

Estimating the Prevalence of Severe Learning Disability in Adults

IPC Working Paper 1

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Introduction

This working paper presents the results of a research project funded by the DH Care Services Efficiency Delivery Programme (CSED) and completed by the Institute of Public Care (IPC) in collaboration with Richard Parrott at Sheffield City Council and Dr Catherine McGrother at the University of Leicester. The project aimed to develop evidence-based estimates of the prevalence of complex learning disability among the adult population and the prevalence of adults with a learning disability living with a parent to inform the commissioning of appropriate services. The information obtained from the research has been designed to be used by CSED's 'Projecting Adult Needs and Services Information System' (PANSI).

Background

Learning disability is a key area of concern to local authority social service departments because there has been a considerable growth in learning disability expenditure brought about by changes to the learning disability population. This growth, it is argued, has been driven by an increase in numbers through improvements in life expectancy, higher levels of dependency, and changed attitudes to service provision.

Valuing People Now¹. noted that: "*data about the increasing demands on learning disability services is not as well researched as for other populations and service areas*" and Valuing People Now: A New Three-Year Strategy for people with learning disabilities (2009)² identified the need to "*support provision of robust data sets to inform local action, and enable partnership boards to benchmark progress*".

There is no easily accessible, authoritative body of knowledge which projects potential populations in this sector and the impact this may have on expenditure. However, developing good forecasting tools is not as straightforward as in older people's demography due to the lack of census data, poor recording by many local authorities, public health bodies and PCTs, and a lack of demographic research. Of the data that is available, there are wide variations in the definitions of who is being counted. Such variations are caused by:

Real changes over time in the numbers of people experiencing disability.
Differences in the way that 'learning disability' is defined.
Methodological differences between surveys³.

The way that learning disability is defined determines the nature of the data being sought and the process of data-collection. In addition to methodological differences between surveys, there are differences in the way data relating to

¹ Department of Health, (2007), Valuing People Now: from Progress to Transformation

² Department of Health, (2009), Valuing People Now: A New Three-Year Strategy for people with learning disabilities

³ Bajekal M, Harries T, Breman R, & Woodfield K (2004) Review of Disability Estimates and Definitions In-House Report No. 128, Department of Work and Pensions, London

service use are collected, often reflecting the needs and priorities of the service provider. There is also likely to be some overlap between databases which may result in double counting.⁴ Even without the variations in how numbers are counted and how disability is defined, predicting numbers into the future can vary due to a range of factors, from economic circumstances to health and well being. Advances in medicine have impacted on the numbers of children experiencing learning disability surviving into young adulthood. For example, ante-natal screening has influenced the numbers of live births of children with both learning and physical disabilities.

Work by Eric Emerson and Chris Hatton⁵ has provided a basis for estimating the number of adults in England with a learning disability. Emerson and Hatton take the prevalence base rates and adjust these rates to take account of ethnicity and of mortality, ie, both increased survival rates of young people with severe and complex disabilities, and reduced mortality among older adults with learning disabilities. By applying the prevalence rates in Emerson and Hatton's report to Office of National Statistics (ONS) population projections, it is possible to estimate the number of people with a learning disability in each local authority (this is the basis of the projections in PANSI).

More recent work by Emerson⁶ has also attempted to provide estimates of those with the most severe levels of disability and hence requiring the highest level of care services. This work, which builds on Emerson's and Hatton's earlier paper, extrapolates data from the School Census Information collated by the Department of Children, Schools and Families.

In estimating future demand there are likely to be two key questions of particular importance to local authorities: are there changes in the number of people with a severe or complex learning disability, and how many people with a learning disability are dependent on parents or relatives to offer care which enables them to remain within the community? Being able to estimate these numbers is enormously important for commissioners and service providers, not only to plan and identify how many people may require services in the future, but also at what level of dependency.

Therefore, IPC aimed to identify two populations:

The numbers of people who have complex or severe learning disabilities by age bands.

The numbers of adults with learning disabilities living with their parents.

