using national statistical returns.

Second, there are potential limitations in the quality and reliability of the information collected through statistical returns:

- To collect information efficiently, the information is collected by local agencies and is reliant on the accuracy of local information systems. Although statistical returns are often checked for obvious errors or inconsistencies, more thorough examination of the accuracy of the information provided is resource-intensive.
- Providing accurate information also relies on accurately identifying people as having a learning disability; it is extremely unlikely that different agencies are identifying people with learning disabilities consistently.
- Most of the information collected through statistical returns does not allow the consistent analysis of sub-groups of people with learning disabilities, for example by age, gender or ethnicity.

Third, there are limitations in the types of information typically collected through statistical returns:

- The information collected has to be numerical to allow the information to be collated and analysed statistically. This means that certain aspects of people's experience may not be easily obtained using statistical returns.
- Information for statistical returns is collected from local agencies through their information systems, which typically collect information from services rather than directly from the people using those services. This typically results in a focus on service resources and service processes rather than outcomes for service users.

There are also specific problems with using the information reviewed in this report to evaluate the situation of people with learning disabilities.

First, there are considerable inconsistencies in definitions of learning disabilities:

- Government departments in their requests for statistical returns rarely provide a clear definition of learning disabilities for local agencies to use when collecting information. Instead, they rely on local agencies to use their own administrative definitions, which are themselves often unclear and inconsistent across agencies.
- Within and across Government departments, many terms are used for people with learning disabilities, some of which reflect terms currently used by Government (learning difficulties, learning disabilities) and some of which do not (mental handicap, mental retardation, mental impairment).
- Within some statistical returns, people with learning disabilities are treated as a sub-group of people with mental health problems.

Second, most of the available information is relatively inaccessible:

- Although most agencies responsible for statistical returns have made great progress in making information freely available and publicly available on the internet, it is rarely presented in ways accessible to non-specialists.
- Because information is collected by many agencies, information is made available separately by each agency, with no single agency responsible for pulling together all the information potentially relevant to people with learning disabilities.
- Within some statistical returns information is collected on people with learning disabilities but not regularly made available publicly.
- A small number of agencies do not make their information freely available and charge for access to the information.
- People accessing information currently may be offended by terms such as mental handicap or mental retardation, or by the classification of people with learning disabilities as a sub-group of people with mental health problems.

Third, there is little evidence of joined-up working between Government departments and other agencies involved in the collection of statistical information concerning people with learning disabilities:

- Different Government departments do not provide a consistent definition of learning disabilities for local agencies to work towards.
- Different agencies often collect similar information from local agencies in ways that are inconsistent, increasing the burden on local agencies.
- Most of the objectives and sub-objectives of *Valuing People* require evaluation across different types of service and support, whereas most current statistical

returns focus on specific types of service and support associated with the particular Government agency collecting the information.

Fourth, much of the information in statistical returns is collected at the level of services specifically designated for people with learning disabilities, rather than at the level of people with learning disabilities using both specialist and mainstream services and supports. If *Valuing People* is successful in its objectives, then people with learning disabilities will become increasingly invisible within information systems as people with learning disabilities use specialist services less and mainstream services and supports more.

Fifth, there may be some challenges in using *Valuing People* objectives and sub-objectives to drive the information collected through national statistical returns:

- The *Valuing People* objectives and sub-objectives would need to be tightened up before they could be evaluated using statistical information.
- The Government and other agencies may still wish to collect information not directly relevant to the objectives of *Valuing People*; for example in evaluating expenditure on services used by people with learning disabilities.
- It is currently unclear whether the objectives of *Valuing People* are the most relevant objectives for people with learning disabilities and their families.
- Issues of equality of access are rarely written directly into the *Valuing People* objectives and sub-objectives; it is important not to lose sight of issues such as disability and race equality as required by legislation.
- Many *Valuing People* objectives require information across a range of services and agencies; the current structure of information collection within individual Government departments makes collecting this “joined-up” information difficult.
- As mentioned earlier, most information collected through statistical returns concerns service resources and service processes, with little emphasis on outcomes for people with learning disabilities and their families. To collect information on outcomes will require substantial investment in gaining information directly from people with learning disabilities and their families.
- *Valuing People* was published in 2001, yet national information to evaluate its objectives is not yet available in early 2005, making the evaluation of progress since the introduction of *Valuing People* difficult.

## **Recommendations**

The first set of recommendations concerns setting priorities for information collection:

- One set of priorities can be derived from *Valuing People* objectives and sub-objectives; these, however, need to be clarified before relevant statistical information can be provided by local agencies.
- A second set of priorities can be derived from the work of inspection agencies; particularly the Commission for Social Care Inspection and the Healthcare Commission. These inspection agencies need to ensure that their performance indicators are inclusive of and relevant to people with learning disabilities. Harmonisation between performance indicators and other information collected through statistical returns would be desirable.
- A third set of priorities concerns the collection of information for ongoing monitoring of resources allocated to supports for people with learning disabilities.

- A final set of priorities concerns the views of people with learning disabilities, their families and other stakeholders on what the most important information is.

The second set of recommendations concerns revising existing statistical returns to reflect information priorities:

- All those currently collecting national information through statistical returns should develop an agreed strategy for developing statistical returns to reflect the priorities outlined above.
- This strategy should be mindful of the need to minimise the burden of information collection from local agencies; statistical returns where possible should be harmonized at both the central level (where information is analysed and used) and the local level (where information is provided).
- A forum for discussion between agencies providing and collecting statistical returns concerning people with learning disabilities should be established.
- If there is to be an increased emphasis on outcome information collected directly from people with learning disabilities, local agencies may require additional support and resources to conduct interviews with people and their families.

The third set of recommendations concerns definitions and terms used to refer to people with learning disabilities:

- Government departments and other agencies collecting national statistical information should as far as possible provide local agencies with a consistent and clear definition of learning disabilities. This definition will need to make a very clear distinction between learning disabilities (as defined in *Valuing People* and used within this report) and specific learning difficulties (e.g., dyslexia).
- The Department of Health should ensure that all national statistics use terms for people with learning disabilities consistent with current Government policy.
- The Department of Health should ensure that people with learning disabilities are not treated as a sub-group of people with mental health problems in statistics.

The fourth set of recommendations concerns the collection of information on sub-groups:

- Wherever possible, people with learning disabilities should be identifiable as a sub-group within all statistical returns, to enable the evaluation of the extent to which people with learning disabilities are participating in mainstream society.
- All agencies collecting information through statistical returns should try to develop a standard set of criteria for identifying sub-groups within datasets; for example by age (with standard age bands), ethnicity and gender.

The fifth set of recommendations concerns nationally representative surveys conducted by the Office for National Statistics and other agencies:

- The Office for National Statistics should consider the development of a short set of questions enabling the identification of people with learning disabilities.
- Questions identifying people with learning disabilities should be routinely included within all general surveys.
- Ongoing national surveys, such as the Health Survey for England, often include booster samples of specific sub-groups on a regular basis to enable more detailed analysis of that sub-group. People with learning disabilities should be considered as a sub-group for regular booster sampling within ongoing national surveys.

- The National Survey of People with Learning Disabilities should be repeated at regular intervals.

The sixth recommendation is that agencies responsible for statistical returns consider the development of datasets focused on individuals rather than services. For example, the dataset on people using the Supporting People programme is an ongoing database of individual users, which enables detailed analysis of the experiences of people with learning disabilities. In contrast, the dataset on hospital activity only identifies appointments with hospital-based learning disability consultants, rather than the inpatient experiences of people with learning disabilities across all hospital services.

Finally, it is clear that there is already a substantial amount of information available concerning services for people with learning disabilities, although the information collected is scattered and often difficult to access. The establishment of an Observatory for Learning Disability Statistics could provide a major ongoing resource for all stakeholders with an interest in national statistics. The functions of such an Observatory could include:

- The collation, analysis and publication of publicly available national statistical data concerning people with learning disabilities in one place.
- Producing an annual digest of national statistics concerning people with learning disabilities.
- Maintaining a regularly updated, easily accessible website containing relevant statistics and signposts to more detailed statistics.
- Providing regular information to various agencies for policy monitoring purposes.
- Working with people with learning disabilities, their families and other stakeholders to ensure that relevant statistical information is made accessible to as many people as possible.
- Advising the Commission for Social Care Inspection, the Healthcare Commission and other inspection agencies on making sure that inspection procedures and performance indicators are inclusive and relevant to people with learning disabilities.
- Advising Government departments and other agencies on methodological aspects of collecting national statistical information concerning people with learning disabilities.
- Advising local agencies on methodological aspects of providing statistical information concerning people with learning disabilities.
- Pro-actively requesting and conducting secondary analysis of datasets where unpublished information is available concerning people with learning disabilities (e.g., analysis of data on communal establishments for people with learning disabilities collected during the 2001 Census).
- Responding to requests for information from a wide range of stakeholders.
- Providing a forum for the discussion of what information should be collected to reflect current policy priorities in education, health and social care concerning people with learning disabilities.

# Introduction

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In March 2001, the Department of Health published the White Paper “*Valuing People*”, designed to establish a framework for the delivery of health and personal social services for children and adults with learning disabilities in England (Department of Health, 2001). The four basic principles of *Valuing People*; rights, independence, choice and inclusion; are also at the heart of Government strategic thinking concerning all disabled people in Britain; with a recent Government report setting the following vision “By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society (Prime Minister’s Strategy Unit, 2005).

To provide clear guidance concerning the desired direction of services for people with learning disabilities, *Valuing People* includes a comprehensive set of 11 overall objectives to be reached for people with learning disabilities, with specific sub-objectives for each overall objective. These objectives and sub-objectives have been designed to allow the Government to evaluate the impact that *Valuing People* is having on people with learning disabilities in England. The 11 objectives are presented in Box 1 below; more details of the specific sub-objectives are presented in Appendix 1.

As Box 1 shows, the set of objectives in *Valuing People* cover the whole spectrum of health, social care and education supports for people with learning disabilities. They are clearly a very demanding set of objectives for services to achieve. They are also a challenge to the Government in terms of the information the Government needs to evaluate the impact of *Valuing People* on the lives of people with learning disabilities. The *Valuing People* objectives require the collection of “joined-up” information across a wide range of services. They also require the collection of information concerning the following types of information (see Hallam & Knapp, 2004):

**Resources.** Broadly speaking, resources are what services have at their disposal to support people with learning disabilities. This can include money (how much services are spending), buildings and staff. It might also include the needs of the person with learning disabilities being supported that might have an impact on the resources required to support him or her, such as the person’s physical and mental health needs or self-care skills.

**Processes.** Processes are what services do with the resources they have. This can include both the quantity and quality of services provided: are there enough services, are they accessible to people with learning disabilities, and do services support people quickly, flexibly, reliably and fairly?

**Outcomes.** Outcomes are about the lives of people with learning disabilities and their families. A service might have lots of resources and be using them well, but are these services having any positive impact on the lives of people with learning disabilities, for example in health, well-being, self-determination and rights?

To evaluate the objectives and sub-objectives in *Valuing People*, information is needed on aspects of resources, processes and outcomes, with a particular emphasis on outcomes for people with learning disabilities and their families.

## **Box 1: Valuing People Objectives**

**OBJECTIVE 1: DISABLED CHILDREN AND YOUNG PEOPLE.** To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

**OBJECTIVE 2: TRANSITION INTO ADULT LIFE.** As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

**OBJECTIVE 3: MORE CHOICE AND CONTROL.** To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need.

**OBJECTIVE 4: SUPPORTING CARERS.** To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

**OBJECTIVE 5: GOOD HEALTH.** To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

**OBJECTIVE 6: HOUSING.** To enable people with learning disabilities and their families to have greater choice and control over where, and how, they live.

**OBJECTIVE 7: FULFILLING LIVES.** To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

**OBJECTIVE 8: MOVING INTO EMPLOYMENT.** To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

**OBJECTIVE 9: QUALITY.** To ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value.

**OBJECTIVE 10: WORKFORCE AND PLANNING.** To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

**OBJECTIVE 11: PARTNERSHIP WORKING.** To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

The Government and other organizations collect a substantial amount of information relevant to services for people with learning disabilities at a national level. Most of this information is in the form of statistical returns from local agencies (for example councils, NHS Trusts, schools) to various Government departments. These returns are then analysed and published, often on an annual basis. They are also often analysed and used by inspection bodies such as the Commission for Social Care Inspection and the Healthcare Commission to evaluate the performance of councils and NHS Trusts (hence they are often called **performance indicators**). There are also several surveys regularly conducted by the Office for National Statistics on nationally representative samples of the general population that may include some information relevant to people with learning disabilities.

However, it is recognised that much of this information may be of limited value in evaluating the objectives and sub-objectives of *Valuing People*. There are several reasons why this may be so:

- Most information is collected by individual government departments on specific services, making it difficult to combine information for the evaluation of the “joined-up” objectives in *Valuing People*.
- Much of the information collected is relatively inaccessible, particularly to non-specialists such as people with learning disabilities and their families.
- To analyse trends over time, the information collected and the questions asked have to be consistent over many years. This means that much of the information collected may reflect old policy priorities rather than the newer objectives outlined in *Valuing People*.
- The information collected may not identify people with learning disabilities as a specific sub-group of people using a particular service.
- Because most of the information is collected from services about people with learning disabilities rather than from people with learning disabilities directly, most of this information concerns service resources and processes, rather than the outcomes of these services for people with learning disabilities and their families.

One way in which the Department of Health has acknowledged these potential limitations in the way information is collected is to commission the project described in this report.

## **The Project**

This report outlines the findings of the first phase of a research project commissioned as part of the Department of Health’s Learning Disability Research Initiative. The Learning Disability Research Initiative is a policy research programme designed to investigate aspects of the implementation of the White Paper *Valuing People*. This research project has the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level. The project has three phases:

**Phase 1:** To locate and map existing national data sources relevant to services for people with learning disabilities, and to assess their potential usefulness for evaluating the impact of *Valuing People*.

**Phase 2:** To work with people with learning disabilities, family members and other stakeholders to identify what information should be collected at a national level to enable the Government to evaluate the impact of *Valuing People*.

**Phase 3:** To develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*.

The first phase of this research project has the following objective and sub-objectives:

- To locate and map existing national data sources relevant to learning disability services/outcomes, with a view to:
  - assessing their reliability and accessibility;
  - identifying significant data gaps, particularly against the objectives of *Valuing People*;
  - producing an initial report on services for people with learning disabilities before the introduction of *Valuing People* in March 2001.

We used several methods to identify national data sources potentially relevant to people with learning disabilities:

- Reviewing information on potential data sources compiled by the Department of Health;
- Contacting the statistics divisions of a wide range of Government departments and other agencies collecting national information potentially relevant to people with learning disabilities;
- Contacting the Office for National Statistics concerning national surveys;
- Reviewing national statistics database internet sites;
- Reviewing national statistics database publications;
- Where possible, conducting secondary data analyses of national survey data to ascertain whether information was available concerning people with learning disabilities;
- Asking all contacts for information on other potential national data sources and contacts.

For all potential data sources available from statistical returns, we collected the following information from the people responsible for analysing the data, websites and publications, using a standardised form:

- Name of data source and agency responsible for the dataset;
- The type of information collected;
- The frequency of data collection and the earliest and latest dates for which information was available at the time of contact;
- Who the information is obtained from;
- The geographical area covered by the information;
- The groups of people included in and described by the dataset;
- How the information is collected and an assessment of the quality of the information;
- What the information is used for;

- Potential relevance to specific Valuing People objectives;
- Contact details and details of how to access the dataset.

This report describes the results from Phase 1 of the project. The report includes a description of the information publicly available from national statistical returns to Government departments and other agencies relevant to people with learning disabilities (see Section 2). This includes a brief description of each dataset, and where possible headline information from each dataset, comparing year 2000-2001 figures (before the publication of *Valuing People*) to the most recent comparable figures available at the time of writing. It is important to note that this report only describes summary information for England as a whole; for many datasets information can be broken down geographically enabling the comparison of regions, councils or NHS agencies. Generally, comparisons at a local level reveal extremely wide variation between local agencies on most of the statistics reported here. It is also important to note that any figures presented on expenditure or costs are the actual costs at the time the information was collected; that is, they are not adjusted for inflation. This is important to bear in mind when interpreting information on changes in expenditure or costs over time.

More standardised information on each dataset in table form is available in Appendix 2; an index to the datasets is presented in Appendix 3, and Appendix 4 outlines the potential relevance of each dataset to specific *Valuing People* objectives. Appendix 5 presents a list of acronyms commonly used when discussing these datasets, and Appendix 6 acknowledges the people and organisations who helped us with this phase of the project.

Information is also presented on national surveys potentially relevant to people with learning disabilities (see Section 3), with a description of each survey and its strengths and limitations concerning people with learning disabilities. Finally, the report draws some conclusions about the potential relevance of current datasets for evaluating the objectives of *Valuing People* (see Section 4).

## National Statistical Returns

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Many government departments currently collect information concerning people with learning disabilities and the services they use. This information is typically collected through statistical returns, where branches of government funded services (such as local authorities, NHS services or education authorities) submit information in a standardised form to the government. Statistical returns are usually collected on a regular basis, typically every year, with summaries of most statistical data being made available on the internet.

This section of the report will briefly describe the national government datasets we have found so far that include information concerning people with learning disabilities. They are organized according to the government department collecting the information; more details on each of the datasets are available in Appendix 2.

The nature of the information collected by statistical returns makes it difficult to organize the datasets by *Valuing People* objectives (datasets may contain information relevant to more than one objective, or information not covered by any of the objectives). Appendix 4 presents a summary of how each dataset potentially relates to each of the *Valuing People* objectives.

Unless specifically stated otherwise, the definition of learning disability/disabilities used is administrative; that is, decisions on who to include as a person with learning disabilities are made by the local organization providing the statistical return to the government, rather than based on a standard definition or classification system.

Where possible, this section also includes some headline information from the dataset being described.

## Department of Health

Many statistical returns collected by the Department of Health include information on people with learning disabilities. Information will be presented here according to individual datasets (comprehensive tabulated information on the characteristics of each dataset is available in Appendix 2).

### Community Care Statistics Supported Residents (index data source 2)

This information is based on statistical returns from councils with social service responsibilities (see <http://www.dh.gov.uk/assetRoot/04/09/62/52/04096252.pdf>), and includes information on adults with learning disabilities (age 18-64) in England whose accommodation is funded (but not necessarily directly managed) by that council. Summary information is also available for individual councils. Relevant information includes:

- The number of people being supported by the council in various types of residential services.

Council supported residents	31 March 2001	31 March 2004
Total	31,075	35,780
Council staffed	5,835	3,890
Registered – independent residential	22,885	28,710
Registered – independent nursing home	985	1,860
Unstaffed - other	1,370	1,320

- The number of people admitted to these services over a financial year, on both a temporary (including short-term support or respite care) and a permanent basis.

Admissions 1 April 2003 – 31 March 2004	Temporary	Permanent
Total	99,315	2,640
Council staffed	70,375	215
Registered – independent residential	22,305	2,035
Registered – independent nursing home	1,360	260
Unstaffed - other	5,280	135

- The number of people supported by the council in residential services outside the boundaries of the council. On 31 March 2004, 11,005 adults aged 18+ with learning disabilities were placed in residential services outside the council boundary. For all people in council funded residential accommodation, the number of adults aged 18+ in residential services outside the council boundary rose from 44,000 on 31 March 2001 to 49,100 on 31 March 2004, although information on the number of adults with learning disabilities in accommodation outside the council boundary on 31 March 2001 is not currently published.

## Community Care Statistics – Private Nursing Homes, Hospitals and Clinics (index data source 1)

This dataset provides information on the number of independent sector registered nursing beds for people with learning disabilities in England (see <http://www.dh.gov.uk/assetRoot/04/02/29/94/04022994.pdf>). This information is most recently available for the financial years 2000-2001, and is available for 2001 NHS regions and 2001 Health Authorities. Responsibility for collecting this information, in a revised format, is now with the Commission for Social Care Inspection. Relevant information includes:

- The number of registered independent sector nursing beds intended for use by people with learning disabilities. On 31 March 2001, there were 3,772 such beds in total; 1,422 in general nursing homes, 2,344 in mental nursing homes, and 6 in private hospitals/clinics.
- The number of occupied independent sector nursing beds occupied by people with learning disabilities. On 31 March 2001 there were 3,410 beds occupied by people with learning disabilities (230 by people aged under 18, 2,630 by people aged 18-64, and 550 by people aged 65 or over).
- The number of registered nursing staff (learning disability) employed in these services. On 31 March 2001, there were 1,870 LD-registered nurses permanently employed (1,690 whole-time equivalent), and 140 temporary/agency/bank LD-registered nurses (60 whole-time equivalent).

## Inpatients formally detained in hospitals under the Mental Health Act (1983) and other legislation (index data source 6)

Rather than using the term learning disabilities, this dataset uses terms from the Mental Health Act (1983); namely mental impairment and severe mental impairment, and are collected annually on the basis of financial years (see <http://www.dh.gov.uk/assetRoot/04/09/72/92/04097292.pdf>). Relevant information includes:

- People detained as inpatients under the Mental Health Act (1983) 2003-2004.

Patients detained under the Mental Health Act (1983) in England – 31 March 2004	All	NHS Trusts	Independent hospitals
Total – mental impairment	957	586	371
Total – severe mental impairment	135	98	37

- The number of formal admissions under the Mental Health Act (1983) 2003 – 2004.

Number of formal admissions under the Mental Health Act (1983) in England – 2003-2004	Mental impairment	Severe mental impairment
Total	127	20
Part II admissions	82	18
Court & prison disposals	41	2
Previous legislation	4	0

## Hospital Activity Statistics (index data source 10; see also data source 15)

This information is collected from NHS healthcare providers on a quarterly basis and summarised both quarterly and annually using financial years (see <http://www.performance.doh.gov.uk/hospitalactivity/>). Summary information is available at the level of Strategic Health Authorities and NHS Trusts, and includes the following information concerning people with learning disabilities:

- The number of available and occupied beds designated for people with learning disabilities in England, according to age categories and type of bed.

Available and occupied NHS beds - England	2000-2001		2003-2004	
	Available	Occupied	Available	Occupied
Total	6,316	5,886	5,212	4,385
Child – short stay	281	189	229	147
Child – long stay	95	66	59	41
Other ages – secure	431	408	514	470
Other ages – short stay	1,323	1,110	1,210	955
Other ages – long stay	4,186	3,731	3,199	2,771
Residential care beds	3,703	No data	2,881	2,693

- The number of outpatient attendances to hospital-based learning disability consultants in England.

Outpatient attendances – learning disability consultants	2000-2001	2003-2004
First attendances - seen	7,497	7,908
First attendances – did not attend (DNA)	851	848
Subsequent attendances - seen	82,731	84,472
Subsequent attendances – did not attend (DNA)	8,136	8,779
Total attendances – seen	90,228	92,380
Total attendances – did not attend (DNA)	8,987	9,627

- The number of attendances at NHS day care facilities in England by people with learning disabilities. In 2002-2003, there were 2,846 people with learning disabilities registered as regular attendees of NHS day care facilities.

