

LDSS Statistical Return & Data Confidentiality

2012

Overview

This paper explains the methodology and rationale of the LDSS Statistical Collection. It explores the implications around confidentiality and the processes in place to ensure that the data provided is protected as far as possible. This paper should be read in conjunction with 'Data sharing review'¹ (Richard Thomas & Mark Walport, July 2008) and the 'Code of Practice on Data Sharing'² (Information Commissioner's Office).

The LDSS Data Collection is co-ordinated on behalf of The Scottish Government by SCLD. SCLD is a Centre for Excellence established as a result of 'The same as you?', the review of services for people with learning disabilities. It is funded by the Scottish Government to support people and organisations across Scotland to make 'The same as you?' a reality for people with learning disabilities and their families. The LDSS Statistical Collection has achieved Official Statistics Status and, as a result, SCLD is recognised as an official statistics provider and is subject to scrutiny and assessment by the UK Statistics Authority.

¹ <http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/datasharingreview.pdf>. This paper was originally available at www.justice.gov.uk in July 2008. Last accessed 17/10/2012.

² http://www.ico.gov.uk/for_organisations/guidance_index/~media/documents/library/Data_Protection/Detailed_specialist_guides/data_sharing_code_of_practice.ashx. Last

accessed 17/10/2012.

Background

The LDSS return collects information in order to chart the progress of ‘The same as you?’ policy (2001)³. Previously an aggregate return to The Scottish Government, it was considered that this type of return limited the analysis which the rich local authority data source could potentially provide. In addition, an aggregate collection does not allow outcomes (e.g. further education and employment) to be related directly to the population therefore increasing the potential for duplicate recording and inaccurate rates. In 2008, the data collection shifted away from collecting data from a ‘service’ point of view, towards collecting data on ‘individuals’ to get an improved understanding and evidence base of all aspects of learning disability services being provided and received in Scotland via the local authority. To plan service delivery effectively, the evidence base must be robust and extensive. To achieve this, LDSS aims to ensure that information is recorded and measured in the same way by everyone. The database can then be used to accurately provide statistical/research evidence around:

- monitoring the progress of the recommendations of “The same as you?” and other policies
- making sure they are being implemented on time, and in the right way
- helping to plan services
- identifying where there are unmet needs

³ <http://www.scotland.gov.uk/Resource/Doc/1095/0001661.pdf>. Last accessed 17/10/2012.

- comparing information across local authority areas and to evidence what is happening nationally.

The LDSS data collection should be seen in the context of improving planning and thus services for people with learning disabilities to enable them to have good outcomes in their lives. It specifically enables progress monitoring of 'The same as you?' overarching recommendation that local authorities should aim to move away from traditional day care settings and towards developing more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially. At the time of 'The same as you?' publication, no national or local figures for the numbers of people with learning disabilities in Scotland existed. Instead, data was based on prevalence figures and, as such, a recommendation was made for local registers to be established.

In addition, an individual level collection addresses issues around data quality and the burden of local authorities having to provide an aggregate return when their social work IT systems provide individual based information. There are also resource issues on the LDSS Team side - the data collection and validation of an aggregate return is a very inefficient process. By working with local authorities, more efficient data collection & validation processes can be utilised. As a result of this, authorities are then able to benefit locally by incorporating LDSS data and outcomes into their Single Outcome Agreements.

Working Together

The LDSS Team are committed to working with Local Authorities to provide the most accurate dataset possible. Comprehensive Guidance on the collection is issued annually in advance of the start of the collection to ensure all data sources are aware of the requirements. Throughout the collection process the LDSS Team remain in close contact with local authorities and quarterly Data Group meetings are held to raise any issues and to discuss progress. In addition, every effort is made to support Local Authorities to collect the required data and to ensure satisfaction with the process. In previous collections, deadline dates have been extremely flexible and once data has been submitted and cleaned, frequency tables are returned to the providing authority for sign off before publication. The LDSS collection is progressive and aims to respond to policy demands and to the needs of the local authority providers. To this end, local authority consultation on the content of the return continues to be an ongoing process.