The methodology used in attempting to identify these populations and calculate reliable prevalence rates is given below. Finally, some conclusions are drawn about the prevalence of complex or severe learning disabilities and the proportion of people with learning disabilities living with their parents.

⁴ Blackburn C, Read J and Spencer N (2007) Can we count them? Scoping data sources on disabled children and their households in the UK., *Child: care, health and development*, 33, 3, 291.295

⁵ Emerson E & Hatton C (July 2004) Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, Institute for Health Research, Lancaster University

⁶ Emerson E (June 2009) Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England, Centre for Disability Research, CeDR Report 2009:1

Methodology

1.1 Identifying the Populations

The methodology for this project commenced by working with local authorities who had learning disability registers generally recognised as being comprehensive. Initially, Sheffield was contacted, as much of the pioneering research by Eric Emerson in this area has been based on the Sheffield register. Following discussion an email was then sent to members of the Learning Disability Special Interest Group explaining the project and asking whether authorities would like to be involved. A similar email was also sent to contacts in local authorities with whom the Institute of Public Care had previously worked, and who it was felt might be interested. In total some thirty local authorities were contacted.

Fifteen of those authorities failed to respond whilst one did respond but did not wish to be involved due their commitment to other projects. Ten authorities expressed a willingness to be involved in the project but only had information on the number of adults with a learning disability in receipt of social services. Even for these people, the registers often did not hold information on their level of learning disability or who they lived with.

Four registers were able to provide the data required. These were: Sheffield, Leicestershire, Essex, and Sutton, Lambeth and Merton⁷. However, following more detailed analysis, only Sheffield and Leicestershire were able to provide sufficiently detailed information to enable reliable projections to be made. The differences in prevalence rates obtained from the different registers can be explained by:

The variety of ways in which people are referred to the registers.

The degree to which health and social care professionals have been made aware of the registers.

The way in which assessments are conducted, ie, interview versus self-administered questionnaire.

The difference in the definitions of severe or complex learning disability that have been used.

1.2 The Registers

The following section describes the Sheffield and Leicestershire registers in more detail focusing on how people are referred to the register and the definitions of severe or complex learning disability that are used.

1.2.1 Sheffield

The Sheffield Learning Disability Case Register was established in 1974. It aims to gather information on people with a learning disability by interview and visits. For children these visits are every two years and for adults every five years.

⁷ Sutton, Lambeth and Merton are grouped together and counted as one because their registers are all managed by 'I Count' Register Services.

The register includes information about people’s ages, the nature and severity of their disabilities, their use of services, and the age of their parents or other caring relatives. The register recorded 3,080 people with a learning disability in Sheffield at June 2008. This represents approximately 6 per 1,000 of Sheffield’s 521,000 population (ONS mid-year estimate 2006). As most people with a learning disability are referred to the register as children and young people, data is increasingly robust over the age of 10 to 15 years.

People are often referred to the register because they have come into contact with a health or social care service and staff have made people aware of the register. Furthermore, people/families can self refer and the register is notified of children whose families consider them to have learning disabilities by the Child Disability Index. Once a person has been referred, an interview is arranged to gather the detailed information held on the register. As mentioned above, these interviews are repeated every two years for children and every five years for adults.

The Sheffield register records Social and Physical Incapacity (SPI) diagnostic ratings, which identify the nature and severity of people’s disabilities. The SPI system consists of nine general categories of disability:

- 1 Non-ambulant
- 2 At least partly mobile with severe incontinence and severe behaviour problems
- 3 Severe behaviour problem
- 4 Severe incontinence
- 5 No severe problems but only partly mobile
- 6 Ambulant but mild behaviour and incontinence problems
- 7 Mild behaviour problem only
- 8 Mild incontinence problem only
- 9 Not incapacitated

In analysing the data, Sheffield staff have found it useful to aggregate the nine SPI categories into three broad groupings (see Table 1).