Attendances at NHS day care facilities	2000-2001	2002-2003
All attenders		
First attendances	No data	2,538
Total attendances	843,106	805,857
Regular attenders		
First attendances	No data	1,817
Total attendances	No data	687,270
Patients using hospital bed		
First attendances	No data	721
Total attendances	No data	118,857
Number of people on register 31 March	No data	2,846

## Hospital Episode Statistics (index data source 8)

This information is collected from NHS healthcare providers in England and summarised on an annual basis according to financial years (see <http://www.dh.gov.uk/PublicationsAndStatistics/Statistics/HospitalEpisodeStatistics/f/s/en>). Unlike most other data sources, for a person to count as having a learning disability a medical consultant has decided that “mental retardation” is the person’s primary diagnosis, according to standard ICD-10 criteria set out by the World Health Organization (World Health Organization, 1992). More specific information according to the nature of the “mental retardation” (mild, moderate, severe, profound, other, unspecified) and basic information on the person’s behaviour (statement of no/minimum impairment of behaviour; significant impairment of behaviour requiring attention/treatment; other impairments of behaviour; without mention of impairment of behaviour) are available. However, summary data are not provided for people with learning disabilities by individual NHS Trusts, or according to the nature of the healthcare interventions conducted. The following information is available concerning hospital services for people with learning disabilities, although it is important to note that these statistics may include people resident in NHS hospitals, and they also include information concerning births of children recognised as having a learning disability:

- Information on finished consultant episodes (periods of continuous in-patient hospital stays under the same medical consultant): in 2000-2001 there were 18,781 finished consultant episodes, compared to 14,625 in 2003-2004.
- Information on admissions to hospital:

Admissions to hospital	2000-2001	2003-2004
All admissions	17,709	14,160
Admissions - male	9,985	8,544
Emergency admissions	1,723	2,045

- Information on waiting lists

Waiting list information	2000-2001	2003-2004
Number of people admitted from a waiting list	7,112	2,476
Average waiting time (days)	7	16
Median waiting time (days)	1	10

- Information on length of stay in hospital, the number of day cases and the total number of bed days:

Length of stay, day cases and total bed days	2000-2001	2003-2004
Average length of hospital stay (days)	193.5	79.3
Median length of hospital stay (days)	3	3
Number of hospital day cases	415	212
Total bed days	361,608	202,151

- Information on the age of people in contact with hospital services:

Age (years)	2000-2001	2003-2004
Average age	22	25
Age 0-14	6,550	3,677
Age 15-59	11,849	10,730
Age 60-74	280	172
Age 75+	102	44

**Health Service Waiting Times (data source 13; see also data sources 12, 14, 16, 17, 18, 19 and 20)**

This information on the number of people waiting for ordinary hospital inpatient admissions, hospital day case admissions and hospital outpatient admissions is provided by healthcare providers and commissioners in England on a quarterly basis (see <http://www.performance.doh.gov.uk/waitingtimes/>). Information is available on a summary basis for England according to the hospital “specialty function” that people can be referred to; this includes “mental handicap”. Information is also available on an NHS/provider basis (i.e. the number of people on the waiting lists of English NHS hospitals, including private patients and patients referred from outside England); and a population-based/commissioner basis (i.e. the number of referrals made by English commissioners, even if the person has been referred to a hospital outside England). Relevant information includes:

- People waiting for admission as an “ordinary” hospital inpatient:

Number of people waiting for admission as “ordinary” hospital inpatients	1/1/2001 to 31/3/2001	1/1/2004 to 31/3/2004
NHS-based figures – total waiting	4	20
Patients waiting <3 months	3	12
Patients waiting 3-5 months	1	6
Patients waiting 6+ months	0	2
Population-based figures – total waiting	5	7
Patients waiting <3 months	5	5
Patients waiting 3-5 months	0	2
Patients waiting 6+ months	0	0

- People waiting for admission as day cases. In the two quarters compared above, there were no people waiting for admission as day cases to the “mental handicap” specialty.

- People referred for a first hospital outpatient appointment:

Number of people waiting for a first hospital outpatient appointment in the “mental handicap” specialty	1/1/2001 to 31/3/2001	1/1/2004 to 31/3/2004
NHS-based figures – number of GP written referral requests	956	1,312
Patients waiting <4 weeks	541	716
Patients waiting 4 to <13 weeks	358	644
Patients waiting 13 to <26 weeks	42	54
Patients waiting 26+ weeks	15	0
N. patients not yet seen waiting 13 to <26 weeks	16	5
N. patients not yet seen waiting 26+ weeks	1	0
Population-based figures – number of GP written referral requests	1,198	863
Patients waiting <4 weeks	734	478
Patients waiting 4 to <13 weeks	404	406
Patients waiting 13 to <26 weeks	47	22
Patients waiting 26+ weeks	13	0
N. patients not yet seen waiting 13 to <26 weeks	10	1
N. patients not yet seen waiting 26+ weeks	1	0

### Community Care Statistics – Referrals, Assessments and Packages of Care (RAP) (index data source 3)

This information is collected annually from councils with social service responsibilities in England using financial years, and has been fully in operation for three years (see <http://www.dh.gov.uk/assetRoot/04/10/43/62/04104362.pdf>).

Summary information is available for individual councils. Information relevant to adults with learning disabilities (aged 18+) in England includes:

- Information on assessment/review, such as:

Number of adults with learning disabilities in England with completed assessments/reviews	2000-2001 (assessments)	2003-2004 (assessments or reviews)
Total	28,500	72,000
18-64	24,000	66,000
65+	4,800	5,600

Anticipated sequel to assessment	2000-2001	2003-2004
Some or all (new) services started/Some (new) services intended but none started	17,000	28,000
No (new) services offered or intended	7,300	34,000
(New) service(s) offered but declined	500	800
Other sequel	3,700	9,300
Sequel not known	No data	No data

Estimated length of time from first contact to completed assessment for new clients – assessments completed	2000-2001	2003-2004
Total assessments completed	3,600	8,000
Less than or equal to 2 days	700 (19.4%)	1,500 (18.8%)
>2 days and less than or equal to 2 weeks	700 (19.4%)	1,200 (15%)
>2 weeks and less than or equal to 3 months	1,200 (33.3%)	2,800 (35%)
>3 months	1,000 (27.7%)	2,500 (31.3%)

- Information on service receipt following assessment, such as:

Estimated length of time from first contact to first service	2000-2001	2002-2003
Total	1,800	5,900
On contact day or next day	300 (17%)	1,100 (19%)
>1 day up to 1 week	200 (11%)	600 (10%)
>1 week up to 2 weeks	100 (6%)	400 (7%)
>2 weeks up to 6 weeks	300 (17%)	1,100 (19%)
>6 weeks up to 12 weeks	300 (17%)	800 (14%)
>12 weeks up to 6 months	200 (11%)	800 (14%)
>6 months	300 (17%)	1,100 (19%)

Estimated number of clients receiving services following assessment	2000-2001	2003-2004
All services	109,000	128,000
Community-based services	91,000	98,000
Day care	58,000	57,000
Meals	2,100	1,900
Home care – home help and overnight respite in person's home	9,100	22,000
Overnight respite elsewhere	11,000	14,000
Short-term residential care (not respite)	4,900	4,900
Direct payments	200	1,900
Professional support	25,000	34,000
Transport	12,000	14,000
Equipment and adaptations	3,600	5,300
Other	8,700	13,000
Local authority residential care	6,300	4,100
Independent sector residential care	25,000	35,000
Nursing home care	1,600	3,400

Estimated number of clients receiving services by ethnic group	2000-2001	2003-2004
Total	109,000	128,000
White	81,400	96,000
Mixed	300	600
Asian/Asian British	1,700	3,000
Black/Black British	1,600	2,500
Other	1,100	1,000
Not declared/known/reconciliation item	23,000	24,900

### **Services provided by Community Learning Disability Nursing Services (index data source 7)**

This information is collected annually from a range of NHS healthcare providers across England, although this dataset is being discontinued beyond the 2003-2004 financial year (see <http://www.dh.gov.uk/assetRoot/04/09/24/54/04092454.pdf> ). Information collected includes:

- The number of initial contacts (new episodes of care): 24,000 in both 2000-2001 and 2003-2004.
- The number of first contacts (different persons receiving care): rising from 54,000 in 2000-2001 to 57,000 in 2003-2004.
- Information on referrals: 17% of referrals were from hospitals in 2000-2001 compared to 16% of referrals in 2003-2004. Of the 23,900 initial contacts in 2003-2004, 13,300 were male referrals and 10,600 female referrals. 4,400 referrals were aged under 16; 12,900 referrals were aged 16-44; 5,400 referrals were aged 45-64; and 1,200 referrals were aged 65 or more.

### **Personal Social Services Expenditure and Unit Costs (index data source 9 and index data source 44)**

This information is collected from councils with social service responsibilities in England annually based on financial years, and has been collected in its current form since 2000-2001 (see <http://www.dh.gov.uk/assetRoot/04/10/40/01/04104001.pdf>) for Personal Social Services expenditure and unit costs. The Institute of Public Finance also produces detailed annual digests of personal social services expenditure derived from the same return (see <http://www.cipfastats.net/socialservices/pssactuals/default.asp>) at a current cost of £300. All expenditure figures are based on actual prices at the time rather than prices adjusted to take account of inflation over time. Summary information is available on the Department of Health website for individual councils; information relevant to services for adults with learning disabilities aged 18-64 years includes:

- Gross personal social services expenditure by type of service:

Gross personal social services expenditure (in millions)	2000-2001	2003-2004
Total	£1,751.9	£2,370.6
Assessment and care management	£104.8	£152.7
Nursing home placements	£35.1	£63.2
Residential care homes	£877.6	£1,174.0
Supported/other residential services	£102.8	£163.5
Direct payments	£1.6	£14.4
Home care	£110.9	£175.3
Day care	£451.4	£558.6
Equipment and adaptations	£0.7	£0.8
Meals	£1.0	£1.5
Other services	£66.3	£66.6

- Unit costs of personal social services:

Unit costs of personal social services – pounds per person per week (unadjusted costs)	2000-2001	2003-2004
Nursing care	£750	£699
Residential care – all provision	£706	£738
Residential care – own provision	£850	£943
Residential care – other provision	£672	£716
Home care	£214	£266
Direct payments	£160	£174
Day care	£221	£245

#### **Social Services Staff in Social Services Departments (index data source 4)**

This information is collected from councils with social service responsibilities in England on an annual basis, with a census date of 30 September (see <http://www.dh.gov.uk/assetRoot/04/10/70/53/04107053.pdf>). Information is available on:

- The number of social services day care staff for adults with learning disabilities: 13,300 (whole time equivalent) staff in 2001 and 13,300 in 2004. Of the day care staff in 2004, 69.7% were female (30.3% male), and 85.2% were white (with 8.8% unknown ethnicity and 6.0% from black and minority ethnic communities).
- The number of social services residential care staff for adults with learning disabilities: 10,500 (whole time equivalent) staff in 2001 increasing to 10,600 staff in 2004. Of the residential care staff in 2004, 76.7% were female (23.3% male), and 82.9% were white (with 9.5% unknown and 7.6% from black and minority ethnic communities).

## **Learning Disabilities Delivery Improvement Statement (LD DIS) (index data source 38)**

This dataset collates information collected from councils with social service responsibilities (these can be estimates rather than counts for some indicators) and other sources, and is now the responsibility of the Commission for Social Care Inspection. Information is collated twice every year, with annual summaries available on CD-ROM (for some indicators there are substantial numbers of councils with no returns). This information is intended to be a comprehensive set of performance indicators for social care services for people with learning disabilities, and the set of performance indicators is revised annually according to current policy priorities. Performance indicators from the LD DIS can also be included in the “Top 50” set of indicators that are used as the basis for the star ratings of council social services, the Personal Social Services Performance Assessment Framework (see below). For Autumn returns (2003 – 2004); the set of performance indicators in the DIS relevant to people with learning disabilities included:

- The amount spent by each council on advocacy expressed as the amount per head of people with learning disabilities known to the council (£59.89 in 2000-2001; £92.84 in 2002-2003).
- The percentage of adults with learning disabilities receiving community based services who are receiving direct payments (0.38% in 2000-2001; 1.06% in 2002-2003).
- The percentage of adults with learning disabilities receiving community based services who are receiving short term breaks (19.60% in 2000-2001; 21.3% in 2003-2004).
- The unit cost of residential and nursing care for adults with learning disabilities (£667.42 in 2000-2001; £736.8 in 2003-2004).
- The number of adults with learning disabilities helped to live at home per 1,000 population aged 18-64 (2.45 in 2000-2001; 2.7 in 2003-2004).
- The gross expenditure on day care for adults with learning disabilities as a percentage of expenditure on all non-residential services (71.28% in 2000-2001; 66.39% in 2002-2003).
- The proportion of expenditure on day and domiciliary services for people with learning disabilities to expenditure on residential provision for people with learning disabilities (0.71% in 2000-2001; 0.9% in 2003-2004).
- The number of people with learning disabilities in work as a percentage of those with learning disabilities known to the council (10.10% in 2000-2001; 11.3% in 2003-2004).
- The proportion of people with learning disabilities receiving services who are from minority ethnic groups (0.60% in 2000-2001; 1.4 in 2003-2004).
- The number of people with learning disabilities known to the local council per 1,000 population (3.52 in 2000-2001; 3.29 in 2002-2003).
- The percentage of staff working in learning disability services achieving at least NVQ Level 2 (22.83% in 2000-2001; 35.4% in 2003-2004).
- The total Learning Disabilities Development Fund (LDDF) (average £128,300 per council in 2003-2004).
- The amount of total LDDF spent:

- promoting the further development of advocacy (average £27,200 per council in 2003-2004);
- supporting the wider introduction of person centred planning (average £31,700 per council in 2003-2004);
- developing supported living approaches for people with learning disabilities living with older carers (average £20,500 per council in 2003-2004);
- modernising day services (average £25,300 in 2003-2004);
- enhancing leadership in learning disability services (average £14,000 in 2003-2004).

### **Social Services Performance Assessment Framework (PAF) (index data source 5)**

This information is collected from councils with social service responsibilities, and represent a “Top 50” set of indicators that are used as the basis for the star ratings of council social services (see <http://www.publications.doh.gov.uk/paf/index.htm>). Data forming the basis of the PAF are collected annually on the basis of financial years, and information is available for individual councils. Currently, two indicators in the PAF concern people with learning disabilities:

- The average gross weekly cost of residential and nursing care for adults with learning disabilities (aged 18-64). In 2000-2001 this cost was £644 per week, rising to £658 per week in 2002-2003.
- The number of adults with learning disabilities (aged 18-64) helped to live at home per 1,000 population. In 2000-2001 this was 2.5 people per 1,000; in 2002-2003 2.6 per 1,000.

### **People registered as blind and partially sighted (index data source 11)**

Information on the number of people registered as blind or partially sighted is collected from local authorities with social service responsibilities in England every three years. The most recent data was collected for 31 March 2003, and is available for people with learning disabilities (see <http://www.dh.gov.uk/assetRoot/04/08/02/45/04080245.xls>). At 31 March 2003:

- Of the 34,145 people registered as blind, 2,160 (6.3%) were people with learning disabilities.
- Of the 31,135 people registered as partially sighted, 1,250 (4.0%) were people with learning disabilities.

## Department for Education and Skills

Although the Department for Education and Skills (DfES) collects considerable statistical information, the classification systems used to identify people with learning disabilities in statistical returns are different from those used in other government departments. The DfES classifies pupils in statistical returns on the basis of the Special Educational Needs (SEN) statementing process; special educational needs is a term covering a broad range of needs, including sub-categories relating to “learning difficulty”, a term similar to but wider in scope than learning disability. Many of the statistics collected by the DfES include data on either special educational needs as a whole or on special schools as a whole; these data are not currently sub-divided into categories relevant to people with learning disabilities. As with Department of Health datasets, information will be presented here according to individual datasets, with comprehensive tabulated information available in Appendix 2 and a summary of how each dataset potentially relates to each of the *Valuing People* objectives available in Appendix 4.

### **Pupil Level Annual School Census (index data source 21) and Special Educational Needs in England (index data source 22)**

Information for these two sources is collected annually in January from all schools in England on an individual pupil basis, beginning in 2002. From January 2004, additional data concerning the special education needs (SEN) of pupils was also collected (see <http://www.dfes.gov.uk/rsgateway/DB/SFR/s000537/sfr44-2004v2.pdf>). Information concerning the number of pupils with SEN in total is available for individual Local Education Authorities, although this information is not broken down by specific types of SEN. The information available concerns the number of pupils at different stages of the SEN process (school action plus and statement of SEN, broken down by the number of pupils in primary schools, secondary schools and special schools.

	Moderate learning difficulty	Severe learning difficulty	Profound & multiple learning difficulty	Autistic spectrum disorder	Total*
<b>Primary schools</b>					
School Action Plus	71,540	3,430	300	5,330	218,680
SEN statement	13,770	3,900	840	10,610	69,610
<b>Secondary schools</b>					
School Action Plus	34,640	750	40	1,800	131,470
SEN statement	23,450	2,320	220	4,900	78,480
<b>All special schools</b>					
School Action Plus	140	390	190	160	1,650
SEN statement	28,380	21,230	6,190	8,450	88,890
<b>Total</b>					
School Action Plus	106,330	4,580	540	7,300	351,800
SEN statement	65,600	27,450	7,250	23,960	236,980

\*Total includes all SEN categories: specific learning difficulty; moderate learning difficulty; severe learning difficulty; profound & multiple learning difficulty;

behaviour, emotional and social difficulties; speech, language & communication needs; hearing impairment; visual impairment; multi-sensory impairment; physical disability; autistic spectrum disorder; other difficulty/disability; unclassified.

### **Connexions Partnership Management Information (index data source 23)**

Information from Connexions Partnership schemes has been collected quarterly since 2002. Information from Connexions Partnerships is collated by the DfES in Sheffield and is not yet routinely published, but information can be made available. The information concerns the cohort of young people aged 16-19 in England who have completed compulsory education and who are considered to have 'Learning Difficulties and Disabilities (LDD)'. The following information was made available to us for the cohort of 16-19 year-olds with LDD for June 2005:

Young people with Learning Difficulties & Disabilities (LDD) aged 16-19	Number	Percentage
<b>TOTAL</b>	<b>143,161</b>	<b>100%</b>
<b>In Education, Employment or Training (EET)</b>		
Full-time education	64,152	44.8%
Employment	31,716	22.2%
Government supported training	8,811	6.2%
Part-time education	414	0.3%
Part-time employment	1,566	1.1%
Personal development opportunities	862	0.6%
Gap year students	114	0.1%
<b>Not in Education, Employment or Training (EET)</b>		
Unemployed	14,141	9.9%
Supporting family – young carers	84	0.1%
Supporting family – teenage parents	1225	0.9%
Illness	1,520	1.1%
Pregnancy	382	0.3%
Not available on religious grounds	5	0.0%
Not economically active	329	0.2%
Other reason NA	291	0.2%
<b>Neither EET nor NEET</b>		
Custodial sentence	593	0.4%
Refugees/asylum seekers who have not yet been granted citizenship	5	0.0%
Current situation not known	16,951	11.8%

## Department for Work and Pensions

The Department for Work and Pensions (DWP) collects a large amount of information potentially relevant to people with learning disabilities. Published information can include data concerning people with learning disabilities, although the ways in which people with learning disabilities are identified are inconsistent and often unclear. Other information potentially relevant to people with learning disabilities is collected (e.g. the New Deal for Disabled People, index data source 34, which includes a category of learning difficulties) but not published according to specific types of disability such as learning disabilities. Finally, some very detailed information is collected by DWP but is not routinely collated or published. Information is presented here according to individual datasets, with comprehensive tabulated information available in Appendix 2 and a summary of how each dataset potentially relates to each of the *Valuing People* objectives available in Appendix 4.

### **Incapacity Benefit and Severe Disablement Allowance (index data source 24)**

Information is collected on a 5% sample of people claiming and receiving Incapacity Benefit and Severe Disablement Allowance (no new claimants from April 2001) in England, and used to estimate national figures (see [http://www.dwp.gov.uk/asd/ib\\_sda.asp](http://www.dwp.gov.uk/asd/ib_sda.asp)). Information is published quarterly. As with the Hospital Episode Statistics (index data source 8), for a person to count as having a learning disability a medical consultant has decided that “mental retardation” is the person’s primary diagnosis, according to standard ICD-10 criteria set out by the World Health Organization (World Health Organization, 1992). Published information is only available on the broader category of “Mental and behavioural disorders”, which includes mental health problems as well as “mental retardation”. Bearing this in mind, relevant information includes:

- The number of claimants and beneficiaries of Incapacity Benefit with “mental and behavioural disorders”:

Incapacity Benefit	31 August 2002	31 August 2004
Claimants - Total	833,000	915,900
Claimants - Men	477,200	523,000
Claimants - Women	355,900	392,600
Beneficiaries - Total	No data	461,200
Beneficiaries – Men	No data	276,900
Beneficiaries - Women	No data	184,400

- The number of people receiving Severe Disablement Allowance with “mental and behavioural disorders”:

Severe Disablement Allowance	31 August 2002	31 August 2004
Total	126,800	119,200
Men	62,200	59,100
Women	64,600	60,100

**Disability Living Allowance (index data source 25), Attendance Allowance (index data source 26) and Carers Allowance (index data source 27)**

As with the information on Incapacity Benefit and Severe Disablement Allowance, information is collected on a 5% sample of people receiving Disability Living Allowance, Attendance Allowance and Carers Allowance in England, and used to estimate national figures

(see [http://www.dwp.gov.uk/asd/asd1/dla/dla\\_quarterly\\_statistics\\_aug04.asp](http://www.dwp.gov.uk/asd/asd1/dla/dla_quarterly_statistics_aug04.asp)).

Information is collected quarterly. Information on the Disability Living Allowance and Attendance Allowance is published reporting the “main disabling condition” to be “learning difficulties”, regarded as a specific type of mental health problem in these statistics. For the Carers Allowance, information is not published concerning whether the person cared for has a learning disability. Relevant information includes:

- The number of people with ‘learning difficulties’ receiving Disability Living Allowance:

DLA allowances	31 August 2002	31 August 2004
Total	233,600	252,500
Core component only	26,500	28,600
Mobility component only	50,400	44,800
Core and mobility components	156,700	179,100

- The number of Disability Living Allowance awards made in the year 1 September to 31 August:

DLA awards	2001-2002	2003-2004
Total	14,200	13,400
Core component only	6,800	5,900
Mobility component only	700	500
Core and mobility components	6,600	7,000

- The number of people with ‘learning difficulties’ receiving Attendance Allowance (the number of Attendance Allowance awards is not published separately for people with learning difficulties):

Attendance Allowances	31 August 2002	31 August 2004
All	3,100	3,000
Higher rate	1,100	900
Lower rate	2,000	2,200

**The New Deal for Disabled People (index data source 32)**

This is a detailed administrative database, with data provided by Jobcentre Plus local office staff. Summary statistics are published up to March 2005 (see [http://www.dwp.gov.uk/asd/asd1/nddp/nddp\\_mar05/nddp\\_qtrly\\_national\\_mar05.pdf](http://www.dwp.gov.uk/asd/asd1/nddp/nddp_mar05/nddp_qtrly_national_mar05.pdf)); although they are not broken down into specific types of disability.