A number of agencies have been consulted with on the details of the LDSS collection. LDSS Team members have met with the Community Care Statistics Branch, Adult Care and Support Division, Information Commissioner's Office, Data Standards Branch and various policy colleagues within the Scottish Government where there is wide support for collecting the LDSS data on an individual basis in order to improve the analytical evidence.

What is collected?

The data items collected by the LDSS return are derived from the National Data Standards Document V4.2 which were produced by the Social Care Data Standards. These Standards went through numerous rounds of consultations before the final version was released and have subsequently been aligned to the Generic Core Data Standards, the Social Care Data Standards Manual V2.0, the National Minimum Information Standards for all Adults in Scotland V 3.0, and the eCARE Multi-Agency Store Data Model V2.9.

The LDSS 2011 data collection collects data on adults with learning disabilities and autism spectrum disorders in Scotland. Specifically, information is to be collected only on those who are aged 16 and over and not in full-time school education. All adults who match these criteria and who are known to the local authority regardless of the services they are currently receiving (if any) should be included in the return. In summary, the information found in 'Box 1' is returned for each individual who has a learning disability or an Autism Spectrum Disorder known to the local authority and who fits the collection criteria.

The LDSS Collection Variables as advised by the LDSS Guidance document are the minimum items for collection on an individual level. The exception to this is the Advocacy variable which is accepted as an aggregate total where necessary due to the nature of this service - the local authority does not have to be informed if someone has sought advocacy. In order to maintain client confidentiality, aggregate information is accepted instead of individual level information. In addition, any data local authorities

wish to provide over and above the minimum will be gratefully received and will contribute greatly to the development of the national dataset.

It is also imperative that Local Authorities complete and return a Commentary Form with their data. The contents of this form are taken into account at analysis stage and allow Local Authorities to identify their data sources and account for any data anomalies or discrepancies. This then allows LDSS analysts to present the most accurate picture of the services a local authority provides and the numbers of people who access them as well as to offer explanations for missing data.

Box 1: Minimum LDSS variables from 2011 (full variable list and codes are available here: <http://www.sclid.org.uk/sclidprojects/LDSS/publications-and-resources/LDSS-guidance>)

- ID number
- Learning disability (Y/N)
- Autism spectrum disorder (ASD)
- Local authority code/health board code
- Person current gender
- Person year of birth
- Ethnic group
- Accommodation type
- Lives with family carer
- Number of people with a learning disability living in the same accommodation
- Advocacy
- Personal life plan
- Further education

- Employment opportunities
- Day opportunities
- Local Area Co-ordination

Names, date of birth and address information is not collected in the LDSS statistical return. SCLD staff will not be able to cross reference the client 'ID number' to any other data sources they have access to. Furthermore, SCLD staff do not have access to any local authority's Management Information System.

Legislation

Social Work (Scotland) Act 1968

<http://www.legislation.gov.uk/ukpga/1968/49>⁴

In the Social Work (Scotland) Act 1968 there are several references for local authorities to provide social welfare data for research purposes. The relevant extract can be found below:

"8 Research

(1)The Secretary of State may conduct or assist other persons in conducting research into any matter connected with his functions or the functions of local authorities in relation to social welfare, and

⁴ Last accessed 17/10/2012.

with the activities of voluntary organisations connected with those functions.

(2)Any local authority may conduct or assist other persons in conducting research into any matter connected with their functions in relation to social welfare.

(3)The Secretary of State and any local authority may make financial assistance available in connection with any research which they may conduct or which they may assist other persons in conducting under the provisions of this section.”

Other Legislation

The collection of individual level data has legislative implications. Outlined below are the main pieces of legislation which will affect the LDSS return:

Data Protection Act 1998

<http://www.legislation.gov.uk/ukpga/1998/29>⁵

The Data Protection Act (DPA) (1998) provides a set of principles which prohibit the misuse of personal information without stopping it being used for legitimate purposes. Essentially the principles state that personal data must be:

- Fairly and lawfully processed;

⁵ Last accessed 17/10/2012.

