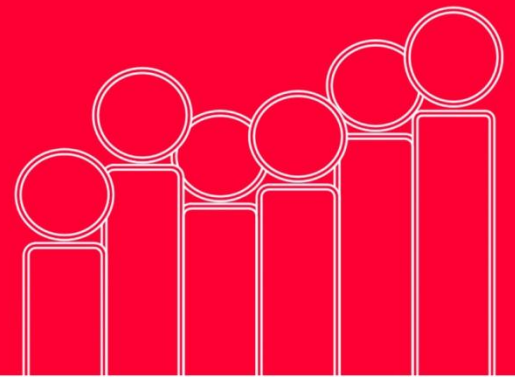




Improving Health and Lives:
Learning Disabilities Observatory


The Use of Pooled Data from Learning Disabilities Registers: A Scoping Review

Eric Emerson and Cath McGrother



Supported by the Department of Health





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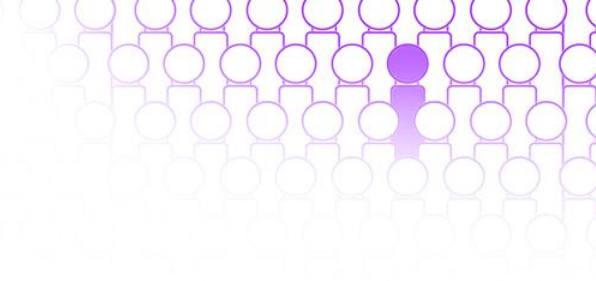
About the Authors

Eric Emerson is Co-Director of the Improving Health and Lives Learning Disabilities Observatory. He is also Professor of Disability & Health Research at the [Centre for Disability Research](#), School of Health & Medicine, Lancaster University and Visiting Professor at the [Australian Family and Disabilities Studies Research Collaboration](#), University of Sydney.

Cath McGrother is the Director of the Leicestershire Learning Disability Register. She is also Professor (Hon) in the Department of Health Sciences at the University of Leicester and Principal Investigator for the government funded project 'Information for Public Health: Learning Disability Register'.

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Introduction

The *Improving Health and Lives Learning Disabilities Observatory* (www.ihal.org.uk) has been established by the Department of Health to:

1. Collate and disseminate information that will support the commissioning of services to reduce the health inequalities faced by people with learning disabilities in England;
2. Support those involved in commissioning and providing services to make better use of available information; and
3. Work toward improving the future scope and relevance of information on the health and well-being of people with learning disabilities.

The aim of this scoping paper is to review the viability and potential value of pooling information across existing learning disabilities registers that would support the commissioning of services to reduce the health inequalities faced by people with learning disabilities. The review is a collaborative venture between the *Improving Health and Lives Learning Disabilities Observatory* and the *Special Interest Group (Learning Disabilities Registers)*.

Learning disabilities registers are information systems that seek to collect and maintain information on the characteristics and needs people with learning disabilities within a defined administrative area. Typically, people identified by registers are either current or potential users of specialised health and/or social care services for people with learning disabilities. Current registers were designed in response to demands for better coordination and continuity of care and support a range of dispersed agencies across the community.

In England, a number of registers have been established based on local government or local health service administrative boundaries. The earliest registers were established in Camberwell, Salford and Wessex the 1960s, often supported by funding from central government. The subsequent wave of registers that were established in the 1970's and 80's (e.g., Sheffield, Leicestershire, Westminster) were more likely to be locally-supported initiatives more closely integrated with local service development and provision.¹ Funding for several current register is at risk due to recent policy and funding changes.

The Functions of Learning Disabilities Registers

The primary functions of current learning disabilities registers are to support the local planning and delivery of health and social care services for people with learning disabilities. These primary functions include:

- *Direct service functions* such as direct referral or signposting of people with learning disabilities to specific services, raising awareness of services among users and carers, enabling online access to specific information on individual service users to relevant providers, dissemination of information to users and carers, confirming eligibility for bus passes, supporting people to self-identify as having learning disabilities when accessing health services or coming in contact with the police.
- *Commissioning, management and planning functions* such as the audit and evaluation of service provision, the validation of GP-held registers, recording existing need (including unmet need) and predicting growth in need for services over time.^{2,3}
- *Public health functions* such as monitoring changes in the level and equity of distribution of need.