## **DWP databases that do not routinely publish information**

The DWP has several databases used for administrative purposes where information is not collated for publication. However, some of these databases may contain information relevant to people with learning disabilities. These databases include:

- **The Benefits Data Systems (index data source 28).** These are detailed administrative databases for managing benefit claims, with data provided by Jobcentre Plus local office staff. Information is collected on various characteristics of benefits claimants, including problems with mobility, memory, and the ability to concentrate, learn and understand, and a learning disability category.
- **The Labour Market System (index data source 29).** This database concerns people involved in Jobcentre Plus work-focussed activity, and is collected and recorded in a very similar way to the Benefits Data System.
- **Workstep (index data source 30).** This database concerns people supported through the Workstep Programme, again collected and recorded in a similar way to the Benefits Data System. This database includes a category of learning disability.
- **Work Preparation Programme (index data source 31).** This database is collected monthly by the DWP, and concerns the number of people involved in the Work Preparation Programme, a programme designed to help jobseekers with disabilities to find work. No information on specific disabilities is recorded.
- **Access to Work Programme (index data source 33).** This database is collected monthly by the DWP, and concerns the number of people involved in the Access to Work Programme, a programme designed to provide support to overcome barriers to people with disabilities working. No standardised information on specific disabilities is required, although details of a person's disability can be written in using a free text field.
- **Social Fund Policy, Budget and Management Information System (index data source 34).** This database is collected monthly using the Social Fund Computer System, and concerns expenditure on various types of Social Fund payments and loans. Data are collected on disability as a category of recipient, without any more specific data being collected.

## Office of the Deputy Prime Minister

The Office of the Deputy Prime Minister collects a substantial amount on information on housing and housing support, clearly relevant to people with learning disabilities. Information is presented here according to individual datasets, with comprehensive tabulated information available in Appendix 2 and a summary of how each dataset potentially relates to each of the *Valuing People* objectives available in Appendix 4.

### Disabled Facilities Grants (index data source 35)

Information in this database is collected annually by Local Authorities concerning the number of disabled facilities grants and expenditure on these grants by financial year, although it is not broken down into specific categories of disability (see [http://www.odpm.gov.uk/stellent/groups/odpm\\_housing/documents/page/odpm\\_housing\\_033342.pdf](http://www.odpm.gov.uk/stellent/groups/odpm_housing/documents/page/odpm_housing_033342.pdf)). Information is also available for regions.

- The number of disabled facilities grants rose from 24,730 in 2000-2001 to 37,170 in 2003-2004, with expenditure also rising (£131 million in 2000-2001 to £202 million in 2003-2004).

### Supporting People Client Record Data (index data source 36).

Information in this database concerns the Supporting People programme, which began on 1<sup>st</sup> April 2003 and provides housing related support services for vulnerable people. Data collection and analysis is managed by the Joint Centre for Housing Research (St Andrews and Dundee Universities). Records are collected for everyone newly in receipt of support from the Supporting People programme or people where their support has changed, with data now available for the financial year 2003-2004 (see [http://www.spkweb.org.uk/search/channels/www.spkweb.org.uk/subjects/client\\_records/annualreport2003\\_2004.pdf](http://www.spkweb.org.uk/search/channels/www.spkweb.org.uk/subjects/client_records/annualreport2003_2004.pdf)). Information is available for England, English regions and individual local authorities. Within each client record, the primary client group of the person is recorded, with learning disabilities being one of the categories. Up to three secondary client groups can also be recorded, again including learning disabilities as a possible category. Relevant information in this database includes:

- The number of people with learning disabilities receiving support from Supporting People. 5,012 people with a primary classification of learning disabilities received support, out of a total of 209,845 people receiving support from Supporting People. Of these 5,012 people, 2,085 (41.6%) had an additional secondary classification, the most common being mental health problems (566 people; 11.3%) and/or complex needs (449 people; 9.0%). In an additional 4,230 people, learning disabilities was recorded as a secondary classification.
- The ethnicity of people with learning disabilities receiving support from Supporting People. Data are available for 4,963 people, of which 4,529 (91.3%) were White; 190 (3.8%) were Black/Black British; 98 (2.0%) were Asian/Asian British; 65 (1.3%) were Mixed; 5 (0.1%) were Chinese and 9 (0.2%) were Other; 67 people (1.3%) refused to give information on their ethnicity.
- The source of referrals for people with learning disabilities. 4,710 referrals (94.0%) were from the person's host local authority and 302 referrals (6.0%) were from another local authority. Referral sources were as follows:

Referral source	Number	Percentage
Local housing authority	433	8.6%
Local authority housing department referral	857	17.1%
Social services	2,338	46.6%
Probation service/prison	29	0.6%
Community mental health team	62	1.2%
Voluntary agency	184	3.7%
Self-referral/direct application	463	9.2%
Nominated under HOMES	1	0.0%
Internal transfer	206	4.1%
Moving from another Registered Social Landlord (RSL)/Housing Association	39	0.8%
Health service/GP	64	1.3%
Youth Offending Team	5	0.1%
Police	15	0.3%
Other	316	6.3%

- The type of accommodation the person with learning disabilities was in immediately prior to receiving support from Supporting People:

Type of accommodation prior to Supporting People	Number	Percentage
General needs local authority tenant	1,119	22.4%
General needs Registered Social Landlord/Housing Association tenant	501	10.0%
Private rented	228	4.6%
Tied home/renting with job	3	0.1%
Owner occupier	27	0.5%
Supported housing	851	17.1%
Direct access hostel	106	2.1%
Sheltered housing	57	1.1%
Residential care home	374	7.5%
Hospital	120	2.4%
Prison	15	0.3%
Approved probation hostel	7	0.1%
Children's home/foster care	48	1.0%
Bed and breakfast	82	1.6%
Short life housing	10	0.2%
Living with family	926	18.6%
Staying with friends	97	1.9%
Any other temporary accommodation	101	2.0%
Rough sleeping	79	1.6%
Other	238	4.8%

- The type of service provided to people with learning disabilities through the Supporting People programme:

Service type	Number	Percentage
Supported housing	2,342	46.7%
Residential care home	91	1.8%
Adult placement	83	1.7%
Supported lodgings	98	2.0%
Women's refuge	9	0.2%
Foyers	18	0.4%
Teen parent accommodation	5	0.1%
Direct access accommodation	229	4.6%
Floating support	2,026	40.4%
Outreach service	46	0.9%
Resettlement services	65	1.3%

### **Supporting People supply information (no table)**

The Office of the Deputy Information also collects supply information on a quarterly basis from local agencies, including the number of households accessing services and the cost of Supporting People services. Information is collected using the subcategory of people with learning disabilities.

### **Homelessness Statistics (index data source 37).**

Information on homelessness is collected quarterly from local authorities in England, including information on the number of homeless families accepted by local authorities with a family member in various priority need categories (see <http://www.odpm.gov.uk/pns//pnattach/20040136/4.xls>). One of these categories is mental illness, which in this dataset includes learning disabilities. In 2000-2001 9,110 homeless families included a person with mental illness, rising to 12,170 in 2003-2004.

## Other Sources of National Data

There are several other national datasets maintained by agencies directly funded by government departments. Information is presented here according to individual datasets, with comprehensive tabulated information available in Appendix 2 and a summary of how each dataset potentially relates to each of the *Valuing People* objectives available in Appendix 4.

### **The Housing Corporation Performance Indicators (index data source 40)**

The Housing Corporation is sponsored by the Office of the Deputy Prime Minister to fund and regulate Housing Associations in England, and collects from housing associations with over 250 homes annual performance indicator information according to financial years (see [http://www.housingcorplibrary.org.uk/housingcorp.nsf/AllDocuments/8E30BA053843B35A80256E52005AC7F8/\\$FILE/R65report\\_web.pdf](http://www.housingcorplibrary.org.uk/housingcorp.nsf/AllDocuments/8E30BA053843B35A80256E52005AC7F8/$FILE/R65report_web.pdf)). This information includes indicators on rent, repairs, vacant dwellings, housing standards and tenant satisfaction. Information is broken down according to whether the houses are supported housing or general needs housing, and also according to specialist associations (those with over 90% of their stock in supported housing). No information is specifically available for people with learning disabilities.

### **Continuous Recording of Lettings (CORE) (index data source 41 and 42)**

Information in this database concerns people living in accommodation managed by Registered Social Landlords, primarily Housing Associations, although local authorities have been invited to contribute data from April 2004. Data collection and analysis is managed by the Joint Centre for Housing Research (St Andrews and Dundee Universities; see also Supporting People Client Record data, index data source 38) for the National Housing Federation and the Housing Corporation. Records are collected quarterly for everyone in accommodation managed by Registered Social Landlords, including general needs lettings, supported housing lettings and sales (information is available on CD-ROM up to 2001-2002; and on the internet from 2002-2003; see <http://www.core.ac.uk/pubs.htm>). Information is available for England, individual local authorities and individual Registered Social Landlord organizations. Within each client record for supported housing, the primary client group of the person is recorded, with learning difficulties being one of the categories. A wealth of information is available for people with learning difficulties living in supported housing rented from Registered Social Landlords, most recently for the financial year 2003-2004, including:

- Information on the number and characteristics of people with learning difficulties renting supported housing, including:
  - the total number of people (1,547 in 2000-2001; 1,802 in 2003-2004);
  - age and gender:

Age	2000-2001		2003-2004	
	Female	Male	Female	Male
16-17	35	45	26	58
18-59	502	801	554	969
60+	45	61	54	60
Total	582	907	634	1,087

- ethnicity:

Ethnic Group	2000-2001	2003-2004
White	1,426 (94.2%)	1626 (93.0%)
Asian/Asian British	18 (1.2%)	38 (2.1%)
Black/Black British	34 (2.2%)	37 (2.2%)
Mixed	12 (0.8%)	35 (2.1%)
Chinese	4 (0.3%)	2 (0.1%)
Other	6 (0.4%)	2 (0.1%)
Refused	13 (0.9%)	8 (0.5%)
Total	1,513	1,748

- economic status:

Economic Status	2000-2001	2003-2004
Full-time employment	42 (2.8%)	36 (2.1%)
Part-time employment	36 (2.4%)	55 (3.2%)
Government training scheme	17 (1.1%)	35 (2.0%)
Unemployed/seeking work	197 (13.0%)	246 (14.2%)
Retired	25 (1.6%)	36 (2.1%)
Not seeking work	102 (6.7%)	118 (6.8%)
Students	44 (2.9%)	51 (2.9%)
Sick/disabled	925 (60.9%)	1,071(61.7%)
New Deal	11 (0.7%)	8 (0.5%)
Other	121 (8.0%)	81 (4.7%)
Total	1,520	1,737

- weekly income: 2000-2001 average=£85.76 median=£74.75; 2003-2004 average=£88.74 median=£77.95;
- housing benefits received:

Housing Benefits	2000-2001	2003-2004
Housing benefit	1,197 (79.7%)	1,398(82.4%)
Residential allowance	184 (12.3%)	67 (3.9%)
Neither	29 (1.9%)	68 (4.0%)
Don't know	92 (6.1%)	164 (9.7%)
Total	1,502	1,697

- Information on the previous tenure of people with learning difficulties before moving to their current home:

Previous Tenure	2000-2001	2003-2004
Local authority tenant	89 (5.8%)	84 (4.7%)
Housing Association general needs tenant	67 (4.3%)	104 (5.8%)
Private tenant	50 (3.2%)	60 (3.3%)
Owning/buying	2 (0.1%)	2 (0.1%)
Living with family/friends	410 (26.5%)	516 (28.6%)
Hostel/shared housing	345 (22.3%)	349 (19.4%)
Probation/bail hostel	6 (0.4%)	5 (0.3%)
SC supported housing tenant	62 (4.0%)	115 (6.4%)
Children's home/foster care	29 (1.9%)	19 (1.1%)
Hospital	79 (5.1%)	82 (4.6%)
Prison	6 (0.4%)	8 (0.4%)
Residential care home	202 (13.1%)	232 (12.9%)
Bed and breakfast	23 (1.5%)	54 (3.0%)
Squatting	2 (0.1%)	3 (0.2%)
Sheltered accommodation	7 (0.4%)	15 (0.8%)
No fixed abode	40 (2.6%)	42 (2.3%)
Other	128 (8.3%)	112 (6.2%)
Total	1,547	1,802

- Information on homelessness before moving to their current home:

Homelessness	2000-2001	2003-2004
Not homeless	1,243 (80.4%)	1,382 (76.7%)
Statutory homeless	89 (5.8%)	166 (9.2%)
Other homeless	204 (13.2%)	245 (13.6%)
Children's Act 1989 referral	10 (0.6%)	9 (0.5%)
Total	1,546	1,802

- Information on the reason for the person's requiring a move to their current housing:

Reason for Current Housing	2000-2001	2003-2004
From short-stay hostel	73 (4.7%)	81 (4.5%)
From institution	278 (18.0%)	228 (12.7%)
To supported self-contained accommodation	274 (17.7%)	372 (20.6%)
To higher support accommodation	292 (18.9%)	380 (21.1%)
Required to leave home	112 (7.2%)	155 (8.6%)
Rough sleeper	37 (2.4%)	45 (2.5%)
Racial harassment	2 (0.1%)	No data
Other harassment	25 (1.6%)	41 (2.3%)
Domestic violence	17 (1.1%)	10 (0.6%)
Physical health	16 (1.0%)	17 (0.9%)
Refugee/asylum seeker	2 (0.1%)	No data
To special adapted accommodation	38 (2.5%)	12 (0.7%)
Leaving family/friends	153 (9.9%)	129 (7.2%)
Alcohol/drug rehabilitation	1 (0.1%)	1 (0.1%)
Probation service order	1 (0.1%)	6 (0.3%)
Evicted	16 (1.0%)	34 (1.9%)
Other	210 (13.6%)	291 (16.1%)
Total	1,547	1,802

- Information on the source of referral initiating the move to current accommodation:

Source of referral	2000-2001	2003-2004
Nominated by local authority	140 (9.0%)	214 (11.9%)
Housing department	23 (1.5%)	47 (2.6%)
Social services	782 (50.5%)	854 (47.4%)
Probation service/prison	41 (2.6%)	22 (1.2%)
Health service/GP	88 (5.7%)	57 (3.2%)
Another Housing Association	22 (1.4%)	24 (1.3%)
Internal transfer	154 (10.0%)	224 (12.4%)
Self-referral/direct application	92 (5.9%)	139 (7.7%)
Youth service	7 (0.5%)	13 (0.7%)
Advice agency	20 (1.3%)	21 (1.2%)
Other voluntary agency	89 (5.8%)	99 (5.5%)
Police	1 (0.1%)	No data
Domestic violence unit	2 (0.1%)	No data
Other	86 (5.6%)	88 (4.9%)
Total	1,547	1,802

- Information on the current accommodation of people with learning difficulties, including:
  - Average weekly rent (£65.91 in 2000-2001; £67.28 in 2003-2004) and total charges (£183.33 in 2000-2001; £195.38 in 2003-2004);

- Tenancy type;

Tenancy Type	2000-2001	2003-2004
Fair rent	9 (0.6%)	8 (0.4%)
Assured	509 (32.9%)	563 (31.2%)
Assured shorthold	403 (26.1%)	589 (32.7%)
Licence agreement	605 (39.1%)	613 (34.0%)
Other	21 (1.4%)	29 (1.6%)
Total	1,547	1,802

- Type of accommodation;

Type of Accommodation	2000-2001	2003-2004
Self-contained flat	277 (18.0%)	398 (17.1%)
Self-contained flat – common facilities	169 (11.0%)	288 (12.4%)
Shared flat	57 (3.7%)	64 (2.8%)
Shared house or hostel	961 (62.3%)	1,439 (62.0%)
Bungalow	65 (4.2%)	103 (4.4%)
Self-contained house	14 (0.9%)	29 (1.2%)
Total	1,543	2,321

- Type of support provided;

Type of Support Provided	2000-2001	2003-2004
Resettlement support	111 (7.2%)	47 (34.0%)
Internal housing management (IHM)	437 (28.3%)	No data
Counselling/support service and IHM	417 (27.0%)	No data
Substantial care/support	541 (35.1%)	No data
Nursing care services	13 (0.8%)	23 (16.6%)
Floating support	24 (1.6%)	68 (49.3%)
Total	1,543	138

- Mobility standards;

Mobility Standards	2000-2001	2003-2004
Aids/adaptations	153 (10.3%)	136 (7.7%)
Mobility standards	444 (29.8%)	640 (36.1%)
Wheelchair standards	217 (14.6%)	253 (14.3%)
None	675 (45.3%)	742 (41.9%)
Total	1,489	1,771

### Higher Education Statistics Agency (index data source 39) and Learning and Skills Council (index data source 43 and 48)

These organizations collect annual data (by academic year) on the number and characteristics of post-school students in higher education (see <http://www.hesa.ac.uk/pi/>) and other forms of post-16 education (see <http://www.lsc.gov.uk/National/Partners/Data/Statistics/Default>). No information is

published concerning people with learning disabilities specifically, although the Learning and Skills Council records information on learning difficulty/disability.

### **The Independent Living Funds (index data source 46)**

These funds are available to support people with disabilities in the UK. Information is published quarterly on the characteristics of people receiving support from the Independent Living Funds (ILF) and the support provided (see <http://www.ilf.org.uk/>). Although information is broken down into applicant need (including severe learning disability), published information is only provided on the total number of people with severe learning disability receiving ILF support in the UK; 4,908 people (29.5% of all people receiving ILF support) at 30 September 2004.

### **The Commission for Social Care Inspection (CSCI) Registration and Inspection Database (index data source 47)**

The CSCI maintain a continuous electronic database of a range of services registered for inspection purposes, with services for people with learning disabilities recorded on the database (see <http://www.csci.org.uk/>). The information is not published but can be made available. It is important to note that this database records the number of services and places specifically registered as being for people with learning disabilities; it does not record the actual number of people with learning disabilities using services, as some services include people with learning disabilities but are not set up specifically for them (e.g. fostering agencies) and not all available places are taken up. Information that was made available to the project for July 2004 includes:

- The number of services and places for children with learning disabilities;

Type of Service	Number of services	Number of places	Average number of places per service
Boarding schools	0	0	n/a
Children's homes	510	3912	7.7
Foster agencies	0	0	n/a
LA fostering agencies	0	0	n/a
Further education college	1	0	n/a
LA adoption service	0	0	n/a
Residential family centres	0	0	n/a
Residential special schools	0	0	n/a
Voluntary adoption service	0	0	n/a

- The number of services and places in care homes for adults with learning disabilities;

Type of Service	Number of services	Number of places	Average number of places per service
Care homes – personal care only	6,226	50,541	8.1
Care homes – with nursing	274	6,508	23.8
Care homes – adult placement	391	826	2.1
Care homes – non-medical	5	38	7.6
Total	6,896	57,913	8.4

## Government Funded Surveys

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In addition to statistical returns, government departments fund or co-fund a range of surveys that potentially address issues pertinent to evaluating the impact of *Valuing People*. In this section we briefly describe and summarise the strengths and limitations of those surveys from which it is possible to derive nationally representative estimates. This means that we only include surveys that either cover the whole population (e.g., the Census) or use sampling strategies that enable us to draw conclusions about the population of England.

### Total Population Surveys: The Census

The Census is undertaken every 10 years by the Office for National Statistics and seeks to collect information on every person resident in the UK. The 2001 Census included a question on whether the person completing it had a 'limiting long-standing illness or disability'. However, no other information was collected regarding the nature of this disability. As a result, it is not possible to identify whether people who complete the Census have learning disabilities.

The 2001 Census did, however, collect information on people living in 'communal establishments'. These include all living situations in which people are living with others who are not related to them and where people share some communal facility (e.g., kitchen). 'Communal establishments' include hospitals, residential care homes and (possibly) supported living arrangements. The 2001 Census collected information on people living in 7,653 'communal establishments' for people with learning disabilities in England and Wales.

Similar information from the 1991 Census was used to provide an overview of supported accommodation for people with learning disabilities in Britain (Emerson & Hatton, 1996, 1998). No reports on the number, location or nature of 'communal establishments' have been published by the Office for National Statistics and it is unlikely whether any such reports will be published. It is possible, however, to commission the preparation of relevant data from the Office for National Statistics<sup>1</sup>.

For further information on the 2001 Census:

<http://www.statistics.gov.uk/census2001/default.asp>

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<sup>1</sup> [http://www.statistics.gov.uk/census2001/pdfs/com\\_order\\_form.pdf](http://www.statistics.gov.uk/census2001/pdfs/com_order_form.pdf)

## Nationally Representative Surveys

In addition to the Census, government departments commission a range of large-scale annual or occasional surveys that provide information that is representative of the population (or a segment of the population) of people in England. In almost all instances, anonymous raw data from these surveys is deposited in the UK Data Archive (<http://www.data-archive.ac.uk>) from where it can be accessed, often at no cost, by registered users.

### Annual Cross-Sectional Surveys

Government departments commission a small number of large-scale annual surveys that collect information on the living conditions of people in England. These surveys are not longitudinal in nature (i.e., they do not track people over time). Instead they seek to collect a nationally representative sample each year. These surveys include the General Household Survey (GHS), the Family Resources Survey (FRS), the Health Survey for England (HSE), the Labour Force Survey (LFS), the British Crime Survey (BCS), the Expenditure and Food Survey (EFS), the Survey of English Housing (SEH), the Annual Population Survey (APS) and the National Statistics Omnibus Survey (NSOS).

With the exception of the APS and EFS, all of these surveys include a screening question on whether each person included in the survey has a 'limiting long-standing illness or disability' (although the exact wording of this question does vary across surveys). For the FRS, NSOS and SEH this is the only information collected. As a result, it is not possible to identify whether people who are included in these surveys have learning disabilities.

The remaining surveys include a supplementary question that is included if the person identifies themselves (or the person they are providing information about) as having a 'limiting long-standing illness or disability'. This supplementary question takes different forms in different surveys, but usually involves people identifying their disabilities from a preset list.

- In the GHS this list contains the item 'learning difficulties'. Analysis of the 2002 GHS indicated that 0.18% of people included (0.37% of children) were identified as having 'learning difficulties'.
- In the HSE this list contains the item 'mental handicap'. Analysis of the data accumulated by HSE from 1991 to 2002 indicated that 173 people (of the 186,820 on whom information had been collected) were identified as having 'mental handicap'. This is equivalent to a prevalence rate of 0.09%.
- In the LFS this list contains the item 'severe or specific learning difficulties (mental handicap)'. Analysis of the quarterly LFS for June-August 2004 indicated that 0.6% of people included were identified as having 'severe or specific learning difficulties (mental handicap)'.
- BCS respondents are specifically asked whether they have 'learning disabilities'. Analysis of the 2002 BCS indicated that 0.6% of people included were identified as having 'learning disabilities'.

The Office for National Statistics (who undertake or manage most of these surveys) are planning, from 2008, to replace the LFS, APS, GHS, EFS and NSOS with one

Continuous Population Survey (CPS: [http://www.statistics.gov.uk/about/consultations/ons\\_consultations/downloads/CPS\\_Consultation.pdf](http://www.statistics.gov.uk/about/consultations/ons_consultations/downloads/CPS_Consultation.pdf) ). This will include an item on limiting long-standing illness. It is not clear, however, whether this will include a follow-up item that would allow the identification of respondents who have learning disabilities.

## **Longitudinal Surveys**

Government departments have commissioned a number of nationally representative longitudinal or panel surveys in order to address specific policy issues. Each of these surveys attempts to follow up a group of people or households over a period of time. Some surveys 'refresh' the panel by recruiting new members to compensate for people dropping out of the survey. These surveys include the British birth cohort surveys, the British Household Panel Survey (BHPS), the Families and Children Study (FACS), the Youth Cohort Survey (YCS), Next Steps (NS) survey and the UK Biobank.

The BHPS and YCS include a screening question on whether each person covered in the survey has a 'limiting long-standing illness or disability'. No further information is collected regarding the nature of the person's disability. As a result, it is not possible to identify whether people who are included in these surveys have learning disabilities.

### *Birth Cohort Surveys*

There are three birth cohort surveys, each of which is designed to follow-up across the lifespan a cohort of children born at a specific point in time.