- Processed for limited purposes;
- Adequate, relevant and not excessive;
- Accurate;
- Not kept longer than necessary;
- Processed in accordance with your rights;
- Kept secure;
- Not transferred abroad without adequate protection;

According to the act, the LDSS data which is to be collected will comprise 'sensitive personal data'.

In order for processing to be lawful under the Data Protection Act, a condition under each of Schedules 2 and 3 must be met. For the LDSS statistical collection the appropriate conditions are:

Schedule 2.6: *"The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interests of the data subject."*⁶

Essentially this means that processing of personal data is allowed if it is in the legitimate interests of the data controller (i.e. the local authority) and the third party to whom those data are disclosed (i.e.

⁶ <http://www.legislation.gov.uk/1998/29/schedule/2>. Last accessed 17/10/2012.

the LDSS Team), provided there is no prejudicial consequences to the individual about whom those data relate.

Schedule 3.10 - Regulation 9 of the Order ⁷: “*The processing –*

(a) is in the substantial public interest;

(b) is necessary for research purposes (which expression shall have the same meaning as in section 33 of the Act);

(c) does not support measures or decisions with respect to any particular data subject otherwise than with the explicit consent of that data subject; and

(d) does not cause, nor is likely to cause, substantial damage or substantial distress to the data subject or any other person.”

In addition to these conditions, section 8(2) of the Social Work (Scotland) Act 1968, as outlined above, provides for local authorities to conduct, or to assist others in conducting, research concerning social welfare. The provision of this function allows reliance on further conditions for processing in Schedules 2:5(b) and 3:7(1)(b) where:

The processing is necessary -

“for the exercise of any functions conferred on any person by or under an enactment.”

⁷ <http://www.legislation.gov.uk/uksi/2000/417>. Last accessed 17/10/2012.

To plan service delivery effectively, the evidence base must be robust and extensive. For example, local authorities should aim to move away from providing care and support in traditional day care settings and move towards developing a more modern, flexible and responsive services which support people in the community through employment, lifelong learning and getting them involved socially. An individual level return enables analysts to provide a more comprehensive understanding of all the services and opportunities a person is receiving as a result of 'The same as you?' policy, and hence this processing is necessitated in order to enable Scottish Ministers to provide the general guidance required under the Social Work Act.

Part IV, Section 33 (Exemptions) of the Data Protection Act covers statistics and research. Sensitive personal data can be used for research or statistical purposes as long as the following conditions are met:

- (a) "that the data are not processed to support measures or decisions with respect to particular individuals, and*
- (b) that the data are not processed in such a way that substantial damage or substantial distress is, or is likely to be, caused to any data subject".*

The DPA states that (sensitive) personal data can be processed for research or statistical purposes even if that was not the original intention of the information. The data *may* be kept indefinitely if it is for research or statistical purposes. Furthermore, the DPA states that (sensitive) personal data can be exempt from Section 7 - Right

of access to personal data if “(a) they are processed in compliance with the relevant conditions, and (b) the results of the research or any resulting statistics are not made available in a form which identifies data subjects or any of them.”

Thomas & Walport (2008) discuss the issue of sharing personal data in the context of research and statistical analysis and how this fits with legislation in their ‘Data Sharing Review’ paper. An extract of their findings can be found below which are particularly relevant to the LDSS statistical return:

“Research and statistical analyses represent important opportunities for using and sharing information.....Developing an evidence base to improve health and social policy in many areas depends on using data derived from collections of personally identifiable material. Wherever possible, such data should be anonymised, but creating anonymised information involves accessing and processing personal information to remove identifiers from it. Many research questions also require the use of coded datasets that no longer contain explicit identifiers, but ultimately allow the data to be linked to a particular individual. Such data are often described as ‘pseudonymised’; and preserving these potential identifiers may be vital, for example, to allow linkage of pseudonymous data about the same person to facilitate a longitudinal study, or for postcode data in cases involving geographically sensitive research questions.”

“The aim here is to allow this important statistical and research analysis to proceed, while minimising the risk of identifying

individuals from within datasets. In our view, the approach of creating and using coded data should be recognised as a legitimate way of safeguarding people’s identities, and data handled in this way should not constitute a breach of the Data Protect Act.....” Thomas & Walport (2008).