Table 1: Categories of Disability

SPI Category	Sheffield Category	Description of Disability
1 - 4	Severe Disability	<ul style="list-style-type: none"> • Severe incontinence • Severe behaviour problems • At least partly mobile with severe incontinence and severe behaviour problems • Non-ambulant
5 - 8	Moderate Disability	<ul style="list-style-type: none"> • Mild incontinence problem only • Mild behaviour problem only • Ambulant but mild behaviour and incontinence problems • No severe problems but only partly mobile
9	Most Able	<ul style="list-style-type: none"> • Not incapacitated

In Sheffield the category 'Severe Disability' was initially used to calculate the prevalence rate for people with complex or severe learning disabilities.

1.2.2 Leicestershire

The Leicestershire Learning Disability Register is a joint venture between the University of Leicester, and Leicestershire and Rutland Health Care NHS Trust, with support from Social Services. The Register was established in 1987 to provide an evidence base for improving the health and quality of life of all people with learning disabilities and their carers. The register currently holds information on 3,666 people aged 19+ and living in the city of Leicester, Leicestershire and Rutland.

Individuals are referred to the register through a variety of health and social care channels including social workers, outreach nurses, day centres and psychiatrists. The register operates a rolling programme of structured home interviews with carers, for which the acceptance rate is 95%. Interviews incorporate the Disability Assessment Schedule (DAS)⁸ and other questions developed for use with this client group.⁹ Information collected includes demographics, skill level, adaptive behaviour, social functioning, behaviour problems, psychological symptoms and carers' health.

The estimated developmental age is calculated from questions on the questionnaire. Seven variables from the home interviews are used to predict this. These include variables concerning intelligence, adaptive functioning and dependency. The equation used to calculate the estimated developmental age is known as the Leicestershire Intellectual Disability (LID) tool and research indicates that it has a diagnostic accuracy of 91%¹⁰.

The level of LD is determined using the International Classification of Disease codes – 10th revision¹¹ (ICD-10) criteria and is based on the estimated developmental age established by the LID tool. A total of 3,061 people out of 3,666 have had an assessment in relation to their level of LD.

1.3 Definitions

In this paper, learning disability refers to the condition as defined by the World Health Organisation's (WHO) International Classification of Diseases (ICD 10)¹² which ranges from mild to profound levels of severity (see Appendix for the various classification levels). Within these various descriptions, service

⁸ Holmes, N., Shah, A., & Wing, L. (1982). The Disability Assessment Schedule: a brief screening device for use with the mentally retarded. *Psychological Medicine*, 12, 879-890.

⁹ McConkey, R., & Walsh, J. (1982). An index of social competence for use in determining the service needs of mentally handicapped adults. *J Ment Defic Res*, 26, 47-61.

¹⁰ Tyrer, F., McGrother, C., Thorp, C., Taub, N., Bhaumik, S., & Cicchetti, D. (2008) The Leicestershire Intellectual Disability (LID) tool: a simple measure to identify moderate to profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 21:268-276

¹¹ See <http://apps.who.int/classifications/apps/icd/icd10online/>

¹² World Health Organisation. (2004), International Statistical Classification of Diseases and Related Health Problems.

http://www.who.int/classifications/icd/ICD-10_2nd_ed_volume2.pdf

commissioners should plan to at least meet the need for those 'with a 'care requirement' and above. This represents those who approach services for help and corresponds to the recognised administrative prevalence level as defined by Emerson and Hatton.

Within this group of those with a care requirement there are two further sub-categorisations: those with complex or severe care needs and within that set, those with profound or multiple care needs.

The complex group is defined on the basis of the long established work by Kushlick¹³ and the National Development Team as people with: severe problems of continence, mobility or behaviour, ie, similar to National Development Team Group IV); or severe repetitive behaviour with no effective speech, ie, representing severe autism). Within this 'complex' sub-group, the most severe level is known as 'profound and multiple', accepted criteria for which have yet to be substantiated although Emerson (op cit) uses that of the Department for Children Schools and Families¹⁴.