- The National Child Development Study (NCDS) is following up children born between 3/3/58 and 9/3/58. Information has been collected on this cohort when participants were 7, 11, 16, 23, 33 and 42 years of age.
- The 1970 British Cohort Study (BCS) is following up children born between 5/4/70 and 11/4/70. Information has been collected on this cohort when participants were 5, 10, 16, 26 and 30 years of age.
- The Millennium Cohort Study (MCS) is following up a representative sample of children born between 1/9/2000 and 31/8/2001 (for England and Wales). Information has been collected on this cohort when participants were 9 months old and is currently being collected at age 3 years. Further rounds of data collection are scheduled when the children are 5 and 7 years of age.

It is possible, by using a combination of variables across successive waves of the NCDS and BCS to identify participants who have learning disabilities. For example, researchers have used NCDS data to look at the living conditions and wellbeing of adults with mild learning disabilities (Maughan, Collishaw & Pickles, 1999). In the most recent round of data collection (2000) identical data was collected by interview for both the NCDS and BCS cohorts. In this round of data collection 1.2% of NCDS and 1.5% of BCS cohort members were identified as having 'learning difficulties'.

The first wave of the MCS collected information on infant development using selected items from the Developmental Screening Test. It would be possible to use

these data to identify infants who were developmentally delayed. It should in future waves of the MCS be possible to identify children who have learning disabilities.

### *Families and Children Study*

FACS is a refreshed panel survey that will run from 1999 to 2006. The data collected in Waves 1-4 (1999-2002) are now available. Initially, FACS was designed to be representative of lone parents and low-income couples with children in Britain. From 2001 onwards the sample was expanded to include moderate to high-income couples with children. It is possible, by using a combination of variables within and/or across successive waves to identify children who have learning disabilities. For example, researchers have used FACS data to look at the association between poverty, supporting a child with learning disabilities and maternal well-being (Emerson, Hatton & Llewellyn, 2004).

### *Next Steps*

This is a longitudinal survey commissioned by the Department for Education and Skills. It plans to follow-up an initial sample of 21,000 young people drawn from Year 9 records at 690 schools in England in school year 2003/4. Approximately 6,000 of the sample are from ethnic minority groups split equally between the main 6 groups. Wave 1 of the data collection will be completed by June 2005. It is expected that it will be possible to identify children with learning disabilities in this survey.

### *UK Biobank*

The UK Biobank Project is funded by the Medical Research Council, the Wellcome Trust biomedical research charity, the Department of Health and the Scottish Executive. It aims to collect information on genes, environment and lifestyle of 500,000 middle-aged adults in the UK. It then aims to monitor the health of participants over their lifetime. It is not clear at present how or whether people with learning disabilities will be included in this project or, if included, whether they will be identified as having learning disabilities. Further information on the UK Biobank Project is available at: <http://www.biobank.ac.uk/>

## **Occasional Surveys**

Finally, government departments commission a wide range of one-off national surveys, three of which are particularly pertinent to the situation of people with learning disabilities.

### *English Survey of Adults with Learning Disabilities*

The Department of Health have commissioned the British Market Research Bureau (BMRB), Central England People First and the Institute for Health Research at Lancaster University to undertake a survey of the living conditions of adults with learning disabilities in England. It involves face to face interviews with 2,750 adults in general households and different types of supported accommodation. Information is being collected on accommodation, employment, education & training, leisure, social relationships, finance & hardship, health, transport, health behaviours, and support

needs. The data will be deposited in the UK Data Archive in September 2005. The final report will be presented to the Department of Health in June 2005. Further information is available at:

<http://www.lancs.ac.uk/fss/ihr/research/learning/projects/natsurvey.htm>

#### *Family Resources Survey Disability Follow-Up*

This involved the collection of additional information on 7,300 people with disabilities that were identified in the 1996/7 Family Resources Survey. Informants were asked about the nature of their disability and the presence and severity of current functional limitations. While it would be possible to use these data to identify a subset of informants who had learning disabilities, initial inspection of the data identified only 60 informants as having learning disabilities.

#### *DWP Disability Survey*

In 2004, the Department for Work and Pensions commissioned the National Centre for Social Research (<http://www.natcen.ac.uk/>) to undertake a feasibility study looking at how Government medium to long term information needs on the experiences of disabled people could best be met. The report will be published in Summer 2005. DWP will take forward the findings from this work in determining how they organize their future research on a broad range of disability issues. It is possible that this will include a longitudinal survey and the expectation is that any such study will make particular efforts to include people from specific impairment groups (such as those with learning disabilities, mental health conditions and progressive conditions).

## Conclusions

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As will hopefully be clear from Chapters 2 and 3, Government departments and other agencies collect a substantial amount of information potentially relevant to people with learning disabilities. Before discussing this information in more detail, we thought it would be useful to present a brief snapshot of what the available information tells us about current services for people with learning disabilities, and what changes there have been since the introduction of *Valuing People*.

### The Current Picture

This section summarises some headline information from the statistical returns described in detail in Section 2, based on the most recent data available at the time of writing. The information is broadly organized around the headings used for the 11 objectives of *Valuing People*; however, it will become apparent that very little of the available information maps directly on to Valuing People objectives or sub-objectives. In particular, the available information almost exclusively focuses on service resources or service processes, with very little information on outcomes for people with learning disabilities.

#### Disabled Children and Young People

In January 2004, there were almost 240,000 children with a statement of Special Educational Needs and a further 350,000 with a Special Educational Needs status of 'School Action Plus'. Over 170,000 of these children (29%) were in the Moderate Learning Difficulty category, of whom 50% were in primary schools, 34% were in secondary schools and 17% were in special schools. Approximately 32,000 children (5%) were in the Severe Learning Difficulty category, of whom 23% were in primary schools, 10% were in secondary schools and 68% were in special schools. Almost 8,000 children (1%) were in the Profound and Multiple Learning Difficulty category, of whom 15% were in primary schools, 3% were in secondary schools and 82% were in special schools. Over 31,000 children (5%) were in the Autistic Spectrum Disorder category, of whom 51% were in primary schools, 21% were in secondary schools and 28% were in special schools.

At July 2004, there were over 500 children's homes specifically registered for children with learning disabilities, with a total of almost 4,000 places.

#### Transition Into Adult Life

According to the Connexions service, in the second quarter of 2005 there were over 143,000 young people aged 16-19 with learning disabilities who had completed compulsory education; the largest proportion of this cohort (45%) were in full-time education. A further 22% of young people were in employment, with 6% in Government supported training schemes and 10% unemployed. For 12% of young people with learning disabilities, their current situation was not known to the Connexions service.

## **More Choice and Control**

Of the average £128,300 Learning Disabilities Development Fund money received per council in 2003-2004, an average £27,200 was spent on promoting the further development of advocacy services and an average £31,700 on supporting the wider introduction of person-centred planning.

In 2003-2004, an estimated 1,900 adults with learning disabilities were using direct payments, at expenditure to social services of 14.4 million pounds (unit cost £174 per person per week).

The number of adults receiving direct payments in 2002-2003 was an estimated 1.1% of total number of adults with learning disabilities using community-based services.

Local authorities spent an estimated £92.84 on advocacy services per person with learning disabilities known to them in 2002-2003.

At 30 September 2004, almost 5,000 people with learning disabilities were receiving support from the Independent Living Fund.

## **Supporting Carers**

In 2003-2004, social services expenditure on home care was 175.3 million pounds (unit cost £266 per person per week); expenditure on equipment and adaptations was 0.8 million pounds. Of the average £128,300 Learning Disabilities Development Fund money received per council in 2003-2004, an average £20,500 was spent on developing supported living services for people with learning disabilities living with older carers.

In 2003-2004, there were an estimated 14,000 adults with learning disabilities using social services overnight respite care away from the person's home, an estimated 22,000 people using overnight respite care in their own home and using home care/help. In 2003-2004, there was an estimated 4,900 people using short-term residential care and 5,300 people receiving equipment or adaptations.

An estimated 20.6% of people with learning disabilities known to local authorities used short-term breaks in 2002-2003. An estimated 2.6 adults with learning disabilities per 1,000 total population aged 18-64 were helped to live at home in 2002-2003, rising to 2.7 in 2003 – 2004.

## **Good Health**

In 2003-2004, there were over 100,000 outpatient appointments made with hospital-based learning disability consultants, 90% of which were kept. Information on inpatient hospital services for people with learning disabilities are also available; however these figures may include long-stay residents in NHS accommodation and births of children recognised as having a learning disability, and may exclude many people with learning disabilities admitted to other hospital services. On this basis, there were approximately 14,000 admissions to inpatient hospital services for people with learning disabilities in 2003-2004 (17% of these are people admitted from a

waiting list and 14% are emergency admissions). There were almost 15,000 inpatient hospital episodes in 2003-2004, with a median length of hospital stay of three days.

According to NHS waiting list figures, only seven people with learning disabilities in England were waiting for admission as an “ordinary” hospital inpatient (2004, 1<sup>st</sup> quarter). In the same period there were 863 GP written requests for referrals to hospital-based learning disability consultants.

Over 1,000 people with learning disabilities were detained as inpatients under the Mental Health Act (1983) in 2003-2004, with 37% of these people being detained in independent hospitals.

In 2003-2004, Community Learning Disability Nursing services reported 24,000 initial contacts with people with learning disabilities, and 57,000 different people with learning disabilities receiving support from a Community Learning Disability Nursing service.

## **Housing**

In 2003-2004, social services expenditure on residential care homes was 1,174.0 million pounds (unit cost £738 per person per week), with a further 163.5 million pounds being spent on supported/other residential services and 63.2 million pounds spent on nursing home placements (unit cost £699 per person per week).

Almost 36,000 adults with learning disabilities aged 18-64 were living in council supported housing services at 31 March 2004; 77% of these people were living in registered independent residential homes. However, 11,000 adults with learning disabilities aged 18+ were placed by councils in residential services outside the council boundary.

According at the Commission for Social Care Inspection, at July 2004 there were almost 7,000 registered care homes specifically for adults with learning disabilities; almost all of these were care homes offering personal care only (90%). Care homes with nursing were larger (average 24 places per home) than care homes offering personal care only (average 8 places per home) and care homes offering adult placement (average 2 places per home).

There were over 5,000 available NHS beds of various types designated for people with learning disabilities in 2003-2004; most of these were long-stay beds for adults.

Of the almost 210,000 people receiving support from the Supporting People programme in 2003-2004, approximately 5,000 people (2%) were given a primary classification of learning disabilities, with approximately 4,200 people (2%) given a secondary classification of learning disabilities. Of the people with a primary classification of learning disabilities supported by Supporting People, 91% were white. The vast majority of people were receiving support in the form of supported housing (46%) or floating support (40%). Before receiving this support, people were living in a wide range of accommodation, the most common being a general local authority tenancy (22%), living with family (19%), supported housing (17%) or a residential care home (8%). Referrals to the Supporting People programme were

most commonly made by social services (47%) or local authority housing departments (17%), although 9% of people with learning disabilities made a direct application.

Between 2003-2004, there were 1,802 people with learning disabilities living in accommodation managed by Registered Social Landlords; 93% of these people were white and 60% were male. People were living primarily in shared houses or hostels (62%), self-contained flats (17%) or self-contained flats with common facilities (12%); and most commonly held assured tenancies (31%), assured shorthold tenancies (33%) or licence agreements (34%). The average rent paid by people with learning disabilities in 2003-2004 was £67.28 per week, although the total charges made by Registered Social Landlords was £195.38. Almost all people with learning disabilities received housing benefit (82%) or residential allowance (4%). The most common forms of support offered by Registered Social Landlords in 2002-2003 were substantial care/support (40%), internal housing management with a counselling/support service (36%) and internal housing management alone (17%). Before moving to their current home, people with learning disabilities were likely to be living in residential care homes (13%), living with family/friends (29%) or in hostels/shared housing (19%); 23% of people were classified as homeless before moving to their current home.

### **Fulfilling Lives**

In 2003-2004, social services expenditure on day services was 558.6 million pounds (unit cost £245 per person per week), with an estimated 57,000 adults with learning disabilities using social services day care. Of the average £128,300 Learning Disabilities Development Fund money received per council in 2003-2004, an average £25,300 was spent on modernising day services.

There were almost 3,000 people with learning disabilities registered as regular attendees at NHS day care facilities in England in 2002-2003, with a total of over 800,000 attendances (each day is counted as an attendance) by people with learning disabilities at NHS day care facilities in England.

In 2003-2004, 34,000 adults with learning disabilities were estimated to be receiving support from a professional, and 14,000 people were using social services transport.

### **Moving Into Employment**

According to the Connexions service, in the second quarter of 2005, 22% of young people aged 16-19 with learning disabilities who had completed compulsory education were in employment; a further 6% were in Government supported training schemes and 10% were unemployed.

An estimated 11.3% of adults with learning disabilities known to the council were “in work” in 2003-2004, according to local authorities.

Of the 1,737 people with learning disabilities living in accommodation managed by Registered Social Landlords in 2003-2004, most were classified as sick/disabled (62%), with 2% in full-time employment, 3% in part-time employment and 2% in Government training schemes or New Deal programmes. People's average income was £88.74 per week.

### **Quality**

There was no available information directly relevant to the quality of services.

### **Workforce and Planning**

On 30 September 2004, there were 13,300 whole time equivalent social services day care staff and 10,600 social services residential care staff.

In 2003-2004, an estimated 35% of staff working in services for people with learning disabilities had achieved an NVQ qualification at Level 2 or higher.

Of the average £116,070 Learning Disabilities Development Fund money received per council in 2002-2003, an average £9,170 was spent on enhancing leadership in services for people with learning disabilities.

### **Partnership Working**

There was no available information directly relevant to partnership working.

### **Other**

Overall, £2,370.6 million was spent on personal social services for people with learning disabilities in 2003-2004; £152.7 million was spent on assessment and care management and £66.6 million was spent on 'other' services.

Councils received an average £128,300 from the Learning Disabilities Development Fund in 2003-2004.

In 2002-2003, it was estimated that people with learning disabilities known to local authorities constituted 3.3 people per 1,000 in the local population.

In 2003 – 2004 it was estimated that 128,000 adults with learning disabilities were receiving some form of support from social services. In terms of ethnicity, 75% of these adults were white and the ethnicity of 19% was not recorded; 6% of adults were from minority ethnic communities. It has also been estimated that 1.4% of the people with learning disabilities using services in 2003-2004 were from minority ethnic communities.

There were 72,000 adults with learning disabilities with completed social services assessments or reviews in 2003-2004, with 39% of these adults starting some new services and/or planning to start new services and 47% not being offered new services on the basis of the assessment.

Of the 8,000 social services assessments completed in 2003-2004, 34% were completed within two weeks of first contact with social services, but 31% were completed more than three months after first contact. Of the 5,900 people for whom estimates were available in 2002-2003, 36% were estimated to be receiving their first service within two weeks of first contact with social services, although 19% had not received services more than six months after first contact.

At 31 August 2004, it was estimated that over 250,000 people with learning disabilities were receiving Disability Living Allowance, with 11% receiving the core component only, 18% receiving the mobility component only and 71% receiving both components. At the same date an estimated 3,000 people with learning disabilities were receiving Attendance Allowance, 30% at the lower rate and 73% at the higher rate.

## **Change Over Time**

The timeframes for which data are available at the time of writing (typically two or three years) are probably too short to expect wholesale changes in the national picture in response to *Valuing People*. Nevertheless, there are some trends over time that can be observed in national statistical returns; it is for others to judge whether these trends are a result of the introduction of *Valuing People*.

### **Disabled Children and Young People**

There is no available information directly relevant to assessing change over time concerning children and young people with learning disabilities.

### **Transition into Adult Life**

There is no available information directly relevant to assessing change over time concerning transition into adult life.

### **More Choice and Control**

From 2000-2001 to 2003-2004, the number of adults with learning disabilities using direct payments increased by 850%, from 200 to 1,900 people. Social services expenditure on direct payments also increased over this time period by 800%, with unit costs per person increasing by 9%. It was estimated that the number of adults with learning disabilities using direct payments as a proportion of all adults with learning disabilities using community-based services rose from 0.4% in 2000-2001 to 1.1% in 2002-2003.

The amount local authorities spent on advocacy services per person with learning disabilities known to them increased by 55% from 2000-2001 to 2002-2003.

## **Supporting Carers**

From 2000-2001 to 2003-2004, social services expenditure on home care increased by 58% (unit costs per person increased by 11%); expenditure on equipment and adaptations also increased by 14%.

From 2000-2001 to 2003-2004, the number of adults with learning disabilities using social services overnight respite care away from the person's home increased by 27%. The estimated number of people using short-term residential care remained the same at 4,900 clients during this period. The estimated number of households with an adult with learning disabilities using home help services increased by 266%, and the number of people receiving equipment or adaptations also increased by 47%.

From 2000-2001 to 2003-2004, the estimated proportion of people with learning disabilities known to local authorities using short-term breaks increased from 19.6% to 21.3%. The estimated number of adults with learning disabilities per 1,000 total population aged 18-64 helped to live at home also increased, from 2.5 per 1,000 in 2000-2001 to 2.7 per 1,000 in 2003-2004.

## **Good Health**

The number of appointments made with hospital-based learning disability consultants increased by 2% in three years, although the proportion of people not attending these appointments remained constant at 10%.

Information on inpatient hospital services for people with learning disabilities are also available; however these figures may include long-stay residents in NHS accommodation and births of children recognised as having a learning disability, and may exclude many people with learning disabilities admitted to other hospital services. On this basis, over three years the number of admissions to inpatient hospital services for people with learning disabilities dropped by 20% (the proportion of people admitted from a waiting list also dropped from 40% to 17%). However, the number of emergency admissions increased by 19% over this period. The number of inpatient hospital episodes also dropped by 22% over this period, with the median length of hospital stay remaining constant at three days.

According to NHS waiting list figures, the number of people with learning disabilities in England waiting for admission as an "ordinary" hospital inpatient remained consistently low over a three-year period (5 people in the 1<sup>st</sup> quarter of 2001; 7 people in the 1<sup>st</sup> quarter of 2004). Across the same period the number of GP written requests for referrals to hospital-based learning disability consultants dropped by 28%.

From 2000-2001 to 2003-2004, there was no change in the number of initial contacts with people with learning disabilities reported by Community Learning Disability Nursing services (24,000), and an increase of 6% in the number of different people with learning disabilities receiving support from a Community Learning Disability Nursing service.

## **Housing**

From 2000-2001 to 2003-2004, social services expenditure on residential care homes increased by 34% (unit costs per person increased by 5%), with an increase of 59% in expenditure on supported/other residential services and an increase of 80% in expenditure on nursing home placements (unit costs per person decreased by 7%).

The number of people with learning disabilities in council-supported residential homes increased from 2000-2001 to 2003-2004; by 25% for registered independent residential homes and by 89% for registered independent nursing homes. However, the number of people with learning disabilities in council-staffed housing services dropped by 33%.

The number of NHS beds designated for people with learning disabilities dropped in all categories from 2000-2001 to 2003-2004 by 20% except for secure beds, which showed an increase of 19%.

From 2000-2001 to 2003-2004, the number of people with learning disabilities living in accommodation managed by Registered Social Landlords increased by 16%, with the proportion of white people (93% - 94%) and men (61% to 63%) remaining relatively constant. There were fairly consistent increases in the number of people living in all types of accommodation, with larger than average proportional increases in less common accommodation types (self-contained flats with common facilities; bungalows; self-contained houses) and a smaller than average proportional increase in shared flats. The number of people with licence agreements increased by 1% from 2000-2001 to 2003-2004, with increases of 11% in the number of assured tenancies and 46% in the number of assured shorthold tenancies. The average rent paid by people with learning disabilities increased by 2% over this time period and the total charges made by Registered Social Landlords increased by 7%. The number of people with learning disabilities receiving housing benefit increased by 17%, although the number of people receiving residential allowance dropped by 64%. Further, from 2000-2001 to 2003-2004 there was a decrease (58%) in the number of people receiving resettlement support.

## **Fulfilling Lives**

From 2000-2001 to 2003-2004, social services expenditure on day services increased by 24% (unit costs per person only increased by 11% over this period), although the estimated number of adults with learning disabilities using social services day care remained reasonably constant over this period at 57,000 - 58,000 people.

The total number of attendances at NHS day care facilities in England dropped by 4% from 2000-2001 to 2002-2003.

From 2000-2001 to 2003-2004, there was an increase of 36% in the number of adults with learning disabilities estimated to be receiving support from a professional, and an increase of 17% in the estimated number of people using social services transport.

## **Moving into Employment**

The estimated proportion of adults with learning disabilities known to the council who were in work increased from 10.1% in 2000-2001 to 11.3% in 2003-2004.

From 2000-2001 to 2003-2004, of the number of people with learning disabilities living in accommodation managed by Registered Social Landlords, the proportion of people classified as sick/disabled increased slightly from 61% to 62%, with the proportion of people in full-time employment dropping from 3% to 2%, the proportion of people in part-time employment slightly increasing from 2% to 3% and the proportion of people in Government training schemes or New Deal programmes increasing from 1% to 2%. People's average weekly income over this period increased by 3%.

## **Quality**

There is no available information directly relevant to assessing change over time concerning the quality of services for people with learning disabilities.

## **Workforce and Planning**

From 2001 to 2004 the number of social services day care staff remained constant at 13,300 whole time equivalent staff, with the number of social services residential staff increasing by 1% from 10,500 (whole time equivalent) staff in 2001 to 10,600 staff in 2004.

From 2000-2001 to 2003-2004, the estimated proportion of staff working in services for people with learning disabilities achieving an NVQ qualification at Level 2 or higher increased from 23% to 35%.

## **Partnership Working**

There is no available information directly relevant to assessing change over time concerning partnership working.

## **Other**

From 2000-2001 to 2003-2004, there was an increase of 35% in the total expenditure on personal social services for people with learning disabilities; there was a 46% increase in expenditure on assessment and care management, although expenditure on 'other' services remained virtually constant (an increase of 0.5%).

Overall, it has been estimated that the proportion of people with learning disabilities known to local authorities per 1,000 in the local population remained similar (3.5 per 1,000 in 2000-2001; 3.3 per 1,000 in 2002-2003). From 2000-2001 to 2003-2004, there was a 17% increase in the estimated number of adults with learning disabilities receiving some form of support from social services. In terms of ethnicity, the proportion of white adults remained constant at 75%; the proportion of people where their ethnicity was not declared/not known or classed as a reconciliation item reduced slightly (21% to 19%), and there was a small increase in the proportion of adults from

minority ethnic communities (4% to 5.5%). It has also been estimated that the proportion of people with learning disabilities known to services from minority ethnic communities increased from 0.6% in 2000-2001 to 1.4% in 2003-2004.

The number of adults with learning disabilities with completed social services assessments or reviews increased by 153% from 2000-2001 to 2003-2004, although some of this increase is due to changes in information presentation from 2002-2003. The proportion of these adults starting some new services and the proportion of adults where new services were planned decreased from 2000-2001 to 2003-2004 (60% to 39%), and the proportion of adults not being offered new services on the basis of the assessment rose from 26% to 47%.

From 31 August 2002 to 31 August 2004, there was an increase of 8% in the estimated number of people with learning disabilities receiving Disability Living Allowance. There was an 8% increase in the number of people receiving the core component only, an 11% decrease in the number of people receiving the mobility component only and a 14% increase in the number of people receiving both components. Over the same time period the estimated number of people with learning disabilities receiving Attendance Allowance dropped by 3%, with an 18% drop in the number of people receiving the lower rate but a 10% increase in the number of people receiving the higher rate.