Registration Service Act 2007

<http://www.legislation.gov.uk/ukpga/2007/18/contents>⁸

The SCLD and the LDSS Team fully comply with the Code of Practice for Official Statistics.

The main principles are:

- Meeting user needs
- Impartiality and objectivity
- Integrity
- Sound methods and assured quality
- Confidentiality
- Proportionate burden
- Resources
- Frankness and accessibility

(<http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf>⁹)

An extract of ‘Principle 5: Confidentiality’ can be found on the following page along with an explicit protocol around using administrative sources for statistical purposes.

⁸ Last accessed 17/10/2012.

⁹ Last accessed 17/10/2012.

Principle 5: Confidentiality

Private information about individual persons (including bodies corporate) compiled in the production of official statistics is confidential, and should be used for statistical purposes only.

Practices

1. Ensure that official statistics do not reveal the identity of an individual or organisation, or any private information relating to them, taking into account other relevant sources of information.
2. Keep confidential information secure. Only permit its use by trained staff who have signed a declaration covering their obligations under this Code.
3. Inform respondents to statistical surveys and censuses how confidentiality will be protected.
4. Ensure that arrangements for confidentiality protection are sufficient to protect the privacy of individual information, but not so restrictive as to limit unduly the practical utility of official statistics. Publish details of such arrangements.
5. Seek prior authorisation from the National Statistician or Chief Statistician in a Devolved Administration for any exceptions, required by law or thought to be in the public interest, to the principle of confidentiality protection. Publish details of such authorisations.
6. In every case where confidential statistical records are exchanged for statistical purposes with a third party, prepare written confidentiality protection agreements covering the requirements under this Code. Keep an operational record to detail the manner and purpose of the processing.

Protocol 3: The use of administrative sources for statistical purposes

Administrative sources should be fully exploited for statistical purposes, subject to adherence to appropriate safeguards.

Practices

1. Observe all statutory obligations and relevant codes of practice in relation to the protection of confidentiality and the handling of personal data.
2. Only base statistics on administrative data where the definitions and concepts are good approximations to those appropriate for statistical purposes.
3. Maximise opportunities for the use of administrative data, cross-analysis of sources and for the exchange and re-use of data, to avoid duplicating requests for information. Where possible, use common information technology and information management systems that facilitate the flow of information between producers of statistics.
4. Ensure that no action is taken within the producer body, or public statement made, that might undermine confidence in the independence of the statistics when released.
5. Prepare, in consultation with the National Statistician, a Statement of Administrative Sources which identifies the following.
 - a. The administrative systems currently used in the production of official statistics.
 - b. Procedures to be followed within the organisation to ensure that full account is taken of the implications for official statistics when changes to administrative systems are contemplated.
 - c. Information on other administrative sources that are not currently used in the production of official statistics but have potential to be so used.
 - d. Arrangements for providing statistical staff, whether inside the producer body or elsewhere, with access to administrative data for statistical purposes.
 - e. Arrangements for auditing the quality of administrative data used for statistical purposes.
 - f. Arrangements for ensuring the security of statistical processes that draw on administrative data.

Data issues 1: Using administrative data as opposed to survey data

Maximising existing administrative data has many strengths over introducing a new sample survey to monitor and inform future policy. Data from sample surveys can contain small numbers for particular variables, for example ethnicity, and as such can be prone to sampling error (as the sample may be a small proportion

of the entire population). In order to achieve meaningful statistical analysis, the sample survey would need to be large and complex and therefore prone to greater respondent error due to the increased administrative burden placed on them. Administrative data collected for the purpose of service provision is more accurate and less influenced by survey questions and length.

Data issues 2: Using individual level data as opposed to aggregate data

A further important consideration for using existing individual level administrative data over aggregate data is to do with the identification of clients from aggregated tables. The LDSS Collection has a strict Data Disclosure strategy and employs a number of methods (for example controlled rounding and data suppression) to ensure data remains confidential at all levels of the dataset. In contrast, asking local authorities to provide several slightly different aggregate tables increases the risk of personal identification from table differencing. This is because it would be extremely difficult to manage the volume of tables from 32 local authorities. The collection of individual level information allows more control over producing aggregate tables as statistical disclosure control can be applied to the dataset before it is used for analysis (see 'Dissemination' section). Individual level data allows better analysis as aggregated data inherently limits the ability of analysts to respond flexibly to policy needs – a good example is age related data, often returned in age bands in aggregate tables you are restricted to set age bands (and indeed in monitoring change over time).