1.4 Calculating prevalence rates

Both the Sheffield and Leicestershire registers held information about the number of people with complex or severe learning disabilities and the number of people living at home with their parents. From the information on the individual databases, prevalence rates for people with complex or severe learning disabilities and those living at home were calculated by age bands. Prevalence was then extrapolated based on the 2006 mid-year population estimates produced by the Office of National Statistics.

The prevalence rates for both populations by age band were compared between the two registers. The initial comparison indicated a considerable variation between the prevalence rates across the two authorities. However, it was soon identified that the reason behind this variation was more a matter of definition than substantive differences in population. When a standardised definition was defined and then applied to the two registers, a much more consistent pattern was achieved (see Table 2 and Chart 1).

As can be seen from the table below there is a considerable difference between the administrative rate¹⁵ (those who may require some social care provision) and the complex or severe group who are likely to require high level provision.

Table 2 – Comparison of administrative and complex prevalence rates of people with a learning disability in Sheffield and Leicestershire (per 1000)

Age band	Leicestershire 'admin' rate	Leicestershire 'complex' rate	Sheffield 'admin' rate	Sheffield 'complex' rate
20-24	6.43	1.84	5.35	2.20

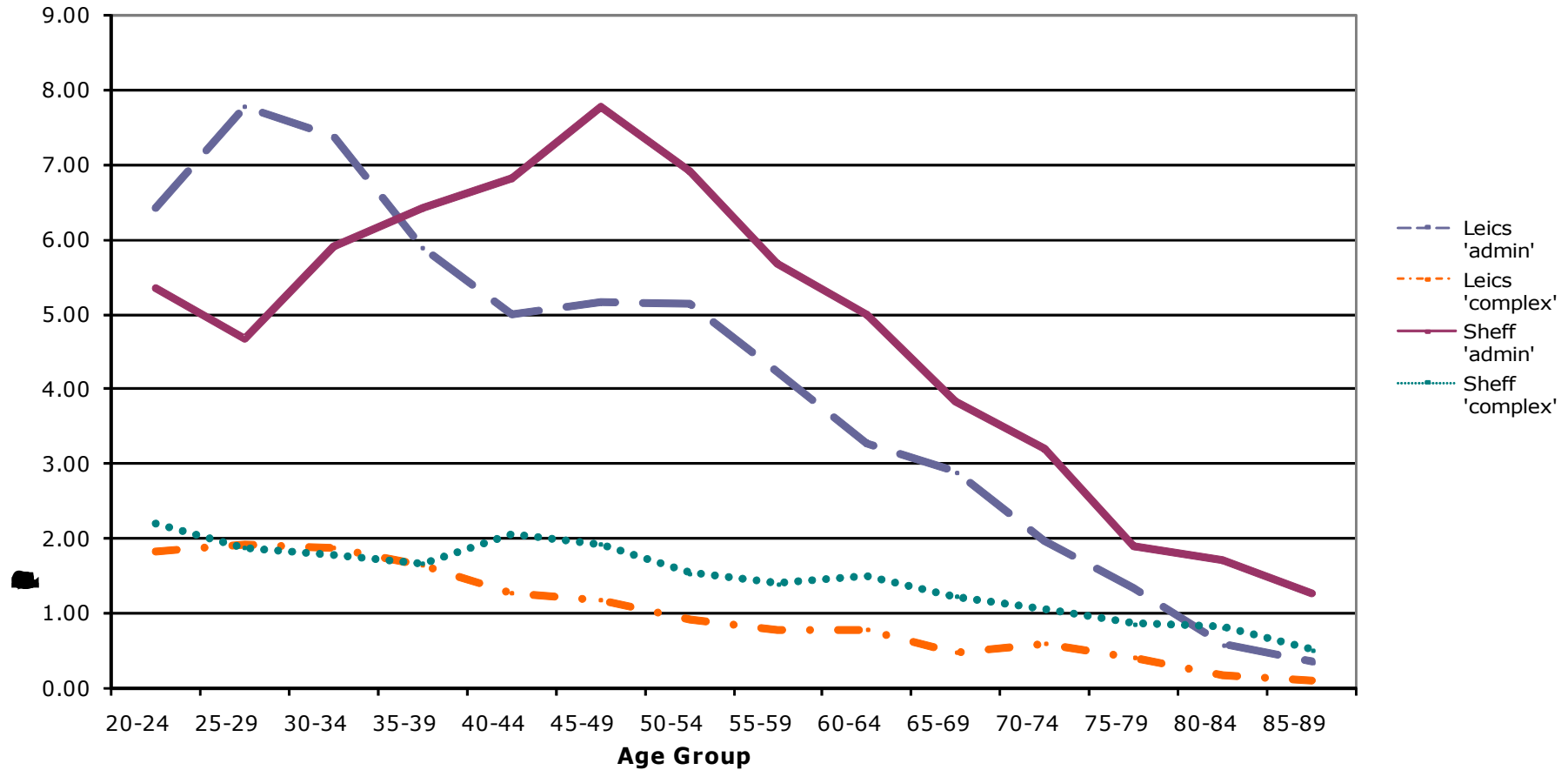
¹³ Kushlick A, Blunden R & Cox GR (1973) A method of rating behaviour characteristics for use in large scale surveys of mental handicap, *Psychological Medicine*, 3, 4, 446-478.