## **How Useful Is The Available Information?**

It is clear that collecting regular statistical information on a national basis is crucial for the Government (and others) to evaluate progress in supporting people with learning disabilities. Collecting information on this basis can:

- Provide comprehensive information for the whole of England, rather than relying on small, unrepresentative samples of people with learning disabilities in particular areas.
- Provide detailed information on trends over time, if the information is collected in the same way year after year.
- Provide information that can be analysed on a local basis, so that comparisons can be made between regions or between individual local authorities or NHS services.
- Provide information on the coverage of services for people with learning disabilities: are services being provided that meet the needs and demands of people with learning disabilities and their families; and are services provided fairly to all people with learning disabilities, for example in terms of ethnicity or gender?
- Provide information on the resources allocated to services for people with learning disabilities; are enough resources being allocated to people with learning disabilities, and are those resources being used wisely?

However, statistical returns collected on a national basis have a number of limitations.

First, the information collected in statistical returns often lags behind current policy priorities:

- To analyse trends over time, the information collected needs to be consistent over time, meaning that the information collected in statistical returns often lags behind current policy priorities.
- Information is collected using the information systems of local agencies (typically local authorities or NHS services), which are often devised specifically to provide the information required in statistical returns. This means that changing the information required involves substantial negotiation with local agencies and considerable lead-in times to enable local agencies to change their information systems.
- New policy priorities often do not come with clearly specified objectives that can be easily evaluated using national statistical returns.

Second, there are potential limitations in the quality and reliability of the information collected through statistical returns:

- To collect information efficiently, the information is collected by local agencies (typically local authorities or NHS services) and is reliant on the accuracy of local information systems. Although statistical returns are often checked for obvious errors or inconsistencies, a more thoroughgoing examination of the accuracy of the information provided is extremely resource-intensive.
- Providing accurate information also relies on accurately identifying people as having a learning disability; it is extremely unlikely that different agencies are identifying people with learning disabilities consistently.
- Most of the information collected through statistical returns does not allow the consistent analysis of sub-groups of people with learning disabilities, for example by age, gender or ethnicity. Such information is important in evaluating whether services are being provided fairly.

Third, there are limitations in the types of information typically collected through statistical returns:

- The information collected has to be numerical to allow the information to be collated and analysed statistically. This means that certain aspects of people's experience (particularly relevant to outcomes) may not be easily obtained using statistical returns.
- Information for statistical returns is collected from local agencies through their information systems, which typically collect information from services rather than directly from the people using those services. This typically results in a focus on service resources and service processes, although there is no principled reason why information on outcomes could not be collected directly from service users and entered into local information systems. However, collecting information directly from people with learning disabilities and their families would require much greater resources than most local agencies currently allocate to information collection.

There are also specific problems with using the information reviewed in this report to evaluate the situation of people with learning disabilities. First, there are considerable inconsistencies in the definition and operationalisation of learning disabilities:

- Government departments in their requests for statistical returns rarely provide a clear definition or operationalisation of learning disabilities for local agencies to use when collecting information. Instead, they rely on local agencies to use their own administrative definitions, which are themselves often unclear and inconsistent across agencies.
- Within and across Government departments, a multitude of terms are used for people with learning disabilities, some of which reflect terms currently used by Government (learning difficulties, learning disabilities) and some which do not (mental handicap, mental retardation, mental impairment). It is unclear whether these different terms are all being used to refer to the same group of people.
- Within some statistical returns, people with learning disabilities are treated as a sub-group of people with mental health problems; the rationale for this is unclear.

Second, most of the available information is relatively inaccessible:

- Although most agencies responsible for statistical returns have made great progress in making information freely available and publicly available on the internet, much of this information is not easily signposted or presented in ways that would be more accessible to non-specialists.
- Because information is collected by a wide range of agencies, information is made available separately by each agency, with no single agency responsible for pulling together all the information potentially relevant to people with learning disabilities.
- Within some statistical returns information is collected on people with learning disabilities but not regularly made available publicly. This information can sometimes be made available if specifically requested, although there can be a charge for these services.
- A small number of agencies do not make their information freely available and charge for access to the information.
- People accessing information currently may be offended by terms such as mental handicap or mental retardation, or by the classification of people with learning disabilities as a sub-group of people with mental health problems.

Third, there is little evidence of joined-up working between Government departments and other agencies involved in the collection of statistical information concerning people with learning disabilities:

- As mentioned previously, different agencies do not provide a consistent definition and operationalisation of learning disabilities for local agencies to work towards, and use inconsistent definitions and terms within as well as across agencies.
- Different agencies often collect apparently similar information from local agencies in ways that are inconsistent, increasing the information collection burden on local agencies.
- Most of the objectives and sub-objectives of *Valuing People* require evaluation across different types of service and support, whereas most current statistical returns focus on specific types of service and support associated with the particular Government agency collecting the information.

Fourth, much of the information in statistical returns is collected at the level of services specifically designated for people with learning disabilities, rather than at the level of people with learning disabilities using both specialist and mainstream services and supports. If *Valuing People* and *Improving The Life Chances of Disabled People* are successful in their objectives, then people with learning disabilities will become increasingly invisible within information systems as people with learning disabilities use specialist services less and mainstream services and supports more.

Fifth, there may be some challenges in using *Valuing People* objectives and sub-objectives to drive the information collected through national statistical returns:

- The *Valuing People* objectives and sub-objectives are written quite broadly, and would need to be tightened up and clearly operationalised before they could be evaluated using statistical information. It may also be useful to clearly describe statistical information in terms of resources, processes and outcomes.
- The Government and other agencies may still wish to collect information not directly relevant to the objectives of *Valuing People*; for example in evaluating expenditure on services used by people with learning disabilities.
- It is currently unclear whether the objectives of *Valuing People* are the most relevant objectives for people with learning disabilities and their families.
- Issues of equality of access are rarely written directly into the *Valuing People* objectives and sub-objectives; it is important not to lose sight of issues such as disability and race equality as required by legislation.
- Many *Valuing People* objectives require information across a range of services and agencies; the current structure of information collection within individual Government departments makes collecting this “joined-up” information challenging.
- As mentioned earlier, most information collected through statistical returns concerns service resources and service processes, with little emphasis on outcomes for people with learning disabilities and their families. To collect information on outcomes (particularly in terms of outcomes such as choice and control) will require substantial investment in gaining information directly from people with learning disabilities and their families. This is currently beyond the resources (both in interviewer time and expertise) of most of the agencies that provide statistical returns to Government. Many national surveys have directly interviewed small numbers of people with learning disabilities and their families using standard interview schedules (see Section 3), but it is likely that such standard interview procedures would need to be modified to maximise participation by people with learning disabilities.
- *Valuing People* was published in 2001, yet national information to evaluate its objectives is not yet available in early 2005, making the evaluation of progress since the introduction of *Valuing People* difficult.

## Recommendations

Although Government departments and other agencies already collect a substantial amount of useful information concerning services for people with learning disabilities, it is clear that much work needs to be done to make national statistics more relevant to *Valuing People* and people with learning disabilities. This final section of the report contains some recommendations for steps to improve the relevance of national statistics to *Valuing People* objectives.

The first set of recommendations concerns setting priorities for information collection; what are the most important resources, processes and outcomes that need to be measured?

- One set of priorities can be derived from *Valuing People* objectives and sub-objectives; these, however, need to be clarified and operationalised very clearly before relevant statistical information can be provided by local agencies.
- A second set of priorities can be derived from the work of inspection agencies; particularly the Commission for Social Care Improvement and the Healthcare Commission. These inspection agencies have statutory responsibilities for deciding and collecting information on performance indicators; they need to ensure that their performance indicators are inclusive of and relevant to people with learning disabilities. As far as possible, harmonisation between performance indicator information and other information collected through statistical returns would be desirable.
- A third set of priorities concerns the collection of information for ongoing monitoring of expenditure and resource allocation to supports for people with learning disabilities
- A fourth set of priorities concerns the views of people with learning disabilities, their families and other stakeholders on what the most important information is; these priorities may offer additional perspectives to those outlined above.
- Finally, it is important to nest information concerning people with learning disabilities within broader strategic priorities being set for disabled people, such as *Improving The Life Chances of Disabled People*.
- Information priorities should be reviewed at regular intervals.

The second set of recommendations concerns altering existing statistical returns to reflect the information priorities established in the first set of recommendations above:

- All those currently collecting national information through statistical returns should develop an agreed strategy for developing statistical returns to reflect the priorities outlined above.
- This strategy should be mindful of the need to minimise the burden of information collection from local agencies; statistical returns where possible should be harmonized at both the central level (where information is analysed and used) and the local level (where information is provided).
- A regular forum for discussion between agencies providing and collecting statistical returns concerning people with learning disabilities should be established. This should include the new Office for Disability Issues to ensure

that statistical returns concerning people with learning disabilities are consistent with those collected for all disabled people and are relevant to broader strategic aims.

- If there is to be an increased emphasis on outcome information collected directly from people with learning disabilities, local agencies may require additional support and resources in terms of staff time and training to conduct interviews with people with learning disabilities and their families.

The third set of recommendations concerns definitions and terms used to refer to people with learning disabilities:

- Government departments and other agencies collecting national statistical information should as far as possible provide local agencies with a consistent and clear definition of learning disabilities. This definition will need to make a very clear distinction between learning disabilities (as defined in *Valuing People* and used within this report) and specific learning difficulties (e.g., dyslexia, dyspraxia, dysgraphia).
- The Department of Health should ensure that all national statistics use terms for people with learning disabilities that are consistent with current Government policy.
- The Department of Health should ensure that people with learning disabilities are not treated as a sub-group of people with mental health problems in national statistics.

The fourth set of recommendations concerns the collection of information on sub-groups:

- Wherever possible, people with learning disabilities should be identifiable as a sub-group within all statistical returns, to enable the evaluation of the extent to which people with learning disabilities are participating in mainstream society as citizens. This may be most efficiently achieved as part of a broader strategy to identify various groups of disabled people.
- All agencies collecting information through statistical returns should try to develop a standard set of criteria for identifying sub-groups within datasets; for example by age (with standard age bands), ethnicity and gender.

The fifth set of recommendations concerns nationally representative surveys conducted by the Office for National Statistics and other agencies:

- The Office for National Statistics should consider the development of a short set of questions enabling the identification of people with learning disabilities within survey samples.
- Questions identifying people with learning disabilities should be routinely included within all general surveys, to ascertain the participation rate of people with learning disabilities.
- Ongoing national surveys, such as the Health Survey for England, often include booster samples of specific sub-groups on a regular basis (for example, children) to enable more detailed analysis of that sub-group. People with learning disabilities should be considered as a suitable sub-group for regular booster sampling within ongoing national surveys.

- The National Survey of People with Learning Disabilities should be repeated at regular intervals.

The sixth recommendation is that agencies responsible for statistical returns consider the development of datasets focused on individuals rather than services. For example, the dataset on people using the Supporting People programme is an ongoing database of individual users, which enables detailed analysis of the experiences of people with learning disabilities. In contrast, the dataset on hospital activity only identifies appointments with hospital-based learning disability consultants, rather than the inpatient experiences of people with learning disabilities across all inpatient hospital services.

Finally, it is clear that there is already a substantial amount of information available concerning services for people with learning disabilities, although the information collected is scattered and often difficult to access. The establishment of an Observatory for Learning Disability Statistics could provide a major ongoing resource for all stakeholders with an interest in national statistics. The functions of such an Observatory could include:

- The collation, analysis and publication of publicly available national statistical data concerning people with learning disabilities in one place.
- Producing an annual digest of national statistics concerning people with learning disabilities.
- Maintaining a regularly updated, easily accessible website containing relevant statistics and signposts to more detailed statistics.
- Providing regular information to various agencies for policy monitoring purposes.
- Working with people with learning disabilities, their families and other stakeholders to ensure that relevant statistical information is made accessible to as many people as possible.
- Advising the Commission for Social Care Improvement, the Healthcare Commission and other inspection agencies on making sure that inspection procedures and performance indicators are inclusive and relevant to people with learning disabilities.
- Advising Government departments and other agencies on methodological aspects of collecting national statistical information concerning people with learning disabilities.
- Advising local agencies on methodological aspects of providing statistical information concerning people with learning disabilities.
- Pro-actively requesting and conducting secondary analysis of datasets where unpublished information is available concerning people with learning disabilities (e.g., analysis of data on communal establishments for people with learning disabilities collected during the 2001 Census).
- Responding to requests for information from a wide range of stakeholders.
- Providing a forum for the discussion of what information should be collected to reflect current policy priorities in education, health and social care concerning people with learning disabilities.

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# Appendix 1: Valuing People Objectives

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## OBJECTIVE 1: DISABLED CHILDREN AND YOUNG PEOPLE

To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

### BY:

#### Sub-objective 1.1

Ensuring early identification of disabled children to enable them to access appropriate and timely intervention and support.

#### Sub-objective 1.2

Ensuring that parents and disabled children receive reliable, comprehensive and culturally appropriate information about services on a multi-agency basis from the statutory and voluntary sectors.

#### Sub-objective 1.3

Increasing the number of disabled children in receipt of a range of family support services and the number of hours provided.

#### Sub-objective 1.4

Maximising the number of children with disabilities/special educational needs who receive good quality co-ordinated care and education in inclusive settings in their own communities.

#### Sub-objective 1.5

Ensuring that disabled children receive appropriate health care throughout childhood so as to enable them to participate fully in education, family and community life.

#### Sub-objective 1.6

Increasing the number of disabled children who use inclusive play, leisure and cultural services including holiday play schemes, after schools clubs and pre-school provision with appropriate support if necessary.

## OBJECTIVE 2: TRANSITION INTO ADULT LIFE

As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

BY:

### Sub-objective 2.1

Ensuring that each Connexions partnership provides a full service to learning disabled young people by identifying them, deploying sufficient staff with the right competencies and co-ordinating the delivery of appropriate supports and opportunities.

### Sub-objective 2.2

Ensuring effective links are in place within and between children's and adult's services in both health and social services.

## OBJECTIVE 3: MORE CHOICE AND CONTROL

To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need.

BY:

### Sub-objective 3.1

Promoting the rights of people with learning disabilities

### Sub-objective 3.2

Enabling advocacy to be available for people with learning disabilities who want or need it.

### Sub-objective 3.3

Making direct payments available to all those people with learning disabilities who request them and who meet the requirements of the scheme.

### Sub-objective 3.4

Developing locally agreed protocols and procedures to ensure services are based upon a person-centred approach.

### Sub-objective 3.5

Ensuring that people with learning disabilities are fully and actively involved in all decisions affecting their lives.

## OBJECTIVE 4: SUPPORTING CARERS

To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

BY:

Sub-objective 4.1

Assessing the needs of carers and putting in place the services required

Sub-objective 4.2

Establishing a complete picture of the number of older carers (ie those aged 70 and over) in the local area in order to plan services in partnership with them.

Sub-objective 4.3

Providing services and support that meet the needs of carers from minority ethnic communities.

Sub-objective 4.4

Making sure that all agencies work in partnership with carers, recognising that carers themselves have needs which must be considered.

## OBJECTIVE 5: GOOD HEALTH

To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

BY:

Sub-objective 5.1

Reducing the health inequalities experienced by people with learning disabilities.

Sub-objective 5.2

Enabling mainstream NHS services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities

Sub-objective 5.3

Promoting the development of NHS specialised learning disability services which are evidence based and delivered with a focus on the whole person.

## OBJECTIVE 6: HOUSING

To enable people with learning disabilities and their families to have greater choice and control over where, and how, they live.

BY:

### Sub-objective 6.1

Increasing the range and choice of housing open to people with learning disabilities in order to enable them to live as independently as possible.

### Sub-objective 6.2

Ensuring people with learning disabilities and their families obtain advice and information about housing from the appropriate authorities.

### Sub-objective 6.3

Enabling all people currently in NHS long-stay hospitals to move into more appropriate accommodation and reviewing the quality of outcomes for people living in NHS residential campuses.

## OBJECTIVE 7: FULFILLING LIVES

To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

BY:

### Sub-objective 7.1

Modernising day services to enable people to exercise real choice over how they spend their days

### Sub-objective 7.2

Enabling people with learning disabilities to have access to a wide range of opportunities for education and lifelong learning in order to promote greater independence and maximise employment opportunities.

### Sub-objective 7.3

Enabling people with learning disabilities to make full use of public and private transport and access mainstream community and leisure services.

### Sub-objective 7.4

Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children gain maximum life chance benefits.

### Sub-Objective 7.5

Making sure that people with learning disabilities receive the social security benefits to which they are entitled.

## OBJECTIVE 8: MOVING INTO EMPLOYMENT

To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

*BY:*

### Sub-objective 8.1

Ensuring that more people with learning disabilities find appropriate employment, including supported employment, which makes the most of their talents and potential.

### Sub-objective 8.2

Making sure that people with learning disabilities are actively helped to access employment related advice and guidance through mainstream and specialist advisory services.

### Sub-objective 8.3

Ensuring that public services provide a lead in the employment of people with learning disabilities.

## OBJECTIVE 9: QUALITY

To ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value.

*BY:*

### Sub-objective 9.1

Demonstrating that people with learning disabilities and their families are increasingly satisfied with services provided.

### Sub-objective 9.2

Ensuring that the needs of people with learning disabilities from minority ethnic communities are recognised and addressed through the provision of appropriate services.

### Sub-objective 9.3

Ensuring that local quality assurance frameworks for social care and health meet the needs of people with learning disabilities.

### Sub-objective 9.4

Ensuring people with learning disabilities receive best value from publicly funded services.

### Sub-objective 9.5

Ensuring that local adult protection policies and procedures (including those for protecting vulnerable victims and witnesses of crime) are in place and fully complied with.

## OBJECTIVE 10: WORKFORCE AND PLANNING

To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

BY:

### Sub-objective 10.1

Introducing the new national framework for training, competencies, qualifications and skill levels in the learning disability workforce.

### Sub-objective 10.2

Promoting awareness among the wider workforce (in areas such as housing, the wider NHS, transport and the Department of Social Security) of the skills, attitudes and knowledge needed to work with people with learning disabilities in a positive and respectful manner.

### Sub-objective 10.3

Ensuring that local workforce plans are developed.

## OBJECTIVE 11: PARTNERSHIP WORKING

To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

BY:

### Sub-objective 11.1

Establishing local learning disability Partnership Boards to take responsibility for local delivery of the White Paper, led by the local council and with the active participation of all key stakeholders.

### Sub-Objective 11.2

Making effective use of the Health Act flexibilities.

### Sub-objective 11.3

Promoting effective partnership working by staff from all relevant disciplines and agencies.

## Appendix 2: Index of data sources

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	Pathways/Adult Basic Skills Strategy Unit's Learning Difficulties and/or Disabilities Pilot - Department for Further Education and Skills/NIACE <b>(no table – early stages)</b>					

TABLE No.	DATA SOURCE/COLLECTED BY		COLLECTION	FREQUENCY		PAGE No.
	Feasibility Survey on long-term disability information requirements - Department for Work and Pensions/ Natcen <b>(no table – early stages)</b>					

## Appendix 3: Data Sources

DATA COLLECTION 1: COMMUNITY CARE STATISTICS - PRIVATE NURSING HOMES, HOSPITALS & CLINICS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Private Nursing Homes, Hospitals and Clinics	Information regarding independent sector nursing homes, private hospitals & clinics in Health Authorities	Annually	2001	1996-2001	Health Authorities for DoH	England	A. General nursing -Physical disability -Learning disability -Mental health -Alcohol/drug misuse -Maternity -Other B. Specialist services -Other specialist

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Private Nursing Homes, Hospitals and Clinics	RH (N) form A RH (N) form B	National totals have been enhanced to allow for missing homes and Health Authorities  For some returns that were not submitted, figures were estimated from the Self-Funders Survey and the Autumn Position Statement data (DIS)	Nursing staff in post by grade and regional area (including registered nurse for learning disability) For group A; homes, beds and staffing by client group (including beds for learning disability)  For group B, as of group A, excluding alcohol/drug misuse or other but including specialist/other specialist  This data is now collected by the Commission for Social Care Inspection (CSCI) for care homes. The Healthcare Commission are responsible for data on private hospitals and clinics	Parliamentary Questions  Ad Hoc queries	5 10	RH (N) form A  RH (N) form B	<a href="mailto:Kate.Anderson@dh.gsi.gov.uk">Kate.Anderson@dh.gsi.gov.uk</a>  Tel:0207 972 5582  Commission for Social Care Inspection  Tel: 0207 979 2000  <a href="http://www.publications.doh.gov.uk/public/sb0209.htm">http://www.publications.doh.gov.uk/public/sb0209.htm</a>

DATA COLLECTION 2: COMMUNITY CARE STATISTICS SUPPORTED RESIDENTS (ADULTS)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Supported Residents	Residential and Nursing Care placements funded by CSSR. Data is collected by type of care, age group, type of accommodation, type of stay and location along with perm and temp admissions	Annually	Oct 2003	1992 - 2003	DoH from CSSRs	Local Authorities for England	Physically/Sensorily disabled  Mental Health Problems  Learning disabilities  Other  All 18 – 64 and 65+

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Supported Residents	SR1 FORM	No info is collected on supported residents in private hospitals and clinics. Councils that submit missing or incomplete data – estimates are prepared and used to produce national estimates	<ol style="list-style-type: none"> <li>1. Council supported residents by type of accommodation and client group</li> <li>2. Council supported residents; permanent and temporary admissions by accommodation type and client group</li> <li>3. Council supported residents by type of accommodation</li> <li>4. Council supported residents in CSSR and registered staffed care homes by client type and type of care</li> <li>5. Council supported residents in permanent and temporary residential and nursing care by age group and type of care</li> <li>6. Council supported admissions in permanent and temporary residential and nursing care by client group and type of care</li> <li>7. Council supported admissions outside the CSSR area for all ages by type of care and client group</li> <li>8. Council supported permanent admissions relating to preserved rights by type of care and age</li> </ol>	<p>Parliamentary Questions</p> <p>Resource allocation</p>	5 6	SR1 FORM	<p>Kate Anderson  <a href="mailto:Kate.Anderson@dh.gsi.gov.uk">Kate.Anderson@dh.gsi.gov.uk</a></p> <p>Tel: 020 7972 5582</p> <p><a href="http://www.publications.doh.gov.uk/public/sb0419.pdf">http://www.publications.doh.gov.uk/public/sb0419.pdf</a></p>

DATA COLLECTION 3: COMMUNITY CARE STATISTICS RAP (REFERRALS, ASSESSMENTS AND PACKAGES OF CARE)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
RAP (Referrals, Assessments & Packages of Care)	Information on number of referrals and community care assessments carried out. Data on community based packages.	Annually	2004	2000/01 – 2002/03  OTHER C.CARE STATS ON SUPPORTED RESIDENTS AND HOME CARE DATING BACK TO THE EARLY 1990'S	Local Authorities for DoH	Each local authority in England	ADULTS ONLY 18+ L.Disability Mental Health Problems Physical Disability Physical & Sensory Disability Fraility Substance Misuse Other Vulnerable people

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
RAP (Referrals, Assessments & Packages of Care).	15 RAP Proformas	1. Some Proforma errors 2. Inconsistent time trend 3. Numerous changes of recording and processing procedures 4. DoH had to estimate some values as some data provided by CSSR were incomplete	1. No. of contacts to council by LA 2. Clients with completed assessments by client type, ethnic group & age 3. Clients with terminated assessments by age 4. Carer assessments by age of carer 5. Length of time from 1st contact to completed assessments for new clients by age, client type & referral 6. Length of time from 1st contact to first service for new clients by age, client type & referral 7. Length of time from 1st contact to provision or commissioning of all spec. 8. Clients receiving services during period by client/service type & age group 9. Clients receiving services by service type & ethnic group client type and age group 10. Number of clients on the books to receive community based services on last day of period by client type, age group and service	Parliamentary Questions  Monitoring targets  Adhoc queries	4 5	RAP Proforma	Kate Anderson <a href="mailto:Kate.Anderson@dh.gsi.gov.uk">Kate.Anderson@dh.gsi.gov.uk</a>  Tel: 020 7972 5582  <a href="http://www.publications.doh.gov.uk/rap/ccstats2003final.htm">http://www.publications.doh.gov.uk/rap/ccstats2003final.htm</a>