Further details are provided on the following pages explaining the data collection/validation processes, and the steps in place to maintain confidentiality as far as possible. This is in order for the LDSS data collection to comply with the DPA and the Statistics & Registration Service Act 2007.

Data collection process

The LDSS Data Collection is an annual return which begins in August each year upon release of the Guidance document. A deadline for data uploads is set and communicated early in the Collection period and every Local Authority is issued with a unique username and password to access the secure data upload system.

LDSS processes take account of the gold standard for information sharing as set out in the Implementation Toolkit for Information Governance. No individual can be identified from the information supplied to LDSS. The LDSS database follows the guidance on acceptable anonymisation as set out by the Confidentiality and Security Advisory Group Scotland.

Local authorities are asked to anonymise their dataset (i.e. remove any names, dates of birth, address information) and to then submit the individual level LDSS information via a unique upload feature on the LDSS website. The LDSS Team have no access to the data until the local authority explicitly submits it to upload feature.

LDSS data returns are protected by well developed IT security procedures. A more detailed outline of these procedures is available on request from the LDSS team.

Any data found to contain any identifying information will immediately be deleted and the Local Authority provider contacted and asked to resubmit. Once the data has been submitted SCLD becomes the data processor for Scottish Government, who is the

data controller. The data is then cleaned and validated. Local authorities are able to view aggregate tables of their data before it is accepted for analysis and publication.

It is planned to implement an encryption method soon which will allow the files themselves to remain encrypted before and after download. Old files on the server are deleted and "shredded".

The secure server used for the LDSS uploads is managed by Hiper Ltd. This team has administrative access to the systems. No staff members in SCLD, other than the LDSS Team, have administrative access to the systems.

User data held on the secure server is not backed up. This ensures that no additional copies of user's data are made. It is the responsibility of the submitter to ensure that they can resubmit their data in the event of a system failure. At the point that the submission is accepted by the LDSS Team, the data is transferred to the SCLD network and is subject to strict corporate arrangements for backup and security.

In addition, all staff members who have any level of access to the LDSS Data (currently comprising SCLD Director, LDSS Team and Castle Ltd) have signed confidentiality documents (see Annex 1).

Consent

In accordance with the Code of Practice for Official Statistics¹⁰ LDSS have a duty to abide by Principle 5 which covers data confidentiality (as well as to the Data Protection Act 1998). In addition to the processes which will be in place surrounding the transmitting, storing and accessing the data (see previously), local authorities are asked to update their fair processing notices for clients and inform them at reviews of how their data will be used by the Local Authority and SCLD. Clients (or their carer) “*have a right to expect that they will be told the purposes for which their information will be used, who will use it, with whom it will be shared, how long it will be retained, and how it can be updated. They further have a right to expect that their information will be handled fairly and securely, and that they will be told all this in a clear and straightforward manner, free from excessively legal or confusing language*” (Thomas & Walport, 2008¹¹). Suggested text to be incorporated by local authorities into their fair processing notices can be found in Box 2.

¹⁰ <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-officialstatistics.pdf>. Last accessed 17/10/2012.

¹¹ <http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/datasharingreview.pdf>. This paper was originally available at www.justice.gov.uk in July 2008. Last accessed 17/10/2012.

Box 2: Fair processing notices – suggested text for local authorities (see Annex 2 for easier to read version)

Your details and information about the services you receive may be shared with the LDSS team at SCLD for statistical purposes only.

- This information will help LDSS to produce statistics which help your Local Authority to plan for future care services. This will help improve
 - services for you and others. Every effort will be made to ensure that your information is kept safe at all times.
 - Only people in the LDSS Team who need to see your information will be able to access it.
 - All pieces of information which could identify you, such as names, dates of birth and postcodes, will be removed before the data is sent to the LDSS Team. LDSS data will be used to produce statistical information. It will not be possible to identify you from this information.