In addition, learning disabilities registers have made a significant contribution to operational and academic research that has been of value far beyond the specific locality covered. Examples of the *research functions* of learning disabilities registers include:

- Estimating the prevalence of learning disabilities, including analyses of the extent to which prevalence varies by ethnic group, level of deprivation and over time.⁴⁻¹⁴
- Monitoring service use and unmet needs among people with learning disabilities, including among people from British minority ethnic communities.^{13, 15, 16}
- Analysing trends in the life expectancy and causes of mortality of people with learning disabilities.¹⁷⁻²¹
- Evaluating service developments.²²
- The development of simple measures of the severity of learning disability.²³
- Investigating the specific needs of sub-groups of people with learning disabilities in relation to such issues as profound multiple learning disabilities,² autism,^{24, 25} Down syndrome,^{19, 21, 26, 27} challenging behaviours,²⁸⁻³⁰ mental health,³¹⁻³³ epilepsy,³⁴ ageing³⁵ and obesity, overweight and underweight.^{36, 37}

In addition, registers have provided sampling frames for research projects (e.g., current Department of Health commissioned research on the prevalence of autism among adults with learning disabilities).^{38, 39}

Existing Learning Disabilities Registers

A brief description of selected current learning disabilities registers is given in the following table.

| Area | Year Established | General Population (2010) | Number of People with Learning Disabilities (2010) | Information Collected |
|-----------------------------|------------------|---------------------------|--|---|
| Sheffield | 1974 | (All) 547,000 | 3,460 | Demographics, service use, questionnaire covering living situation, abilities, behaviour problem, diagnoses if known |
| Harrow | 1984 | (All) 228,100 | (18+) 800 | Service use & unmet service needs, level of ability/disability, future plans or wishes, circumstances, personal information, daytime activities, challenges and so on |
| Leicestershire ^a | 1987 | (20+) 745,100 | (20+) 3753 | Health & Social needs, Disabilities, Mental health, behaviour, service use, carers health, welfare & benefits, Household |
| Sutton ^b | 1991 | (18+) 148,800 | (18+) 925 | Comprehensive personal information and including health, abilities, challenging behaviour etc and data on carers. |
| Merton ^b | 1992 | (18+) 164,500 | (18+) 633 | Comprehensive personal information and including health, abilities, challenging behaviour etc and data on carers. |
| Lambeth ^b | 2002 | (18+) 229,400 | (18+) 976 | Comprehensive personal information and including health, abilities, challenging behaviour etc and data on carers. |
| Sefton ^c | 2004 | (All) 282,958 | 1453 | Current housing arrangement, parent/carers details, current & previous work & training, health, future housing wants, other support, PCP, Leisure activities, direct payments, hate crime |

^a <http://www2.le.ac.uk/departments/health-sciences/research/primary/had/projects/ldr?searchterm=aims>

^b www.i-count.org www.registerservices.nhs.uk

| Area | Year Established | General Population (2010) | Number of People with Learning Disabilities (2010) | Information Collected |
|-----------|------------------|---------------------------|--|-----------------------|
| Greenwich | 2010 | (All) 267,000 | 806 | n/a |
| Bexley | 2010 | (All) 226,382 | 495 | n/a |

^c <http://sefton.ldpb.info>

Current and Future Capacity for Pooling Data

Previous projects have successfully combined information across two or more learning disabilities registers.⁵⁻⁷ For example, the Institute for Public Care pooled data across the Sheffield and Leicestershire registers to explore the age-related prevalence and needs of people with severe learning disabilities.⁷ The Centre for Disability Research pooled information across learning disability registers and operational databases in 24 Local Authorities/District Councils in England to estimate the age-related administrative prevalence of learning disabilities and, more recently, to estimate the likely age profile of users of adult social care services.^{5, 6, 40} In a related project the Centre for Disability Research pooled mortality data across registers to estimate likely mortality among current users of adult social care services.⁴⁰

However, pooling data across separate registers (and operational databases) involves a number of challenges resulting from the inconsistency across registers in relation to such factors as:

- conceptual and operational definitions of learning disabilities;
- the coverage and process of identifying people with learning disabilities;
- the nature of information collected to describe the characteristics and needs of people;
- the process of information collection (e.g., interview, postal questionnaire);
- the geo-demographic characteristics of the population covered.