DATA COLLECTION 4: PERSONAL SOCIAL SERVICES STAFF OF SOCIAL SERVICES DEPARTMENTS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
PERSONAL SOCIAL SERVICES STAFF	Detail of all staff (full and part time) directly employed by Social Services Departments	Annually	2004	1994 - 2004	DoH from CSSR	England	Adults with learning disabilities Elderly/Elderly mentally infirm Mixed client group Adults with physical disabilities Adults with mental health problems Children with learning disabilities

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
PERSONAL SOCIAL SERVICES STAFF	SSDS001 FORM	Does not cover agency staff or staff in the independent or voluntary sector  A high percentage of staff with ethnic origin unknown	PSS LA staff by category Central and strategic staff by category, gender and ethnic origin Area Office/Field Work Staff by category, gender and ethnic origin WTE staff in day care/residential provision by client type, gender and ethnic origin LA Social Service staff by gender and ethnic origin		10	SSDS001	Ian Flaxten <a href="mailto:ian.flaxten@dh.gsi.gov.uk">ian.flaxten@dh.gsi.gov.uk</a>  Tel: 020 7972 5595  <a href="http://www.publications.doh.gov.uk/public/sb0409.pdf">http://www.publications.doh.gov.uk/public/sb0409.pdf</a>

DATA COLLECTION 5: PERFORMANCE ASSESSMENT FRAMEWORK (PAF)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
PAF	Indicators based on data collected in various DH statistical collections	Annually	Nov 2003	1998/99 – 2002/03	DoH from CSSR	CSSRs in England	Children and families Older people Adults with learning disabilities Adults with mental illness Adults with physical disabilities

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
PAF	DoH statistical returns including KS1, PSS EX1, RAP, SR1		50 indicators covering a variety of aspects of PSS.		3 6 7	DoH statistical returns including KS1, PSS EX1, RAP, SR1	Ian Flaxten <a href="mailto:Ian.Flaxten@dh.gsi.gov.uk">Ian.Flaxten@dh.gsi.gov.uk</a> 020 7972 5595 <a href="http://www.publications.doh.gov.uk/paf/index.htm">www.publications.doh.gov.uk/paf/index.htm</a>

DATA COLLECTION 6: INPATIENTS FORMALLY DETAINED IN HOSPITALS UNDER THE MENTAL HEALTH ACT 1983 AND OTHER LEGISLATION FOR NHS TRUSTS, CARE TRUSTS, PCTs AND INDEPENDENT HOSPITALS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST – LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
INPATIENTS FORMALLY DETAINED	Provides detail of detentions under the MHA 1983 – those which are detained for their own health or the safety of others	Annually	March  England level summary data is published in a statistical bulletin the previous November	1996-97  2002-03  (Detained patient data held from 1987-88)	SD2C	England data broken down for NHS facilities to provider within SHA within GOR and for independent hospitals to SHA within GOR.	Patients detained under the MHA 1983 and other legislation who fall under the following mental categories: Mental illness Psychopathic Disorder Mental impairment Severe mental impairment Not specified Data is not broken down by these mental categories.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
INPATIENTS FORMALLY DETAINED	KP90	Fit for the purpose – Data is within the public domain	Detail is given across groups by; Admissions by gender, including: - court and prison disposals - previous legislation Changes in legal status Uses of Part II of the Act Detained patients resident in hospital Data broken down by: Trusts, Care Trusts and PCTs for NHS facility data and by SHAs for independent hospital data.	Data is used by: DH NHS –Trusts, Care Trusts, PCTs & SHAs. Social Services. Professional bodies. Academics. Used within DH to assess the potential impact of proposed revisions to Mental Health legislation, and the current impact of ongoing Mental Health policy initiatives.	-	KH15  KH16  KO37	<a href="mailto:Paul.Thatti@dh.gsi.gov.uk">Paul.Thatti@dh.gsi.gov.uk</a>  Tel: 020 7972 5546  Most recent edition available at:  <a href="http://www.publications.doh.gov.uk/public/inpatients2003.htm">http://www.publications.doh.gov.uk/public/inpatients2003.htm</a>   England level statistical bulletin available at:  <a href="http://www.publications.doh.gov.uk/public/sb0422.htm">http://www.publications.doh.gov.uk/public/sb0422.htm</a>

DATA COLLECTION 7: COMMUNITY LEARNING DISABILITY NURSING SERVICE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
COMMUNITY LEARNING DISABILITY NURSING	Summary aggregate data showing community learning disability nursing service patients by age and sex and by source of referral	Annually	Oct 2003	Financial years 1988-89 to 2002-03	Any NHS Trusts, Primary Care trusts, Care Trusts that provide a service Last collected for 2003-04 financial year; now discontinued	England; data available by individual service provider and can be grouped by GOR	No specific groups

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
COMMUNITY LEARNING DISABILITY NURSING	DoH return KC58, made either on paper or using internet facility	Each year a few of the 120 or so service providers are not able to complete the return (eg 7/127 in 2002-03)		Internal reporting  Policy making	5	Extracted from local sources	Lesz Lancucki 020 7972 5533 <a href="mailto:lesz.lancucki@dh.gsi.gov.uk">lesz.lancucki@dh.gsi.gov.uk</a>  <a href="http://www.publications.doh.gov.uk/public/kc580304/">http://www.publications.doh.gov.uk/public/kc580304/</a> ).

DATA COLLECTION 8: HOSPITAL EPISODE STATISTICS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
HES	<p>HES provides admitted patient care details by NHS hospitals in England.</p> <p>HES collects over 12 million records each year, including medical specialties and details of private patients treated within NHS hospitals.</p> <p>HES is currently being extended to cover Outpatient appointments</p>	Quarterly for monitoring purposes; annually for publication	December (2002-03 data was 3/12/2003)	1989-90 to 2002-03	DoH	England. Broken down by various geographies.	<p>A large list of differing specialties but the main groups of interest here are:</p> <ul style="list-style-type: none"> <li>-Learning Disability (formerly known as Mentally handicapped)</li> <li>-Mental illness</li> <li>-Child and adolescent Psychiatry</li> </ul>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
HES	Data sent electronically from care providers to NHS-wide clearing service (NWCS) for onward transmission to commissioner s. HES is extracted from NWCS.	Data undergoes cleaning and validation to make it as useable as possible. However, HES is reliant on hospital trusts to ensure data quality and provide complete, accurate and reliable coded data.	<p>People treated in hospital under the Learning Disability specialty were until recently referred to as Mentally Handicapped.</p> <p>Measures include:</p> <ul style="list-style-type: none"> <li>- finished consultant episodes</li> <li>- admissions</li> <li>- male / female</li> <li>- emergency/ elective</li> <li>- time waited</li> <li>- ave. length of stay</li> <li>- age</li> <li>- day case / ordinary admission</li> <li>- bed days</li> </ul>	<p>Wide variety of users</p> <ul style="list-style-type: none"> <li>- DH Official statistics eg briefing, enquiries, policy monitoring.</li> <li>- SHAs, PCTs, Trusts, etc, eg management and commissioning.</li> <li>- Healthcare Commission, eg investigations, performance ratings, Clinical Governance Reviews, Benchmarking.</li> <li>- Audit Commission.</li> <li>- Public health, eg PHOs, Small Area Health Statistics Unit.</li> <li>- Academic &amp; research organizations.</li> <li>- Other, eg Dr Foster.</li> </ul>	5	Currently NHS-wide Clearing Service; this will change with the National Programme for IT	<p><a href="mailto:sd2hes@dh.gsi.gov.uk">sd2hes@dh.gsi.gov.uk</a>  Enquiries tel: 0207 972 5529  Website:</p> <p><a href="http://www.dh.gov.uk/PublicationsAndStatistics/Statistics/HospitalEpisodeStatistics/fs/en">http://www.dh.gov.uk/PublicationsAndStatistics/Statistics/HospitalEpisodeStatistics/fs/en</a></p>

DATA COLLECTION 9: PERSONAL SOCIAL SERVICES EXPENDITURE AND UNIT COSTS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
PSS EX1	Expenditure by type of service and type of expenditure/income	Annually	2004	2000/01 – 2002/03 Prior to this data was collected on the ODPM R03 return	DoH from CSSRs	England	Older people Physically disabled adults Learning disabled adults Mentally ill adults Asylum Seekers Children's/Families Services

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
PSS EX1	PSS EX1 return submitted to the DoH by CSSRs	Some of the unit costs submitted by councils were very high or low and not all councils were able to submit revised data in the time available.	<ol style="list-style-type: none"> <li>1. Expenditure on Personal Social Services by client group with expenditure split between own provision and provision by others</li> <li>2. Personal Social Services gross current expenditure by client groups across assessment and care management, residential provision and day/domiciliary care (incl. fostering services)</li> <li>3. Residential provision expenditure by client group (incl. children's/families/ older people)</li> <li>4. Day and domiciliary provision expenditure by client group (incl. children's/families/ older people)</li> <li>5. Historical trend of gross current expenditure</li> <li>6. Unit costs and their comparisons ie. direct payments, day care, meals etc.</li> </ol>		6 7	PSS EX1 (THIS ALSO COLLECTS DATA FOR THE DoH PSS PAF	<p>Ian Flaxten  <a href="mailto:ian.flaxten@dh.gsi.gov.uk">ian.flaxten@dh.gsi.gov.uk</a></p> <p>Tel: 020 7972 5595</p> <p><a href="http://www.publications.doh.gov.uk/public/pss_stat.htm">http://www.publications.doh.gov.uk/public/pss_stat.htm</a></p>

DATA COLLECTION 10: INPATIENT, DAY CARE AND RESIDENTIAL BEDS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Inpatient, Day Care and Residential beds	The KH03 provides a count of available and occupied bed days by broad ward classification. It includes both inpatient, day case and residential beds across all sectors of the NHS.	The KH03 is an annual return and relates to available and occupied bed days over a 12 month period between 1 April of one year and 31 March of the following year.	The information is published annually on the Department of Health's website. The information on the return is published in the "Hospital Activity Statistics" bulletin, the detailed booklet "Bed availability and Occupancy for England" and "Health and Personal Social Services Statistics".	It has been collected since 1960 to present  But please note: it was collected in a different form.	Department of Health	England	Learning Disability

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Inpatient, Day Care and Residential beds	Web base via the KH03	Excellent – no issues	This return identifies the number of bed days for each NHS <a href="#">HEALTH CARE PROVIDER</a> which are available for <a href="#">PATIENTS</a> to have treatment or care. It must only include beds in units managed by the provider, not beds commissioned from other providers. Note that cots for well babies and the occupancy of such cots are excluded from all parts of KH03. The return KH03 relates to the 12 month period, between 1 April of one year and 31 March of the following year. The return should be made within two months of the end of the year to which it relates - by 31 May at the latest. A return is required from each NHS HEALTH CARE PROVIDER. The return KH03 records supporting facilities (Part 1) and bed availability (Part 2) within an NHS HEALTH CARE PROVIDER.		5 6		<a href="http://www.performance.doh.gov.uk/hospitalactivity">http://www.performance.doh.gov.uk/hospitalactivity</a>

DATA COLLECTION 11: REGISTERED BLIND AND PARTIALLY SIGHTED PEOPLE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Registered Blind and Partially Sighted People	Detailed statistics on persons registered with CSSRs in England as being blind or partially sighted	Triennial	Dec 2003	1982- 2003	CSSRs for DoH	England	Blind Partially Sighted Blind or partially sighted with a deaf or hearing impairment Partially sighted and blind people with additional disabilities (including learning disabilities)

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Registered Blind and Partially Sighted People	SSDA 902 form	Blind people with additional disabilities is possibly underestimated Multiple disability (ie. deaf or hard of hearing) were asked to be counted as either deaf or hard of hearing Registration of blindness is voluntary and there is a reliability issue in terms of councils reviewing and updating their records	1. Number of registered blind/partially sighted by number/ age group 2. Number of new registrations for blind and partially sighted by age group 3. Proportion of people on register as blind/partially sighted by age group 4. Comparison of proportion of people on register as blind/partially sighted with a deaf or hearing impairment 5. Number of registered blind people/partially sighted with an additional disability by category of disability/age group	Parliamentary Questions  Ad Hoc queries	-	SSDA 902	<a href="mailto:Kate.Anderson@dh.gsi.gov.uk">Kate.Anderson@dh.gsi.gov.uk</a> Tel: 020 7972 5589/5582  <a href="http://www.dh.gov.uk/assetRoot/04/08/02/45/04080245.xls">http://www.dh.gov.uk/assetRoot/04/08/02/45/04080245.xls</a>

DATA COLLECTION 12: WAITING TIME PERFORMANCE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Waiting Time Performance	The Department requires HQ and Strategic Health Authorities to manage waiting time performance.	Quarterly	Information on the return is not published directly; however, the details are used to confirm the responsible population based waiting list statistics.		Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Waiting Time Performance	Web Base via KH07AR	Excellent – no issues	The return KH07AR is submitted by <a href="#">NHS TRUSTS</a> and <a href="#">PRIMARY CARE TRUSTS</a> and is based on the population for which the NHS Trust or Primary Care Trust is responsible. This includes all patients registered with GPs who form part of the PRIMARY CARE TRUSTS including those who are not resident within the Primary Care Trust's geographical area. If a patient waiting for admission to hospital does not have an NHS GP, the responsible Primary Care Trust is determined by the postcode of the patient's home. <a href="#">PATIENTS</a> treated under out of area treatments (OATs) are exceptions, who should be counted by the 'main commissioner'. This is normally the PCT with the highest value of Service Agreements with the NHS Trust	The Department uses the information from this return to help monitor national waiting list trends. These are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more effectively.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 13: WAITING TIMES AND HEALTH CARE PROVIDERS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Waiting Time Performance	The Department requires HQ and Strategic Health Authorities to manage waiting time performance.	Quarterly	Information on the return is not published directly; however, the details are used to confirm the responsible population based waiting list statistics.		Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Waiting Time Performance	Web Base via KH07AR	Excellent – no issues	The return KH07AR is submitted by <a href="#">NHS TRUSTS</a> and <a href="#">PRIMARY CARE TRUSTS</a> and is based on the population for which the NHS Trust or Primary Care Trust is responsible. This includes all patients registered with GPs who form part of the PRIMARY CARE TRUSTS including those who are not resident within the Primary Care Trust's geographical area. If a patient waiting for admission to hospital does not have an NHS GP, the responsible Primary Care Trust is determined by the postcode of the patient's home. <a href="#">PATIENTS</a> treated under out of area treatments (OATs) are exceptions, who should be counted by the 'main commissioner'. This is normally the PCT with the highest value of Service Agreements with the NHS Trust	The Department uses the information from this return to help monitor national waiting list trends. These are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more effectively.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 13: WAITING TIMES AND HEALTH CARE PROVIDERS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
HQ/Regional Offices Waiting Times	The Department requires performance management measures of waiting times by HQ and Regional Offices on a <a href="#">HEALTH CARE PROVIDER</a> basis. The information is used for monitoring Health Authorities and Trusts	Quarterly	Information on the return is published in the Quarterly Review, Hospital Waiting List Statistics: England, Health and Personal Social Services and the Annual Reports.	June 1987 onwards	Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
HQ/Regional Offices Waiting Times	Web Base via the KHO7	Excellent – no issues		. The resulting statistics on 'waiting times' are used to help develop policies and indicate changes that enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more efficiently. Information on the return is also used in Public Expenditure Survey (PES) negotiations and supports risk analysis, the production of in-patient and out-patient modelling and Departmental accountability.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 14: HEAD QUARTERS/REGIONAL OFFICES AND WAITING TIMES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Head Offices/ Regional Offices and Waiting Times	The Department requires performance management measures of waiting times by HQ and Regional Offices.	Quarterly	Information based on the return is not published directly; however, the details are used to confirm the responsible population based waiting list statistics.		Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Head Offices/ Regional Offices and Waiting Times	Web Base via the KHO6R	Excellent – no issues	The KH06R return is submitted by <a href="#">PRIMARY CARE TRUSTS</a> and is based on the population for which the Primary Care Trust is responsible. This includes all patients registered with GPs who form part of the PRIMARY CARE TRUST, including those who are not resident within the Primary Care Trust's geographical area. If a patient waiting for admission to hospital does not have an NHS GP, the responsible Primary Care Trust is determined by the postcode of the patient's home. <a href="#">PATIENTS</a> treated under out of area treatments (OATs) are exceptions, who should be counted by the 'main commissioner'. This is normally the PCT with the highest value of Service Agreements with the NHS Trust.	The Department uses this information to help monitor national waiting list trends. These are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more efficiently. Information on the return is also used in Public Expenditure Survey (PES) negotiations and supports risk analysis, the production of in-patient and out-patient modelling and Departmental accountability.	5		<a href="http://www.performance.doh.gov.uk/waitingtimes/">http://www.performance.doh.gov.uk/waitingtimes/</a>

DATA COLLECTION 15: OUT –PATIENT ACTIVITY AND ATTENDANCES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Out-patient Activity and Attendances	The Department requires data about out-patient activity split between the various <a href="#">TREATMENT FUNCTION CODES</a> . The return provides Performance Management information on the ratios of <a href="#">FIRST ATTENDANCES</a> to subsequent attendances; and the level of <a href="#">PATIENTS</a> who do not attend for their appointments (DNAs). The information on DNAs is used to monitor any progress in their reduction.	Quarterly			Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Out-patient Activity and Attendances	Web base via the QMOP	Excellent – no issues	<p>The return is completed by <a href="#">NHS TRUSTS</a> and <a href="#">PRIMARY CARE TRUSTS</a> providing out-patient services on one or more sites.</p> <p>The return records information on all <a href="#">OUT-PATIENT ATTENDANCE CONSULTANTS</a> taking place within the quarter/year, whether taking place within a <a href="#">CONSULTANT CLINIC SESSION</a> or outside a session. The only proviso is that the PATIENT must have seen a <a href="#">CONSULTANT</a> (or a doctor acting for the CONSULTANT) for examination or treatment. In addition, the return records information where the PATIENTS did not attend their appointments which should have taken place within the quarter/year</p>	The information on DNAs is used to monitor any progress in their reduction.	5		<a href="http://www.performance.doh.gov.uk/hospitalactivity/">http://www.performance.doh.gov.uk/hospitalactivity/</a>

DATA COLLECTION 16: WAITING TIMES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Waiting Times	The return provides performance management measures of waiting times and helps to identify those organizations who have failed to meet the standards of the NHS Plan.	Quarterly		December 1993 onwards	Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Waiting Times	Web Base via the QMO8	Excellent – no issues		The information is used to model out-patient activity and waiting times.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 17: PRIMARY CARE TRUSTS AND WAITING TIMES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Primary Care Trusts and Waiting Times	The Department and <a href="#">STRATEGIC HEALTH AUTHORITIES</a> require an aggregate return from <a href="#">PRIMARY CARE TRUSTS</a> (as commissioners) covering their responsible population's experience with consultant out-patient services, split between the various <a href="#">TREATMENT FUNCTION CODES</a> .	The central return QM08R is completed quarterly by PRIMARY CARE TRUSTS (as commissioners) and is based on the population for which the PRIMARY CARE TRUST is responsible		September 1997 onwards	Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Primary Care Trusts and Waiting Times	Web Base via the QMO8R	Excellent – no issues	This includes all patients registered with GPs who form part of a Primary Care Group and <a href="#">PRIMARY CARE TRUST</a> for which the PRIMARY CARE TRUST is responsible, including those who are not resident within the PRIMARY CARE TRUST's geographical area. If a patient waiting for admission to hospital does not have an NHS GP, the responsible Primary Care Group or Primary Care Trust is determined by the postcode of the patient's home. <a href="#">PATIENTS</a> treated under out of area treatments (OATs) are exceptions who should be counted by the 'main commissioner'.	The return provides performance management measures of waiting times against standards of the NHS Plan.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 18: WAITING TIMES AND HEALTH AUTHORITIES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Waiting Times and Health Authorities	The Department requires performance management measures of waiting times by HQ and Regional Offices.	Quarterly	Information based on the return is published in the statistics press notice and in the quarterly book, Hospital Waiting List Statistics (Responsible Population Based).	June 1993 onwards	Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Waiting Times and Health Authorities	Web Base via the QF01	Excellent – no issues	The return QFO1 is submitted by HEALTH AUTHORITIES and is based on the population for which the Health Authority is responsible. This includes all patients registered with GPs who form part of Primary Care Groups and HEALTH AUTHORITIES for which the Health Authority is responsible including those who are not resident within the Health Authority's geographical area. If a patient waiting for admission to hospital does not have an NHS GP, the responsible Primary Care Group or Primary Care Trust is determined by the postcode of the patient's home. The Health Authority's geographical area is divided up among its Primary Care Groups and Primary Care Trusts for this purpose. The responsible Health Authority is then determined from the Primary Care Group's or Primary Care Trust's line of accountability, as usual. <a href="#">PATIENTS</a> treated under out of area treatments (OATs) are exceptions, who should be counted by the 'main commissioner'. This is normally the HA with the highest value of Service Agreements with the NHS Trust.	The information is used for monitoring HEALTH AUTHORITIES. The resulting statistics on waiting times are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more effectively. Information on the return is also used in Public Expenditure Survey (PES) negotiations and supports risk analysis, the production of in-patient and out-patient modelling and Departmental accountability.	5		<a href="http://www.performance.doh.gov.uk/waitingtimes/">http://www.performance.doh.gov.uk/waitingtimes/</a>

DATA COLLECTION 19: NHS TRUSTS/PRIMARY CARE TRUSTS AND WAITING TIMES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Health Care Providers and Waiting Times	The Department requires performance management measures of waiting times on a <a href="#">HEALTH CARE PROVIDER</a> basis..	Quarterly	Information based on the return is not published directly; however, the details are used to confirm the provider based waiting list statistics.		Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Health Care Providers and Waiting Times	Web Base via the KHO7A	Excellent – no issues	The return KH07A is provider-based and submitted by NHS Trusts and Primary Care Trusts regardless of where the patients live. The return includes all deferred and suspended patients, including those who are: private patients and patients from overseas.	The Department uses the information from this return to help monitor national waiting list trends. These are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more effectively. Information based on the return is not published directly; however, the details are used to confirm the provider based waiting list statistics	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 20: HEAD QUARTERS/REGIONAL OFFICES AND WAITING TIMES							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Head Offices/ Regional Offices and Waiting Times	The Department requires performance management measures of waiting times by HQ and Regional Offices.	Quarterly	Information based on the return is not published directly; however the details are used to confirm the provider based waiting list statistics.		Department of Health	England	Mental handicap

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Head Offices/ Regional Offices and Waiting Times	Web Base via the KH06	Excellent – no issues	The return KH06 is provider-based and is submitted by NHS Trusts and Primary Care Trusts regardless of where the patients live. The returns are for all patients waiting for admission to NHS hospitals, excluding planned admissions i.e. it includes patients who are: Private patients and patients from overseas.	Information on the return is used in Public Expenditure Survey (PES) negotiations and supports risk analysis, the production of in-patient and out-patient modelling and Departmental accountability The Department also uses this information to help monitor national waiting list trends. These are used to develop policies and indicate changes which can enable <a href="#">ELECTIVE ADMISSION LISTS</a> to be managed more effectively.	5		<a href="http://www.performance.doh.gov.uk/waiting-times/">http://www.performance.doh.gov.uk/waiting-times/</a>