¹⁴ See Every Child Matters: Glossary
http://www.dcsf.gov.uk/everychildmatters/glossary/?i_ID=119

¹⁵ The 'administrative' prevalence rate – those people registered with a learning disability corresponds to the projections of 'moderate or severe' learning disability in PANSI.

Age band	Leicestershire 'admin' rate	Leicestershire 'complex' rate	Sheffield 'admin' rate	Sheffield 'complex' rate
25-29	7.78	1.92	4.67	1.88
30-34	7.39	1.87	5.90	1.79
35-39	5.89	1.64	6.42	1.67
40-44	5.00	1.28	6.82	2.05
45-49	5.16	1.17	7.77	1.93
50-54	5.14	0.93	6.90	1.54
55-59	4.24	0.77	5.66	1.40
60-64	3.28	0.79	4.98	1.49
65-69	2.89	0.48	3.83	1.22
70-74	1.96	0.58	3.21	1.05
75-79	1.32	0.39	1.88	0.85
80-84	0.58	0.18	1.69	0.81
85-89	0.34	0.10	1.26	0.50
All ages	4.77	1.16	5.31	1.64

Chart 1: Comparison of Sheffield and Leicestershire learning disability Case Register populations 20+ (Administrative population and 'complex needs')



Following the comparison and checking of the datasets, an average was taken to obtain age-banded prevalence rates for adults with complex learning disabilities as a proportion of the 'administrative' prevalence rate, and for people with learning disabilities living with their parents. Thus, for example, an average of 33% of people on the learning disability registers aged 18 to 24 have a complex or severe learning disability (see Table 3).

Table 3 – Percentage of people registered with a learning disability that have a complex or severe learning disability