The latest LDSS statistics publication can be found at:

If you would like more information, please get in touch with:

LDSS Team
SCLD, 6th Floor,
Merchant Exchange,
20 Bell Street,
Glasgow G1 1LG
Website: www.sclld.org.uk
Tel: 0141 559 5720

Explicit consent will not be asked for the purposes of LDSS. This is due to several reasons. Firstly, the scale of the data collection (based on *existing* Management Information) makes this an incredibly large exercise to audit, and furthermore may result in incomplete datasets and bias – which is of particular importance in statistical analysis. Secondly

the end result is an anonymised dataset which will only be used for statistical purposes by LDSS (and the relevant local authority). The data will therefore not be used to influence decisions or actions in respect to an individual or be used to cause substantial damage or distress for that individual. Finally, people who have a learning disability and/or an Autism Spectrum Disorder can be very vulnerable and the local authority and SCLD were unable to determine whether appropriate procedures for capacity and consent were being adhered to locally.

As part of the ‘Data Sharing Review’ by Thomas and Walport (2008) they discuss the need for consent in different contexts an extract can be found below which is of particular relevance in the context of the individual LDSS dataset:

“A prominent and recurring theme throughout the review was the degree to which people should be able to exercise choice and control over information about themselves. The debate over consent was polarised and complex, and no consensus emerged. This is not surprising.”

“We support the instinctive view that wherever possible, people should give consent to the use or sharing of their personal information, allowing them to exercise maximum autonomy and personal responsibility. However, achieving this in practice is not so simple. It is unrealistic to expect individuals ever to be able to exercise full control over the access to, or the use of, information about them. This is because of a number of factors, not least practical difficulties in seeking and obtaining consent in many circumstances. Moreover, there are many circumstances in which it is not useful, meaningful or appropriate to rely on consent, or indeed to

obtain fresh consent at a later stage for the reuse of personal information for a different purpose.”

“.....there are strong arguments that for research and statistical purposes, where the identity of individuals is not material to the research, a requirement to obtain consent could prevent or impede worthwhile studies [and so damage the development of healthcare provision, for example]. In this area, relying on individual consent to share data does not seem to be appropriate.” Thomas and Walport (2008).

The LDSS data is extracted from administrative systems. The purpose of collecting this data is not to influence decisions or actions in respect to an individual. The purpose of collecting individual level information is for statistical and research purposes only.

Dissemination

Even though personal identifiers are not included in the LDSS dataset, the dataset can still potentially be disclosive. For example, if the LDSS information is used in conjunction with local knowledge then a client *may* be identified. To reduce the risk of this occurring, statistical disclosure control will be applied to all analyses based on the LDSS data. The aim of disclosure control is to ensure that any statistical analyses will not reveal the identity of an individual or any private information relating to them. Moreover, this is in line with the ‘Code of Practice for Official Statistics, Principle 5’.

Specific disclosure risks of the LDSS dataset are as follows:

Sensitive Information

SCLD considers all of the LDSS data to be sensitive as it relates to individuals with a learning disability and/or Autistic Spectrum Disorder and as such any tables of analysis containing counts of 5 or below, will be subject to statistical disclosure control.

Small Geographies

Data published at a very small geographical level, such as data zone level, presents a high disclosure risk because it is easier to identify an individual from within a small population than a large one. SCLD therefore, only publish statistics at larger geographies for example, local authority and Scotland level.

Disclosure by Differencing

Disclosure by differencing occurs when comparing two or more tables reveals information that is not available in any single table. For example, one table containing ages 60-64 year olds and another containing 60-65 year olds, could be differenced to reveal values for 65 year olds.

In summary, and to address the specific issues, post-tabular disclosure control will be applied to the individual level dataset before it is used for analysis by LDSS analysts in the form of cell suppression and controlled

rounding.¹² Examples can be found here:
<http://www.sclد.org.uk/sclدprojects/LDSS/publications-and-resources/statistics-releases>¹²

This statistical disclosure control methodology has been developed in conjunction with Scottish Government statisticians.