DATA COLLECTION 21: PLASC (PUPIL LEVEL ANNUAL SCHOOL. CENSUS)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
PUPIL LEVEL ANNUAL SCHOOL CENSUS	<p>Information on individual pupils collected as individual pupil records</p> <p>Also collected is information on teaching, support staff, classes as taught and admission appeals from maintained and non-maintained special schools</p>	Annually	2004	Data has been collected from schools for many years (as far back as the 70's) but data at pupil level has been being collected since 2002	From schools via their MIS (Management Information Systems) to the LEAs for checking and transmission to DfES	England	<p>A new group for 2004 is Learning Difficulty ie. SEN type</p> <ul style="list-style-type: none"> <li>-Specific learning difficulty</li> <li>-Moderate learning difficulty</li> <li>-Severe learning difficulty</li> <li>-Profound &amp; multiple learning difficulty</li> <li>-Behaviour, emotional and social difficulties</li> <li>-Speech, language and communication needs</li> <li>-Hearing Impairment</li> <li>-Visual Impairment</li> <li>-Multi-Sensory Impairment</li> <li>-Physical disability</li> <li>-Autism Spectrum Disorder</li> <li>-Other difficulty/disability</li> <li>-Unclassified</li> </ul>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
PUPIL LEVEL ANNUAL SCHOOL CENSUS	Electronic collection - MIS for PLASC	The data excludes Pupil Referral Units, General Hospital Schools and Independent Schools.  Primary and Secondary learning difficulty is recorded	Data is collected on; -General School Information -Individual Pupil data (including statement of SEN) -Teaching staff -Education support staff -Classes as taught -Pupil and teacher reconciliations -Admission appeals	Detail from the individual pupil records from PLASC along with pupils' Key Stage and examination results will provide additional data for schools, LEAs and other agencies that will assist in raising standards, increased accuracy for funding and policy development. Also; -Statistical development -Permanent Exclusions -Parliamentary Questions -External queries/ internal analysis -Supplying detail to external contractors for research basis	1	MIS/PLASC	<a href="mailto:James.Foley@dfes.gsi.gov.uk">James.Foley@dfes.gsi.gov.uk</a> Tel: 01325-392648  <a href="mailto:Mike.Battle@dfes.gsi.gov.uk">Mike.Battle@dfes.gsi.gov.uk</a>  <a href="http://www.dfes.gov.uk/rsgateway/DB/SFR/s000457/index.shtml">http://www.dfes.gov.uk/rsgateway/DB/SFR/s000457/index.shtml</a>

DATA COLLECTION 22: SPECIAL EDUCATIONAL NEEDS IN ENGLAND							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
SEN	Data is collected at pupil level from all maintained schools in England (plus non-maintained special schools). Pupil characteristics data includes SEN status and type of SEN for those on School Action Plus or with Statements.	Annually	SEN Statistics are published annually in a Statistical First Release	2004 is latest data available. Pupil level data was first collected in 2002.	DfES	England	All pupils in maintained schools (and NMSS)

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
SEN	Census	National Statistics			1	Some of this data is from PLASC. However some is from the SEN2 survey that schools complete for pupils without a SEN statement.	<a href="mailto:Richard.WHITE@dfes.gsi.gov.uk">Richard.WHITE@dfes.gsi.gov.uk</a> Tel: 0207 925 5173  <a href="http://www.dfes.gov.uk/rsgateway/DB/SFR/s000537/sfr44-2004v2.pdf">http://www.dfes.gov.uk/rsgateway/DB/SFR/s000537/sfr44-2004v2.pdf</a>

DATA COLLECTION 23: CONNEXIONS PARTNERSHIP							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Connexions Partnerships	Numeric	Quarterly & six monthly	June / Sept / Dec / Mar	2002 – 2004	SCYPG, DFES Sheffield	England	LDD

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Connexions Partnerships	NEXUS Web based system	Good	16-19 year olds and those 20-24 with LDD		2 7	Connexions Partnerships	<a href="mailto:David.Grellier@dfes.gsi.gov.uk">David.Grellier@dfes.gsi.gov.uk</a>  DfES Moorfoot, Sheffield

DATA COLLECTION 24: INCAPACITY BENEFIT AND SEVERE DISABILITY ALLOWANCE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
IB & SDA	Details of benefits for the long term sick and people with disabilities	Quarterly	2003	..... -2004	DWP benefits office from medical certificates that contain a medical code (BA CODE) assigned by the particular medical practitioner	England	<ul style="list-style-type: none"> <li>-Mental and behavioural disorders</li> <li>-Mental and behavioural disorders due to Psychoactive Substance use</li> <li>-Schizophrenia, Scizotypal and Delusional disorders</li> <li>-Mood Affective Disorders</li> <li>-Neurotic, Stress Related and Somatoform disorders</li> <li>-Behavioural Syndromes associated with Physiological disturbance and Physical factors</li> <li>-Mental Retardation</li> <li>-Disorders of Psychological Development</li> <li>-Behavioural and emotional disorders</li> <li>-Unspecified Mental Disorder</li> </ul>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
IB & SDA	The BA CODE is entered onto the benefit computer system. Once the 5% scan of benefit data is taken the BA code is converted into an ICD code (WHO) and statistical tables produced	Figures are unlikely to include every person with learning disabilities claiming IB or SDA as they may be incapacitated for another reason. Also, only the diagnosis by the medical practitioner is used. Finally, figures are subject to a high degree of sample error and are a simple guide	IB and SDA across all groups by male/female/all totals		3 8	Medical certificates	<a href="mailto:Morag.Mccannon@dwp.gsi.gov.uk">Morag.Mccannon@dwp.gsi.gov.uk</a> Tel: 0191 225 3251  <a href="http://www.dwp.gov.uk/asd/ib_sda.asp">http://www.dwp.gov.uk/asd/ib_sda.asp</a>

DATA COLLECTION 25: DISABILITY LIVING ALLOWANCE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
The Disability Living Allowance Computer System	Admin 5% Sample	Quarterly	Quarterly (Feb, May, Aug, Nov)	Aug 1992 – Aug 2004	Quarterly 5% scan	Government Office Regions, Local Authority, Parliamentary Constituency	Disabled 3+ Numerous groups including Learning Difficulties

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
The Disability Living Allowance Computer System	Data Tapes with snapshot scan received quarterly	Scan contains 5% which is rated up for publications	Contains all Disability Living Allowance Cases information.	Data loaded and information used for quarterly publications and ad hoc analysis	3	Scan from DLA Computer System	Nathan Scorer <a href="mailto:Nathan.scorer@dwp.gsi.gov.uk">Nathan.scorer@dwp.gsi.gov.uk</a> 0191 225 7094  <a href="http://www.dwp.gov.uk/asd/asd1/dla/dla_quarterly_statistics_aug04.asp">http://www.dwp.gov.uk/asd/asd1/dla/dla_quarterly_statistics_aug04.asp</a> .

DATA COLLECTION 26: ATTENDANCE ALLOWANCE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
The Attendance Allowance Computer System	Admin 5% Sample	Quarterly	Quarterly (Feb, May, Aug, Nov)	Nov 1995 – Aug 2004	Quarterly 5% scan	Government Office Regions, Local Authority, Parliamentary Constituency	Disabled 65+ Numerous groups including Learning Difficulties

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
The Attendance Allowance Computer System	Data Tapes with snapshot scan received quarterly	Scan contains 5% which is rated up for publications	Contains all Attendance Allowance Cases information.	Data loaded and information used for quarterly publications and ad hoc analysis	3	Scan from AA Computer System	Nathan Scorer <a href="mailto:Nathan.scorer@dwp.gsi.gov.uk">Nathan.scorer@dwp.gsi.gov.uk</a> 0191 225 7094  <a href="http://www.dwp.gov.uk/asd/asd1/aa/aa_quarterly_statistics_aug04.asp">http://www.dwp.gov.uk/asd/asd1/aa/aa_quarterly_statistics_aug04.asp</a>

DATA COLLECTION 27: CARERS ALLOWANCE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
The Carers Allowance Computer System	Admin 100% Sample	Quarterly	Quarterly (Feb, May, Aug, Nov)	September 2001 – current	Quarterly 5% scan	Government Office Regions, Local Authority, Parliamentary Constituency	Carers 16+

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
The Carers Allowance Computer System	Data Tapes with snapshot scan received quarterly	Scan contains 100% CA claimants	Contains all Carers Allowance Case Information	Data loaded and information used for quarterly publications and ad hoc analysis	3	Scan from CA Computer System	Nathan Scorer <a href="mailto:Nathan.scorer@dwp.gsi.gov.uk">Nathan.scorer@dwp.gsi.gov.uk</a> 0191 225 7094 <a href="http://www.dwp.gov.uk/asd/asd1/ca/ca_quarterly_statistics_aug04.asp">http://www.dwp.gov.uk/asd/asd1/ca/ca_quarterly_statistics_aug04.asp</a>

DATA COLLECTION 28: BENEFITS DATA SYSTEM							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Benefits Data System  Separate systems for IB, IS, JSA etc	Admin data for managing benefits claims	Live systems	N/A	1999	Jobcentre Plus local office staff	GB down to local office and post code	A long list of disabilities is used/ recorded for people on IB. I don't know what is recorded on other benefit systems. Gender and age available but not ethnicity, other than by linking to LMS

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Benefits Data System  Separate systems for IB, IS, JSA etc	electronic	Audited system so better than LMS on some issues. There are some errors remaining but most of these can be cleaned with automated rules (note this is only done with the data feeds for analysis, not the faster data feeds for MI and live case management)		-Managing individual customers  -Management Information  - Performance monitoring  - Evaluation  - Policy development  - Official statistics	3 8		There is no single person (They are big systems). For data analysis/evaluation the best first point of contact is:- Nicky Tarry Data Services Unit Information & Analysis Directorate DWP 80 Hanover Way S3 7UF 0114 2497450  <a href="mailto:nicky.tarry@dwp.gsi.gov.uk">nicky.tarry@dwp.gsi.gov.uk</a>  Depending on specific enquiries I will try to forward to an appropriate person.

DATA COLLECTION 29: LABOUR MARKET SYSTEM							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Labour Market System (LMS)	Involvement in Jobcentre Plus work focused activity for all customers	Live system data feeds drawn at various times. I have monthly data	N/A	1998	Jobcentre Plus local office staff	Great Britain. Will contain local office in all cases and postcode in most cases	None Mobility Manual Dexterity Physical Co-ordination Continence Ability to lift, carry or otherwise move everyday objects Speech, hearing or eyesight Memory or ability to concentrate, learn or understand Perception of the risk of physical danger Cumulative effect of several of the above Past Disability Progressive Condition Recurring Condition Severe Disfigurement Existing PWD client Gender, age, ethnicity and many others also asked.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Labour Market System (LMS)	Electronic system. Data input by staff, customer usually present.	Variable. Some fields are mandatory, some voluntary.	Holds info on customers, staff, vacancies & training opportunities and employers.	<ul style="list-style-type: none"> <li>- Managing individual customers</li> <li>- Management Information</li> <li>- Performance monitoring</li> <li>- Evaluation</li> <li>- Policy development</li> <li>- Official statistics</li> </ul>	8	LMS is a primary source itself.	<p>There is no single person (it's a big system). For data analysis/evaluation the best first point of contact is:-</p> <p>Nicky Tarry  Data Services Unit  Information &amp; Analysis Directorate  DWP  80 Hanover Way S3 7UF  0114 2497450</p> <p><a href="mailto:nicky.tarry@dwp.gsi.gov.uk">nicky.tarry@dwp.gsi.gov.uk</a></p> <p>Depending on specific enquiries I will try to forward to an appropriate person.</p>

DATA COLLECTION 30: WORKSTEP							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
WORKSTEP Evaluation Database	Administration data for the WORKSTEP programme – records people supported through this programme	Monthly	This data is not routinely published.	Contains records for people who were actually on the programme at 1st April 2001. After that the database is cumulative.	<p>The data is taken from the operational payments database. This has three sources.</p> <p>1.Registration data is collected on the referral form by the Disability Employment Advisor at Jobcentre Plus offices or by the WORKSTEP provider (a few are authorised to refer people to the programme directly). This data is entered on to the WORKSTEP payments system by the central WORKSTEP payments team - part of the WORKSTEP policy team at Jobcentre Plus.</p> <p>2. Updates on the progress and location of clients on the programme are inputted by WORKSTEP providers.</p>	England, Scotland and Wales. The data can be analysed in a variety of ways such as clients postcode, Jobcentre Plus Region and District, Ward.	<p>Everyone on WORKSTEP has a disability as defined by the DDA.</p> <p>These are broken down into the following groups.</p> <p>Conditions Restrict Mobility Dexterity Visual Impairment Hearing And/Or Speech Impairment Long Term Medical Conditions Learning Disability Mental Health Neurological Conditions Other Health Conditions Prefer Not To Say</p>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
WORKSTEP Evaluation Database	<p>Source 1 (as in 'collected by) is recorded on paper forms (WS REF for DEA referrals &amp; WS REF(P) for provider referrals).</p> <p>Source 2 is entered by providers using a web based electronic form (you can see the screens in the attached IT guide)</p>	<p>Variable to poor</p> <p>Database only records primary disability</p>	<p>This is an evaluation database based on administrative records for people on the WORKSTEP programme</p> <p>Like all our databases, these records can be linked to our other databases and Inland Revenue data using the unique identifier 'ORCID'</p>	<p>The database is used to calculate outcome payments for providers. It is also a source of management information to inform the development of the programme.</p> <p>The database is used for the programme evaluation for analysis and sampling.</p>	8	WORKSTEP Payments database is the original source	<p>Lisa Naylor</p> <p>0114 209 8246</p> <p><a href="mailto:lisa.m.naylor@dwp.gsi.gov.uk">lisa.m.naylor@dwp.gsi.gov.uk</a></p>

DATA COLLECTION 31: WORK PREP.							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Work. Prep.		Monthly		At least 2003 and more held in regions	Head office	England, Scotland and Wales  regional	Only people with a disability or health condition  Type of disability/health condition is not recorded

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Work. Prep	Clerical stencil	Variable	<ul style="list-style-type: none"> <li>- numbers of customers referred to Work Prep programmes</li> <li>- numbers of customers who start on the programme</li> <li>- numbers of customers who complete the programme</li> <li>- numbers of job entries achieved from the completers</li> <li>- numbers of other positive outcomes achieved from the completers</li> <li>- spend details by region</li> </ul>	Administration of the programme	8	Original data source	Lisa Naylor  0114 209 8246  <a href="mailto:lisa.m.naylor@dwp.gsi.gov.uk">lisa.m.naylor@dwp.gsi.gov.uk</a>

DATA COLLECTION 32: NEW DEAL FOR DISABLED PEOPLE							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST – LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
NDDP	Details of customers voluntarily registering for NDDP	Data input as customers register – data drawn every month	Aggregate registration and job entry figures are published monthly.	July 2001 to present	Jobcentre Plus / DWP Supplied electronically by programme providers to Jobcentre Plus / DWP	UK (not including Northern Ireland who have a different NDDP provision).  We do not regularly publish figures on a local / regional basis though a breakdown is available in the first NDDP Synthesis Report published by the department in August 2004.	Gender Age Ethnicity Disability / Health conditions (See below for list).  Mental health condition Neck and / or back condition Legs and / or feet condition Arms and / or hands condition Heart condition or blood pressure Stomach, liver, kidney or digestion conditions Progressive illness not covered in other categories Epilepsy Visual impairment Chest and / or breathing condition Diabetes Learning difficulties Hearing impairment Skin conditions or allergies Speech impairment Other Prefers not to say

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
NDDP	Web based data entry system (data entered by programme providers)	Good data quality levels.		<ul style="list-style-type: none"> <li>- Internal reporting</li> <li>- Policy making</li> <li>- Contract management</li> <li>- External reporting</li> </ul>	8	Mainly original, some imported in final dataset.	<p>Lisa Naylor 0114 209 8246</p> <p><a href="mailto:lisa.m.naylor@dwp.gsi.gov.uk">lisa.m.naylor@dwp.gsi.gov.uk</a></p> <p><a href="http://www.dwp.gov.uk/asd/asd1/nddp/nddp_september2004.asp">http://www.dwp.gov.uk/asd/asd1/nddp/nddp_september2004.asp</a></p>

DATA COLLECTION 33: ACCESS TO WORK							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Access to Work database	Administrative data – record of clients who have received support through this programme, including what support they have received	Monthly	Not published	1994 to current	Jobcentre Plus	England, Scotland and Wales	<p>Only people with a disability or health condition who are supported through this programme.</p> <p>No coded disability data is collected. Details of disability are recorded in a free text field</p>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Access to Work database	Electronically recorded by certain Jobcentres	Variable to poor		Administration of the programme	8	Original data	<p>Lisa Naylor</p> <p>0114 209 8246</p> <p><a href="mailto:lisa.m.naylor@dwp.gsi.gov.uk">lisa.m.naylor@dwp.gsi.gov.uk</a></p>

DATA COLLECTION 34: SOCIAL FUND PBMIS (POLICY, BUDGET AND MANAGEMENT INFORMATION SYSTEM)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Social Fund Policy, Budget and Management Information System (PBMIS)	Summary data from the Social Fund Computer System	Monthly	Some data is published in the annual report by the Secretary of State for Work and Pensions on the Social Fund each July.	1995/96 to present	Summarized by EDS from the Social Fund Computer System.	UK. Originally by Benefits Agency district. From May 2002 to the present, there has been a boundary change programme in Great Britain to move from Benefits Agency districts (129 in total) to Jobcentre Plus Districts (90 in total).	No data specifically on people with learning difficulties/disabilities. Some data on disabled people.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Social Fund Policy, Budget and Management Information System (PBMIS)	Individual cases are recorded on the Social Fund Computer System which supports the decision making and payment process for Social Fund applications . Data from this system is fed to PBMIS.	Good, but with a few known problems	Summary data from the Social Fund Computer System	Used to support Social Fund operations and strategy and to provide statistical data for several purposes.	3		Elizabeth Major, room 450, IAD OR3 (Social Fund), DWP, The Adelphi, 1-11 John Adam Street, London, WC2N 6HT Phone: 020 7962 8966 E-mail: <a href="mailto:Elizabeth.Major@dwp.gsi.gov.uk">Elizabeth.Major@dwp.gsi.gov.uk</a>

DATA COLLECTION 35: DISABLED FACILITIES GRANTS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Office of the Deputy Prime Minister's (ODPM's) Housing Investment Programme Returns	Numbers and amounts of housing renewal grants under the 1989, 1996 and 2003 Act by Renovation Grants, Disabled Facilities Grants, HMO Grants, Common Parts Grants and Minor Works Assistance.  Grant applications are made from clients via local council's housing or environmental departments.	Annually	Around Dec/Jan each year	1996/97 - 2003/04	354 LAs in England by the Housing Statistics and Data division, ODPM	District, Regional and England National.	Disabilities

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Office of the Deputy Prime Minister's (ODPM's) Housing Investment Programme Returns	Electronically through the departments' interform collection system.	100% Response .	Number and/or amount of disabled facilities grants paid up to 2002/03 Number and amount of total renewal grants paid up to 2002/03 Number of total renewal and disabled facilities grants paid up to 2002/03	Live table publication, Housing Statistics Annual Volume.	6	Original	<a href="mailto:lan.rutherford@odpm.gsi.gov.uk">lan.rutherford@odpm.gsi.gov.uk</a>  020 7944 3323  <a href="http://www.odpm.gov.uk/stellent/groups/odpm_housing/documents/page/odpm_house_033342.pdf">http://www.odpm.gov.uk/stellent/groups/odpm_housing/documents/page/odpm_house_033342.pdf</a>

DATA COLLECTION 36: SUPPORTING PEOPLE CLIENT RECORD DATA							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Client Record Data	Client Record forms are filled in by every new Supporting People service user. The Client Record data then collects all these forms into one database.	We receive 4 quarterly Client Record datasets and then one final dataset also containing late cases.	NA	Data first collected March 2003. Last dataset received by ODPM (11th Nov) - this is the Q2 2004/5 data.	Service Providers (these include local authorities, voluntary organizations, private companies) fill in the Client Record forms. They then send them to the Client Record office in St Andrews who produce the Client Record dataset which is sent to ODPM.	England. Data available by Supporting People Administering Authorities.	A question asks the primary and secondary client groups a client belongs to. This is question 7 on the Client Record form. A number of these groups identify clients with disabilities. A further question establishes the clients age, sex and ethnic origin.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Client Record Data	Client Record forms filled manually or electronically.	Data is of a good quality - very few missing values or errors.	-	Data currently mainly used for internal reports. A number of tables are produced displaying key information and reports written on key features. These tables and reports will soon be published on the Supporting People website.	6	Original	<p>Andrew Powell  <a href="mailto:Andrew.Powell@odpm.gsi.gov.uk">Andrew.Powell@odpm.gsi.gov.uk</a></p> <p>Tel: 0207 944 4816</p> <p><a href="http://www.spkweb.org.uk/search/channels/www.spkweb.org.uk/subjects/client_records/annualreport2003_2004.pdf">http://www.spkweb.org.uk/search/channels/www.spkweb.org.uk/subjects/client_records/annualreport2003_2004.pdf</a></p>

DATA COLLECTION 37: P1E/HOMELESSNESS STATISTICS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
HOMELESSNESS STATISTICS – P1E	P1E - Local Authority activity under the homelessness provisions of the 1996 Housing Act	Quarterly and annually	Quarterly (51 working days after each quarter)  Annually (not published)	1978 - till present	Local authorities	England	Age, Ethnicity, Physical disability, Mental illness or disability

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
HOMELESSNESS STATISTICS – P1E	Electronic & paper	Validated	The purpose of this return is to collect information on English local housing authorities' discharge of their duties under the homelessness legislation. Summary details are published by the ODPM in the quarterly Statutory Homelessness Statistical Release, and annually in Housing Statistics.	Internal reporting, policy making and external requests	6	Original	Peter Stubbs  <a href="mailto:Peter.stubbs@odpm.gsi.gov.uk">Peter.stubbs@odpm.gsi.gov.uk</a>  020 7944 3322  <a href="http://www.odpm.gov.uk/pns//pnattach/20040136/4.xls">http://www.odpm.gov.uk/pns//pnattach/20040136/4.xls</a> ).