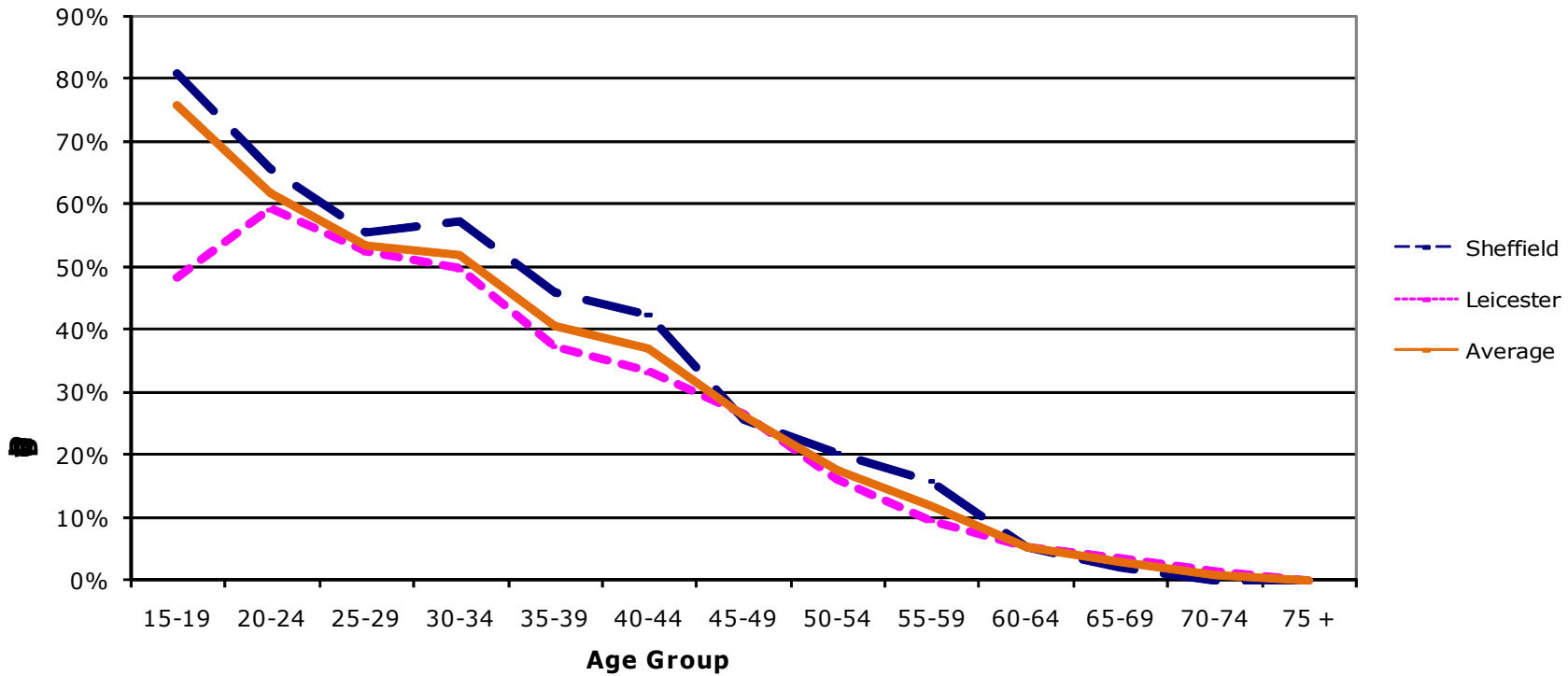
Age range	% of people registered with a learning disability
18-24	33%
25-29	29%
30-34	27%
35-39	27%
40-44	27%
45-49	24%
50-54	20%
55-59	21%
60-64	27%

So far the discussion has focussed on the definitional issues concerning those with severe or complex needs. There was less of a problem in establishing those people with a learning disability who lived with a parent and as can be seen from Chart 2 below there was a considerable degree of uniformity between the two registers. With the increased longevity of people with a learning disability there is for the first time the potentiality of those people outliving their parents despite having moderate to severe needs (the administrative rate). This not only poses problems in terms of care and support but also issues concerning wealth and inheritance.

Table 4 – Percentage of people registered with a learning disability who live with a parent

Age range	% of people registered with a learning disability who live with a parent
20-24	66%
25-29	54%
30-34	49%
35-39	42%
40-44	36%
45-49	27%
50-54	18%
55-59	12%
60-64	5%

Chart 2: Percentage of learning disability population living with parent



Source: Fluctuations in the average change with increasing age-band are not significant and a smoothed curve has been used for projections in PANSI

Conclusions

Learning Disability represents the second highest level of social care expenditure¹⁶ yet the amount of predictive information available to care commissioners in order to plan future commitments is highly limited. Often this is compounded by the populations being counted being relatively small in number (and hence prone to statistical error) yet high in cost for those with the greatest level of needs.

This research has attempted to expand that knowledge by differentiating between populations likely to be known to social care through LD registers and those with more complex or severe needs who are likely to require a higher level of service provision. The intention was to provide at least a crude basis by which authorities could assess what proportion of people with a learning disability known to them might have complex or severe needs.