There are, however, some basic and simple tests that can be applied to register data in order to ensure minimum quality. These include:

- *Ascertained prevalence lying within expected boundaries.* Better established registers typically report administrative prevalence rates of between 0.3-0.5% of the adult population. Prevalence rates lying outside of these boundaries should be deserving of close scrutiny. Typically outlying rates are lower and may reflect significant levels of under-ascertainment, although low 'true' prevalence rates are likely to occur in some areas as a result of past or current patterns of service development (e.g., high levels of out of area placements, failure to develop local services for people who had previously been institutionalised).
- *Ascertained prevalence rates being higher for men than women, especially at younger ages.* Substantial epidemiological evidence suggests that learning disabilities are somewhat more common among men.^{41, 42} Failure for these differential rates to be reflected in register data would be deserving of close scrutiny.
- *Ascertained prevalence rates decline systematically with age.* Substantial epidemiological evidence suggests that, as a result of the reduced life expectancy of people with learning disabilities, age-specific prevalence rates should systematically decline with age, especially during middle age and later.⁴¹⁻⁴³



Current Capacity

Recent projects have indicated the viability and value of pooling information across registers (and some operational databases) to derive estimates of:

- Age and gender specific administrative prevalence rates of learning disabilities; ⁵⁻⁷
- Age (and possibly) gender specific mortality rates among adults with learning disabilities who are users or likely potential users of learning disabilities services. ⁴⁰

Developing and updating robust estimates of administrative prevalence and mortality would be of considerable value in:

- Estimating likely need for specialised health and social care services for adults with learning disabilities nationally and in areas that do not currently possess robust registers or operational databases;
- Monitoring changes in the administrative prevalence of learning disabilities over time;
- Monitoring changes in the mortality among people with learning disabilities over time;
- Increasing the robustness of models that seek to forecast future changes in the need for specialised health and social care services for adults with learning disabilities nationally and locally.

Future Capacity

There are numerous areas in which pooling information across registers (and some operational databases) has the potential to strengthen the commissioning of efficient and effective services for people with learning disabilities. In particular, pooling information has the potential for generating more robust information on the situation and needs of particular groups of people with learning disabilities such as people who also have autism, people with more severe or profound learning disabilities and people with challenging behaviours or mental health difficulties. Realising this potential will, however, involve addressing the inconsistency across registers in relation to the nature of information collected that could be used to identify people with additional needs.

Conclusions & Recommendations

Learning disabilities registers have and continue to constitute a valuable resource. Locally, there are good examples of learning disabilities registers contributing significantly to direct service provision, local commissioning, planning and management and broader public health initiatives. More broadly they have provided a rich resource for applied policy relevant research, including in such areas as forecasting future need for specialised health and social care services for adults with learning disabilities both nationally and locally.


It is recommended that the *Improving Health and Lives Learning Disabilities Observatory* and the *Special Interest Group (Learning Disabilities Registers)* work together (and with interested other parties) in order to:

1. Develop a simple set of criteria that could provide a test of minimum acceptable data standards for the inclusion of registers (or operational databases) in any pooling exercise.
2. Undertake an annual data pooling exercises commencing in late 2010 in relation to estimating the:
 - a. age and gender specific administrative prevalence of learning disabilities;
 - b. age-specific mortality rates among adults with learning disabilities who are users or likely potential users of learning disabilities services.
3. Explore the possibility of pooling information from 2011 onwards on the situation and needs of particular groups of people with learning disabilities such as people who also have autism, people with more severe or profound learning disabilities and people with challenging behaviours or mental health difficulties.

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