DATA COLLECTION 38: DELIVERY IMPROVEMENT STATEMENT (DIS)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
PADI	Up to date info about the improvement performance of CSSRs across England	Twice yearly	2003	..... - 2003	CSCI (formally Social Services Inspectorate) from CSSRs	England	Learning disability Learning difficulty Physical and sensory disability Mental Health

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
PADI	DIS (Delivery and Improvement Statement) electronically and from KIGS (Key Indicator Graphical System) and then entered onto PADI (Performance Assessment Data and Information) using DIAT (Delivery and Improvement Analysis Tool)		<p>The amount spent by each council on advocacy expressed as the amount per head of people with learning disability</p> <p>% of all adults of all client groups receiving community based services who are in receipt of direct payments</p> <p>% of adults with learning disabilities receiving community based services receiving short term breaks</p> <p>% of carers aged 65+ for whom a plan has been agreed</p> <p>Unit cost of residential and nursing care for adults with learning disabilities</p> <p>Gross expenditure on day care as a % of expenditure on all non-residential services</p> <p>Adults under 65 with learning difficulties</p> <p>Adults with learning disabilities (18 – 64)</p>		3 4 6 7		<p><a href="mailto:Graham.Booth@csci.gsi.gov.uk">Graham.Booth@csci.gsi.gov.uk</a></p> <p><a href="mailto:Mike.Beazley@csci.gsi.gov.uk">Mike.Beazley@csci.gsi.gov.uk</a></p>

DATA COLLECTION 39: HIGHER EDUCATIONAL STATISTICAL AGENCY HESA)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
HESA	HESA collects across 5 main data sets; -Student -Student First Destinations -Staff -Finance -Non-Credit course records	Annually	2003	1994/95 - 2003	The institution on their student registration forms	England	-No known disability -Dyslexia -Blind/are partially sighted -Deaf/have a hearing impairment -Wheelchair user/have mobility difficulties -Personal care support -Mental health difficulties -Unseen disability eg. Diabetes, epilepsy, asthma -Multiple disabilities -A disability not listed above -Information not sought -Not known

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
HESA	Electronically through HE institutions via student registration forms using JANET	All data received passes through a robust data quality procedure. HESA have been awarded the BS EN ISO 9002 and BS7799 – Security Certificate (International quality standard)	Disability groups covered by;  <ul style="list-style-type: none"> <li>- Research for a higher degree</li> <li>- Taught courses for a higher degree</li> <li>- Other postgraduate</li> <li>- First degree</li> <li>- Other undergraduate</li> <li>- Totals</li> </ul> By full time/part time/female/male students	-Collected for statutory customers ie. Funding councils -Ad-hoc queries -For publish reference volumes based on students, finance, staff etc.	2	Student registration forms	<a href="mailto:Izzy.Garnier@hesa.ac.uk">Izzy.Garnier@hesa.ac.uk</a> Tel:01242 211134  <a href="http://www.hesa.ac.uk/pi/">http://www.hesa.ac.uk/pi/</a>  <a href="http://www.lsc.gov.uk/National/Partners/Data/Statistics/Default">http://www.lsc.gov.uk/National/Partners/Data/Statistics/Default</a>

DATA COLLECTION 40: Housing Associations/ Independent Organisation Schemes							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Housing Association & Independent Organisation Schemes	Schemes approved and their client types	Annually	March 2004	1999	Registered Social Landlords (RSL's) provide input but the Housing Corporation collects	By region and local authority throughout England	Mental Health  Learning disabilities  Physical disabilities

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Housing Association & Independent Organization Schemes	Electronically	Reliable	RSLs input information about the schemes they are proposing to develop into the Information Management System during the bidding round. As part of this they specify who the proposed houses are for. Each scheme has two client priority groups. Some bids put in by RSLs include bids for homes for people with learning disabilities.	Report to ODPM Informs inspection Targets tenants need by impacting on allocation decisions	6	Yes	<a href="mailto:Andrew.Eagles@housingcorp.gsx.gov.uk">Andrew.Eagles@housingcorp.gsx.gov.uk</a>  <a href="http://www.housingcorplibrary.org.uk/housingcorp.nsf/AllDocuments/8E30BA053843B35A80256E52005AC7F8/\$FILE/R65report_web.pdf">http://www.housingcorplibrary.org.uk/housingcorp.nsf/AllDocuments/8E30BA053843B35A80256E52005AC7F8/\$FILE/R65report_web.pdf</a>

DATA COLLECTION 41: RSR (REGULATORY AND STATISTICAL RETURN) AND CORE (CONTINUOUS RECORDING OF LETTINGS)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Regulatory and Statistical return	Annual census of housing association stock	Annually	Data available for 2004 (as at 31 March 2004).	Survey goes back to 1988, but disability not collected consistently through the years.	Corporation (via contractors)	Disability, gender etc nationally, but stock details available at LA level including sheltered and wheelchair dwellings.	Disability, gender, ethnic origin of HA staff and governing body members
CORE (Continuous Recording of lettings)	A letting log is completed every time a letting is made. The data comes across every quarter	Quarterly	Data for the financial year to 2004 available.	Survey goes back to 1989, but the consistency of question not guaranteed	Corporation (with part funding from ODPM) via contractors	Ethnic origin, wheelchair and disability by postcode and LA	Disability, ethnic origin of tenants

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Regulatory and Statistical return	Electronic and paper	None	The tables (for 2003) and forms are available on the RSR survey website	Informs policy Answers Parliament First source of data for the HA sector Academic research etc	6	Original	Pragati Somaia (0207-393-2243) email: <a href="mailto:Pragati.Somia@housingcorp.gsx.gov.uk">Pragati.Somia@housingcorp.gsx.gov.uk</a>  <a href="http://www.rsrsurvey.co.uk">www.rsrsurvey.co.uk</a>
CORE (Continuous Recording of lettings)	Electronic and paper		Data is available from the Corporation and more information on the CORE website	Same as above, also tenant profiles etc	6	Original	Tracey Goulding (0207 393 2125) or Pragati Somaia (as above)  <a href="mailto:Tracy.Goulding@housingcorp.gsx.gov.uk">Tracy.Goulding@housingcorp.gsx.gov.uk</a>  <a href="http://www.CORE.ac.uk">www.CORE.ac.uk</a>

DATA COLLECTION 42: CORE (CONTINUOUS RECORDING OF LETTINGS)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
CORE and the National Housing Federation	Housing association and local authority data	Quarterly		Apr 1996 to present (HAs); Apr 2004 onwards (LAs)	HAs & LAs send a completed letting form to CORE (St Andrews). CORE send data to the National Housing Federation	England	Learning disability

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
CORE and the National Housing Federation	Electronic and paper			Tenant profiles	6	Data received from CORE. The Housing Corporation also access the same data.	<a href="mailto:Georgem@housing.org.uk">Georgem@housing.org.uk</a> Tel: 0207 067 1097

DATA COLLECTION 43: LEARNING AND SKILLS COUNCIL							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
LEARNING AND SKILLS COUNCIL	Most of the data on learners is collected via an Individualised Learner Record.	Annually		Limited data on disability collected from 1994/95 onwards. More extensive data from 2000/01.	The relevant institution and forwarded to LSC	England	Data is collected for all publicly-funded learners in post-16 education and training other than HE and school sixth forms - over 5 million learners. Disability groups are as follows;  -Learning difficulty/disability and/or health problem

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
LEARNING AND SKILLS COUNCIL	Electronically - either as data files (most providers) or by manual entry through a website (some smaller providers)	.	<p>There are 4 main items of information in relation to learners;</p> <ul style="list-style-type: none"> <li>-whether the learner has a learning difficulty/disability/ health problem (including those in adult and community learning)</li> <li>-the learner's main disability</li> <li>-the learner's main learning difficulty</li> <li>-additional support funding (either FE or work based learning)</li> </ul> <p>SC also funds those learners with difficulties and/or disabilities in specialist colleges. Also funds school sixth forms but the DfES collects this data along with other pupils in schools.</p>	<p>Used internally for analysis and has also been fed into mapping systems reviewing provision for learners with learning difficulties and/or disabilities.</p> <p>More recently, a statistical first release has contained information for the first time on success rates for learners with a learning difficulty/disability compared to those who do not have this type of disability.</p>	2 7	ILR	<p><a href="mailto:Colin.Stronach@lsc.gov.uk">Colin.Stronach@lsc.gov.uk</a></p> <p>Tel 024 7682 3733</p>

DATA COLLECTION 44: PERSONAL SOCIAL SERVICES ESTIMATES/ACTUALS AND CIPFA							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Personal Social Services Statistics 2003-04 Estimates	Book, Electronic (CD or Internet access to subscribers)	Annually	June 2004	2003-04 edition was the 30th publication	CIPFA	England, Wales, Scotland	All Adult Client Groups and Children's Services
Personal Social Services Statistics 2002-03 Actuals	Book, Electronic (CD or Internet access to subscribers)	Annually	July 2004	2002-03 edition was the 53rd publication	CIPFA	England, Wales, Scotland	All Adult Client Groups and Children's Services

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Personal Social Services Statistics 2003-04 Estimates	CIPFA questionnaire	All data validated by CIPFA			6 7		<a href="http://www.cipfastats.net/socialservices/pss/actuals/default.asp">http://www.cipfastats.net/socialservices/pss/actuals/default.asp</a>
Personal Social Services Statistics 2002-03 Actuals	Joint CIPFA/Department of Health questionnaire	All data validated by CIPFA and Department of Health					

DATA COLLECTION 45: GPRD (GENERAL PRACTICE RESEARCH DATABASE)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
General Practice Research Database (GPRD)	Data added to the patient's electronic record by their GP.	Continually		1987-2004	GPRD Division of the Medicines and Healthcare products Regulatory Agency (MHRA) from contributing GP practices who use VISION practice management systems	UK	All patients registered with contributing GPs

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
General Practice Research Database (GPRD)	Electronically	Continually monitored	GPRD collects data from over 300 GP practices which accounts for approximately 5% of the UK population. Amounting to approximately 2.5-3 million longitudinal patient records.	Descriptive epidemiology, Drug safety, pharmacoconomics, Health outcomes, prescribing analysis, Health service planning, clinical trials planning	5	Yes	<a href="mailto:Admin@gprd.com">Admin@gprd.com</a> Tel: 0207 084 2383

DATA COLLECTION 46: INDEPENDENT LIVING FUND (ILF)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
ILF	A national resource to support disabled people. A discretionary trust making 4 weekly cash payments to people as a contribution towards privately engaged personal care/domestic costs aiding people to live in their own homes as opposed to living in residential care. Clients must be severely disabled/mentally disabled and must already be receiving AA or DLA highest rate care component. The ILF expects all its users to use half of their DLA care component towards care costs. Users who receive income support and live alone or living with others who are receiving DLA would also be entitled to SDP –Severe Disability Premium. All of this should be used to pay for care.	Quarterly	2004	1992/3 - 2004	LA application forms passed on to the ILF	Great Britain, available by authority	<ul style="list-style-type: none"> <li>-Severe Learning disability</li> <li>-Multiple Sclerosis</li> <li>-Cerebral Palsy</li> <li>-Spinal injury</li> <li>-Brain damage</li> <li>-Cerebro-vascular</li> <li>-Muscular dystrophy</li> <li>-Epilepsy</li> <li>-Arthritis</li> <li>-Mental illness</li> <li>-Spina bifida</li> <li>-Parkinson's disease</li> <li>-Friedreichs ataxia</li> <li>-Huntingdon's disease</li> <li>-Motor neurone disease</li> <li>-Dementia</li> <li>-Polio</li> <li>-Cancer</li> <li>-AIDS</li> <li>-Hydrocephalus</li> <li>-Respiratory diseases</li> <li>-Heart disease</li> <li>-Physical malformation</li> <li>-Blood disease</li> <li>-Osteoporosis</li> <li>-Skin disease</li> </ul>

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
ILF	Application form, DWP Enquiries, data from Users		Data covering disability type, age, gender, household status, geographical distribution, numbers in receipt of income/funding along with the services that social services provide and their charges,		3 6		<a href="mailto:funds@ilf.org.uk">funds@ilf.org.uk</a>

DATA COLLECTION 47: REGISTRATION AND INSPECTION DATABASE – CSCI (FORMALLY NCSC)							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
R & I DATABASE	Details of regulated services, maximum registered places, applications, variation and enquiries.	Continuous		2000 - 2004	Area offices record data onto the R&I database electronically	England	-Learning disabilities are recognized as a group on the database.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
R & I DATABASE	Collected from organizations/ bodies and then stored on CSCI's data collection system – R&I database		<p>A number of types of services are covered within this database</p> <ul style="list-style-type: none"> <li>-Boarding schools</li> <li>-Children's homes</li> <li>-Care Homes</li> <li>-Domiciliary Care Agencies</li> <li>-Further Education Colleges</li> <li>-Fostering Agencies</li> <li>-Local authority Fostering Services</li> <li>-Nurses Agencies</li> <li>-Residential Family Centres</li> <li>-Residential Special Schools</li> <li>-Voluntary Adoption Agencies</li> <li>-Local Authority Adoption Service</li> </ul>	<p>Internal reporting</p> <p>Register and inspecting the services</p> <p>External reporting ie. Parliamentary question, press enquiries, members of general public.</p>	1 9	R & I database	<a href="mailto:Jenny.Wells@csci.gsi.gov.uk">Jenny.Wells@csci.gsi.gov.uk</a>

DATA COLLECTION 48: LSC (LEARNING AND SKILLS COUNCIL) SPECIALIST COLLEGE PLACEMENTS							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
LSC Learners with Learning Difficulties and/or Disabilities Placements Process (Specialist College Placements)	Management and contract information for specialist college placements	Continuous Collection	NA	Reliable: Sep 1998 to July 2004	Local Learning and Skills Councils	England (subdivided into 47 local areas)	Learners attending LSC funded specialist colleges

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
LSC Learners with Learning Difficulties and/or Disabilities Placements Process (Specialist College Placements)	Local LSC entry onto bespoke application from applications (applications compiled by Connexions)	Full accuracy 10%; Effective accuracy 95%	Information used to manage the placements process – manage applications, decisions about placements, level of support required, programme details, production of contracts, drives payment process, monitoring placements	See description	2	Applications drawn from variety of sources (school reports, medical reports, etc.)	Beverley Burgess LLDD Group Programme Manager Learning and Skills Council Cheylesmore House Quinton Road Coventry CV1 2WT <a href="mailto:Beverley.Burgess@lsc.gov.uk">Beverley.Burgess@lsc.gov.uk</a>  024 7682 3361

DATA COLLECTION 49: Incapacity Benefit Pilot							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Incapacity Benefit Pilot	Information about work history, health to determine readiness for work	An extract is produced monthly	Not published	October 2003 to present	DWP	IB pilots: Renfrewshire, Derbyshire, Bridgend, Somerset, Gateshead, Essex, East Lancashire	Those submitting new claims to IB in these areas after October 2003 Disability categories are the same as those used for LMS

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Incapacity Benefit Pilot	Web based form	Good	This database collects information about a persons ability to return to work.	Monitoring and sampling and analysis	8	Original source via interview undertaken by PA with IB customer	Nicky Tarry 0114 249 7450 <a href="mailto:nicky.tarry@dwp.gsi.gov.uk">nicky.tarry@dwp.gsi.gov.uk</a>

DATA COLLECTION 50: Job Retention and Rehabilitation Pilot							
SOURCE	DATA TYPE	DATA FREQ.	PUB. DATE	EARLIEST - LATEST YEAR	COLLECTED BY	GEOGRAPHIC	GROUPS COVERED
Job retention and rehabilitation	Administrative data – record of clients who have received support through this programme, including what support they have received	Monthly	Not published	1st April 2003 to 31st March 2005	Providers	6 pilot areas Sheffield Greater Glasgow Tyneside Teesside Birmingham West Kent	Not exclusively people with a disability  Disability / health condition categories are attached.

SOURCE	COLLECTION METHOD	DATA QUALITY	DESCRIPTION	PRESENT DATA USAGE	DIRECT AND/OR POSSIBLE VP LINKS	ORIGINAL DATA SOURCE	CONTACT/ ACCESS DETAILS
Job retention and rehabilitation pilot	Web based system	good		Evaluation of pilot	5 8	Original data	Nicky Tarry – 0114 249 7450 <a href="mailto:nicky.tarry@dwp.gsi.gov.uk">nicky.tarry@dwp.gsi.gov.uk</a>

## Appendix 4: Data Sources Mapped Onto Valuing People Objectives

SOURCE	1	2	3	4	5	6	7	8	9	10	11
1.Private Nursing Homes, Hospitals and Clinics											
2.Community Care Statistics (Supported Residents - Adults)											
3.Community Care Statistics (RAP – Referrals, Assessments and Packages of Care)											
4.Personal Social Services Staff of Social Services Departments											
5.Performance Assessment Framework											
6.Inpatients formally detained in hospitals											
7.Community Learning Disability Nursing											
8.Hospital Episode Statistics											
9.Personal Social Services Expenditure and Unit Costs											
10.Inpatient, Day Care and Residential Beds											
11.People Registered as Blind and Partially Sighted											
12.Waiting Time Performance											
13.Health Care Providers and Waiting Times (Health Authorities and NHS Trusts)											
14.HQ/Regional Offices and Waiting Times											
15.Outpatient Activity and Attendance											
16.Waiting Times											
17.Primary Care Trusts/Strategic Health Authorities and Waiting Times											
18.Health Authorities and Waiting Times											
19.NHS Trusts/Primary Care Trusts and Waiting Times											
20. HQ and Regional Offices Waiting Times (NHS Trusts and Primary Care Trusts)											
21.Pupil Level Annual School Census (PLASC)											
22.SEN											
23.Connexions Partnership											
24.Incapacity Benefit and Severe Disability Allowance											
25.Disability Living Allowance											
26.Attendance Allowance											
27.Carers Allowance											
28.Benefits Data System											
29.Labour Market System											
30.Workstep											
31.Work Prep.											

SOURCE	1	2	3	4	5	6	7	8	9	10	11
32.New Deal for Disabled People											
33.Access to Work											
34. Social Fund Policy, Budget and Management Information System (PBMIS)											
35.Disabled Facilities Grants/Renewal Grants											
36.Supporting People Client Record Form											
37. P1E – Homelessness statistics											
38.Delivery Improvement Statement - Commission for Social Care Inspection											
39.Higher education student statistics – HESA											
40.Housing Associations & Independent Organizations Scheme - Housing Corporation											
41. RSR/Housing Association Stock Census and CORE – Housing Corporation											
42.CORE – National Housing Federation											
43.Individualised Learner Records - Learning and Skills Council (LSC)											
44.Personal Social Services (Estimates) - CIPFA											
45.Electronic Patient Records - GRPD											
46.Independent Living Fund											
47.Registration and Inspection Database - Commission for Social Care Inspection (CSCI)											
48.Learners with Learning Difficulties and/or disabilities Placements Process - Learning and Skills Council											
49..Pathways to Work Pilot - Department for Work and Pensions											
50.Job Retention and Rehabilitation Pilot - Department for Work and Pensions											
Supporting People Supply Data – Office of the Deputy Prime Minister											
Pathways/Adult Basic Skills Strategy Unit's Learning Difficulties and/or Disabilities Pilot - Department for Further Education and Skills/NIACE											
Feasibility Survey on long-term disability information requirements – Department for Work and Pensions/Natcen											

## VALUING PEOPLE OBJECTIVES

- 1 – DISABLED CHILDREN AND YOUNG PEOPLE
- 2 – TRANSITION INTO ADULT LIFE
- 3 – MORE CHOICE AND CONTROL
- 4 – SUPPORTING CARERS
- 5 – GOOD HEALTH
- 6 – HOUSING
- 7 – FULFILLING LIVES
- 8 – MOVING INTO EMPLOYMENT
- 9 – QUALITY
- 10 – WORKFORCE AND PLANNING
- 11 – PARTNERSHIP WORKING

## Appendix 5: Acronyms

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AA – Attendance Allowance

BDS – Benefit Data System

CA – Carers Allowance

CCG – Community Care Grants

CIPFA – The Chartered Institute of Public Finance and Accounting

CLDN – Community Learning Disability Nurses

CORE – Continuous Recording of lettings

CSCI – Commission for Social Care Inspection

CSSR – Councils with Social Services Responsibilities

DDA – Disability Discrimination Act

DEA – Disability Employment Advisor

DfES – Department for Education and Skills

DFG – Disabled Facilities Grants

DIAT – Delivery and Improvement Analysis Tool

DIS – Delivery Improvement Statement

DLA – Disability Living Allowance

DNA – Did Not Attend

DoH – Department of Health

DWP – Department for Work and Pensions

EDS – Electronic Data Systems

EET – Employment, Education or Training

ESDS – Economic Social Data Services

FACS – Families and Children Study

FE – Further Education

GORs – Government Office Regions

GP – General Practitioner

GPRD – General Practice Research Database

HA – Health Authorities

HE – Higher Education

HES – Hospital Episode Statistics

HESA – Higher Education Statistics Agency

HQ – Headquarters  
IB – Incapacity Benefit  
ICA – Invalid Care Allowance  
ICD – International Classification of Diseases  
ILF – Independent Living Fund  
ILR – Individualised Learner Record  
IS – Income Support  
JA – Job Seekers Allowance  
JANET – Joint Academic NETwork  
KIGS – Key Indicator Graphical System  
LA – Local Authority  
LDD – Learning Disability and/or Difficulty  
LDPB – Learning Disability Partnership Board  
LEA – Local Education Authority  
LMS – Labour Market System  
LSC – Learning and Skills Council  
MHA – Mental Health Act  
MHRA – Medicines and Healthcare products Regulatory Agency  
MI – Management Information  
MIS – Management Information System  
Natcen – National Centre for Social Research  
NCSC – National Care Standards Commission  
NCSR – National Centre for Social Research  
NDDP – New Deal for Disabled People  
NEET – Not in Employment, Education or Training  
NHS – National Health Service  
NMSS – Non-Maintained Special Schools  
NWCS – NHS Wide Clearing System  
OATs – Out of Area Treatments  
ODPM – Office of the Deputy Prime Minister  
ONS – Office for National Statistics  
PA – Personal Adviser  
PADI – Performance Assessment Data and Information  
PAF – Performance Assessment Framework

PBMIS – Policy, Budget and Management Information System  
PCG – Primary Care Group  
PCT – Primary Care Trust  
PES – Public Expenditure Survey  
PWO – Person With Disability  
PLASC – Pupil Level Annual School Census  
PSS – Personal Social Services  
PSSRU – Personal Social Services Research Unit  
RAP – Referrals, Assessments and Packages of Care  
RNIB – Royal National Institute for the Blind  
RSLs – Registered Social Landlords  
RSR – Regulatory and Statistical Return  
SCYPG – Supporting Children and Young People’s Group  
SDA – Severe Disability Allowance  
SDP – Severe Disability Premium  
SEN – Special Educational Needs  
SENCO - Special Educational Needs Co-coordinator  
SHA – Strategic Health Authority  
SR – Supported Residents  
VPST – Valuing People Support Team  
WHO – World Health Organization  
WTE – Whole Time Equivalent

## Appendix 6: Acknowledgements

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British Institute of Learning Disabilities  
Bristol University  
Cabinet Office  
Central England People First  
Commission for Social Care Inspection  
Department for Constitutional Affairs  
Department for Environment, Food and Rural Affairs  
Department for Further Education and Skills  
Department for Transport  
Department for Work and Pensions  
Department of Health  
Department of Trade and Industry  
Employers' Organization for Local Government  
Higher Education Statistics Agency  
Home Office  
Independent Living Fund  
Joseph Rowntree Foundation  
Kings College, London  
Learning and Skills Council  
Learning and Skills Development Agency  
Literacy Trust  
Medicines and Healthcare products Regulatory Agency  
Mencap  
Mental Health Foundation  
National Centre for Social Research  
National Housing Federation  
National Patient Safety Agency  
Office for National Statistics  
Office for Standards in Education  
Office of the Deputy Prime Minister  
Personal Social Services Research Unit

Royal College of General Practitioners  
Royal National Institute for the Blind  
Royal National Institute for the Deaf  
Sense  
The Audit Commission  
The Basic Skills Agency  
The Chartered Institute of Public Finance and Accounting  
The City and Guilds of London Institute  
The Disability Rights Commission  
The Foundation for People with Learning Disabilities  
The Housing Corporation  
The London School of Economics and Political Science  
The Museums, Libraries and Archives Council  
The National Institute of Adult Continuing Education  
The Training Organization for the Personal Social Services  
The Treasury  
The University of Essex  
University of Kent  
The University of St. Andrews  
University of Warwick  
University of York  
Values Into Action  
Valuing People Support Team