In addition, the work also numerically highlighted the impact that increased longevity might have in families where the primary care giver may die through showing how many people with a learning disability lived with at least one parent.

There is clearly a need for further work to explore the rate of change in dependencies amongst the LD population whether through severity of disability or through longevity. This work highlights, as has other research, that one of the key issues concerns definitions and the impact this has on accurate counting. It seems disappointing that of thirty authorities contacted only two felt their data was comprehensive enough to contribute to a piece of work which was not complex in terms of the trends it was attempting to measure.

Despite the effort expended in maintaining disability registers if they do not count people consistently and to a common set of definitions the information they contain is always likely to remain suspect. In addition, although not evaluated in this paper, there is an impression that Joint Strategic Needs Assessments, have done little to add to our store of knowledge about future trends in LD populations. The case is for further work which can:

- Identify the kinds of data commissioners might need to collect and analyse in order to develop strategic plans over the next five to ten years.
- Establish common definitions and collection methods to the acquisition of data through LD registers.
- Identify how such information can more effectively influence the next round of JSNAs.

Without a systematic and detailed approach to the collection of data, local authorities will be unable to adequately meet the needs of their learning disability populations. The changes in demographics and the current economic climate make the need for further work in this area even more imperative.

¹⁶ Gross expenditure by councils on social care for adults was around £15bn in 2006-07.. Of this expenditure, around £3.29bn (21.9%) was spent on adults aged 18-64 with learning disabilities (including Supporting People funding).

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Appendix: Concepts and general principles of learning disability

The inherent concepts that underlie learning disability are those of 'lifelong intellectual impairment' and associated 'limitation of social functioning' constituting the social condition of learning disability and conforming to general principles recognized by the WHO International Classification of Functioning, Disability and Health (ICF). Another closely related concept involves 'arrested or incomplete development of mind' which forms the basis for the medical condition of mental retardation as recognized by the WHO ICD-10. This condition is characterised by impairments manifested during the developmental period which contribute to overall intelligence (i.e. cognitive, language, motor and social ability). The ICD-10 also recognises that the degree of developmental mental retardation is usually based on intelligence which may be estimated using *mental age*, and is aligned with levels of *social adaptation* and *dependency*. Thus, mental retardation integrates these *three* inherent concepts and defines levels of mild, moderate, severe and profound disorder.