The LDSS dataset is used to produce an annual statistics publication¹³ and to provide analysis for numerous ad hoc requests by internal (SCLD) and external stakeholders (e.g voluntary organisations, private sector and other local authorities and Government Departments).

Easy Read versions of the LDSS Statistics Release are also produced to enable people with learning disabilities and their families to access the data.

Audit

Official statistics are assessed by the Statistics Authority¹⁴ against the ‘Code of Practice for Official Statistics’ (this includes against the principle concerning confidentiality).

Annex 1 Agreement outlining personal responsibility concerning security and confidentiality of information relating to LDSS dataset

During the course of your time on LDSS working with the SCLD, you will have access to the LDSS dataset which is confidential information which must not be disclosed to any other person unless in pursuit of your

¹² Last accessed 17/10/2012.

¹³ <http://www.sclد.org.uk/sclدprojects/LDSS/publications-and-resources/statistics-releases>. Last accessed 17/10/2012.

¹⁴ <http://www.statisticsauthority.gov.uk/assessment/index.html>. Last accessed 17/10/2012.

duties of assisting with the collection, data checking, analysis and publication of LDSS data. This condition applies during your time working with SCLD and after that employment ceases.

Confidential information includes the content of the dataset, identifying codes and passwords and any other confidential information you may acquire in checking the consistency and quality of the data.

The Data Protection Act 1998 regulates the use of all personal information and includes electronic and paper records of identifiable individuals. SCLD is registered in accordance with this legislation. If you are found to have used any information you have seen or heard whilst working on the LDSS contract you and your employer may face legal action.

I understand that I am bound by a duty of confidentiality and agree to adhere to my personal responsibilities to comply with the requirements of the Data Protection Act 1998 and to the conditions required by SCLD for the purposes of LDSS work, viz:

- To keep access passwords in a secure place and not to disclose them
- To store code lists (electronic and hard copy) separate from data and data output
- To keep electronic data and data output in a password protected location
- To keep hard copy data and data output in a secure location
- To ensure that computer terminals are not left unattended while processing the data and that all records, including computer screens and printouts of registered data, are never left in such a manner that unauthorised persons can obtain access to them. Computer screens must always be cleared when left unattended and you must ensure you log out of computer systems, removing your password
- To ensure that hard copy output is kept securely
- To ensure that any breach of security or confidentiality is immediately reported to the Director or Chair of the LDSS Board
- Not to attempt to identify any individual contained in the dataset
- Not to transfer the data to other media (including cartridge, disk, CD-ROM, memory stick, floppy disk or other computerised storage media) except for the agreed method of system back ups

- Not to make any unauthorised electronic transfer of the data
- Not to disclose the data or analysis to any unauthorised party before publication
- Agree to adhere to data disclosure controls as advised by SCLD

NAME OF ORGANISATION:
JOB TITLE:
PRINT NAME:
SIGNATURE:
DATE:

Annex 2 Fair Processing Notice (Easy Read Version)



- LDSS is collecting information about people who have a learning disability or an Autism Spectrum Disorder.

- You do not have to do anything. LDSS will ask for information like the services you use from your Local Authority.

- The information they collect will help LDSS and your Local Authority to plan for care and support services in the future. This will help to make services better for you and others.



- LDSS will try to make sure that the information they get about you is always kept safe.

- Only people in the LDSS Team who need to see your information will be able to look at it.

- The information that is collected will be used to write a report containing lots of numbers. We call these numbers 'statistics'.

- No one will know the information that is in the report is about you. Personal information like your name, date of birth and postcode will not be put in the report.





You can look at the LDSS statistics reports by going to this website:

<http://www.sclد.org.uk/sclد-projects/LDSS/publications-andresources>¹⁵

If you would like to know more or have any questions, you can contact:



LDSS Team
SCLD,
6th Floor,
Merchant Exchange,
20 Bell Street,
Glasgow G1 1LG



0141 559 5720



LDSS@sclد.co.uk



¹⁵ Last accessed 17/10/2012.