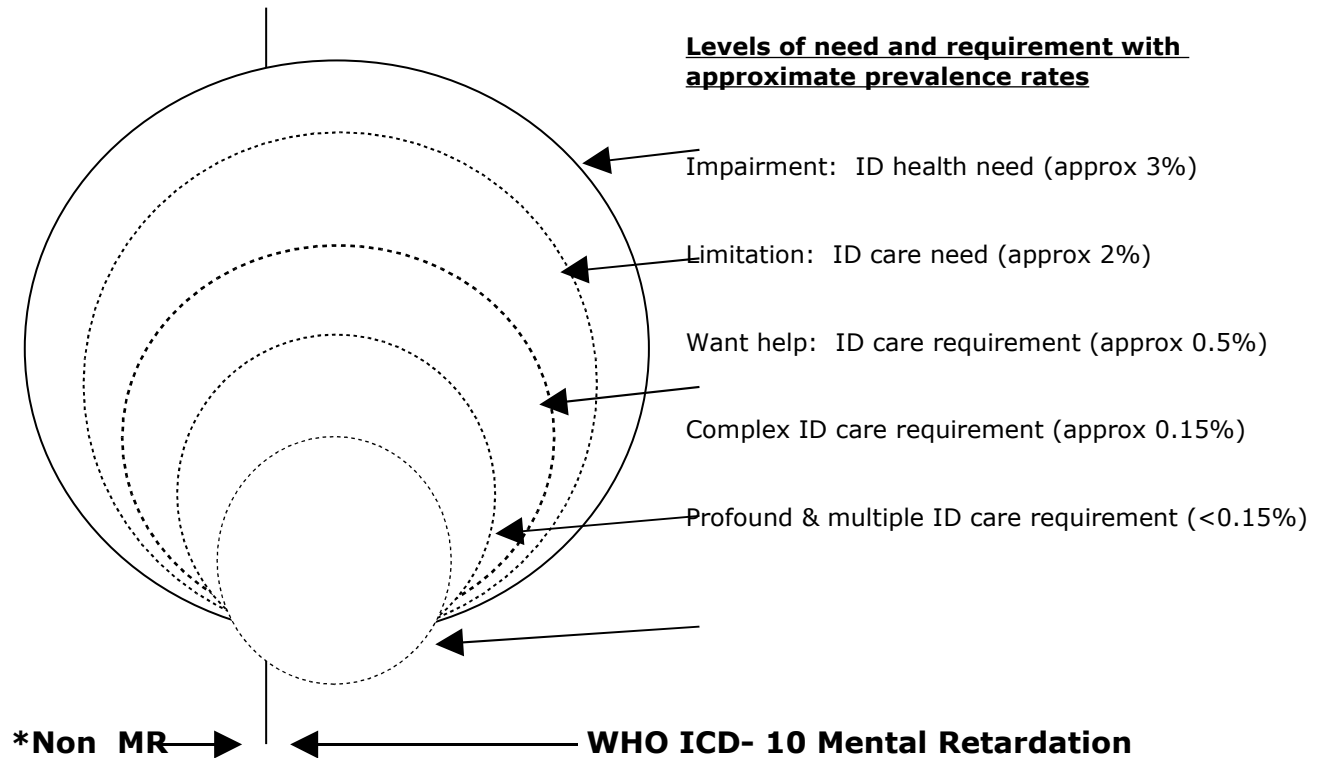
In practice, learning disability and mental retardation are synonymous. The thresholds for both are defined in terms of developmental intellectual impairment with social dysfunction (i.e. disability). However, mental retardation has WHO recognised severity levels, whereas learning disability does not. In addition the severity levels of mental retardation involve a third inherent concept of dependency. This may be an advantage from the point of view of service provision. The current internationally recognised name of this condition is intellectual disability (ID).

Service provision relates to conditions of 'need', originally recognised by Bradshaw. Frankel and Stephens have distinguished 'health need' (i.e. a concept of disorder) from 'care need' (i.e. a subset defined by professional criteria) within which they recognise 'care requirement' (defined by the individual) as wanting help.

It should be acknowledged that conditions exist with similar intellectual, social and dependency problems that result from loss of adult intellectual capacity rather than arrested development. Conditions occurring in young adulthood (e.g. head injury) generate needs more in common with mental retardation than occurrence in later life (e.g. dementia). However, these conditions do not constitute mental retardation.

One advantage of these concepts is that they can be combined within a series of subsets to represent a rational hierarchy (see Diagram below). This may facilitate understanding and agreement between different perspectives on various thresholds and measures.

Lifelong intellectual disability



Impairment (health need): People with a lifelong intellectual impairment, currently defined as an IQ < 70 or mental age <12 for mental retardation / learning disability.

Limitation (care need): Intellectual impairment that limits a person's learning capacity and thereby significantly affects social functioning. Those affected are likely to *need help* to maintain their basic independence and safety.

Want help (care requirement): people with limitation or care need who *want help* from services. This constitutes the care requirement and is synonymous with administrative prevalence for population based LD registers representing people likely to be known to services

Complex or severe care requirement: people with a care requirement who have severe additional problems associated with high levels of dependency, likely to require relatively high levels of care

Profound and multiple care requirement: people with a care requirement who have profound and multiple problems with the most severe level of dependency, likely to require the highest level of care

WHO Mental Retardation: *Arrested or incomplete development of mind; involves developmental impairment of intellect and related cognitive, language, motor and social dysfunction. This includes head injury in childhood*

*** Non Mental Retardation** *represents long term problems with intellectual impairment and social functioning for non-developmental reasons, including head injury after childhood. Dementia is excluded from this definition because it is a relatively short term problem occurring at the end of life.*