

Scottish

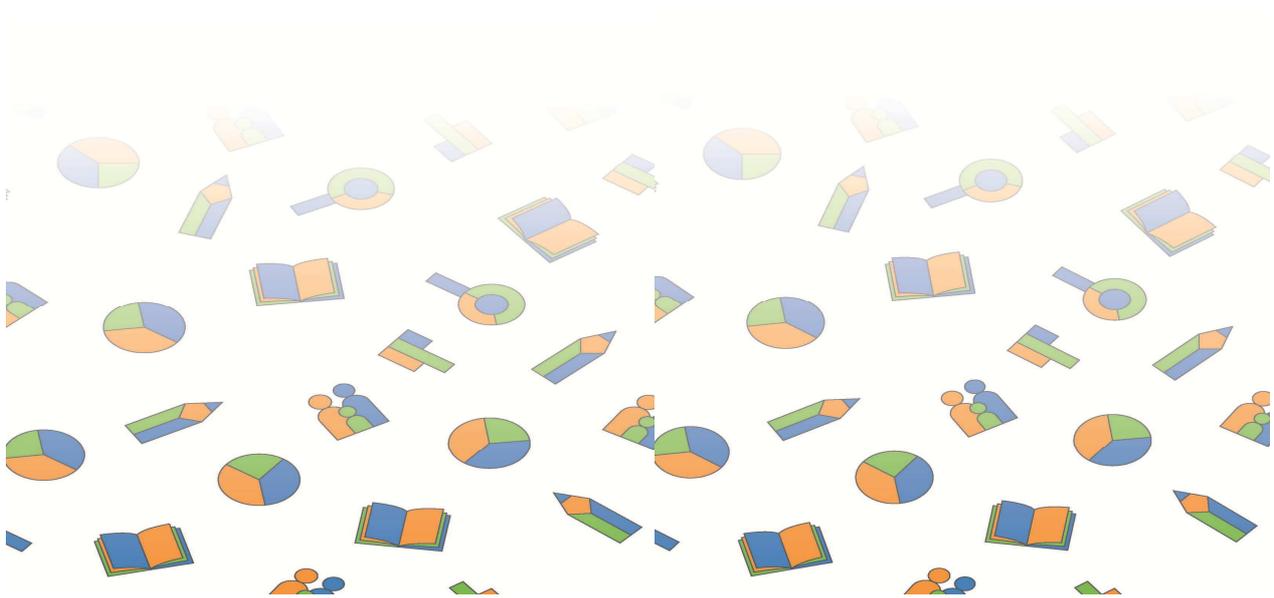
Learning Disabilities

Observatory

What Are Learning Disabilities? How Common Are Learning Disabilities?

Sally-Ann Cooper, Angela Henderson, Myrthe Jacobs,
Elita Smiley

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1. What are learning disabilities?

People have learning disabilities from birth, or develop them during infancy or childhood. A person with learning disabilities needs additional support with learning whilst at school, and with daily activities at school and as they live through their adult life. There are several definitions of learning disabilities, and some definitions require the person to have an intelligence quotient less than 70, such as the World Health Organisation's International Classification of Diseases.

Intelligence quotients are measured by intelligence tests (for example, testing verbal skills, reaction times and speed of learning new tasks), which allows a person's scores to be compared with the range of scores achieved by large numbers of people on the same test. However, a person is much more than a number. Whilst people with learning disabilities may share some characteristics with other people with learning disabilities, such as needing additional support when at school, finding it hard to manage money and bills without help as an adult, or having insatiable appetite if they have Prader-Willi syndrome, every person is unique. Each child inherits a vast amount of genetic information from both their parents which is not shared with other children with learning disabilities, and as they grow up, their environment and experiences also shapes their development, interests, fears, hopes, ambitions, and characteristics. So even when a person has a clear genetic cause for their learning disabilities such as Down syndrome, they are unique from all other persons with Down syndrome.

People with learning disabilities learn throughout their life. A person who needs some additional support for learning in school may have acquired enough skills and experience when they are adults to live independently, hold down a job, have a close relationship and children. Their intelligence quotient would still be measured as less than 70, but they are not requiring much more additional support in their daily life than another person. Does such a person still have learning disabilities? By definition, no they do not. If they required social work or health services, would they go to the learning disabilities service for their care? Unlikely. Do they identify themselves as having learning disabilities? Probably not; and if not this view should be respected. However, a considerable proportion of children do go on to need lifelong support in view of their learning disabilities.

2. How many people have learning disabilities in Scotland?

Learning disabilities are quite common. There are more children than adults with learning disabilities. This is because children with learning disabilities need additional support at school to get the best chance to learn academic skills like reading and writing. As children and adults gradually learn skills, they may no longer need support to lead independent lives. Additionally, people with learning disabilities do not live as long as other people, so there are fewer people in older age groups.

2.1 Data sources

2.1.1 Pupil Census

According to Scotland's Pupil Census¹, in 2014, 15,600 school-age children (2.3% of all school-age children) had learning disabilities.

2.1.2 Scotland's census, 2011

According to Scotland's Census, 2011², 5,234 children (0.6% of all school-age children) and 21,115 adults (0.49% of all adults) had learning disabilities.

2.1.3 Learning Disabilities Statistics Scotland

According to the Learning Disabilities Statistics Scotland³ (managed by the Scottish Commission for Learning Disabilities), in 2014, 25,842 adults had learning disabilities and were:

- aged 18 and over, or aged 16 or 17 and not in full time education, and
 - known to Local Authority learning disabilities services currently or in the past three years.
- Of the 25,842 adults, approximately 98.2% were aged 18 or over.

2.2 Why do figures differ between data sources?

The difference is because of the definitions used, and the purposes for which the information was gathered. Scotland's Census, 2011 asked the person completing the Census form (typically the child's parent) whether the child had learning disabilities. In contrast, there is an advantage for a child at school who is on the boundary of learning disabilities and low average intelligence to be recorded as having learning disabilities, as they will qualify for, and likely benefit from additional support for learning. For the adults, whilst the results were more similar, in the Census, the person completing the form was asked whether each person had learning disabilities, so this question was self-rated, or rated by the person completing the form on their behalf. In contrast, the Learning Disabilities Statistics Scotland records information on people who are known to Local Authorities learning disabilities services.

3. Scotland's Pupil Census

3.1 How many children have learning disabilities according to Scotland's Pupil Census?

According to Scotland's Pupil Census, there has been a steady increase in the number of pupils with learning disabilities, from 8,956 in 2008 to 15,600 in 2014. This is not solely due to the increase in the number of total pupils from 2008 to 2014, as the prevalence of learning disabilities has also increased, from 1.3% in 2008 to 2.3% in 2014. This is a 74.2% increase in the number of pupils recorded with learning disabilities from 2008 to 2014. The increase was the highest from 2009 to 2010 and from 2010 to 2011 with increases of 24.9% and 27.2% respectively. This relates to changes in practice and recording, rather than changes in the actual prevalence of learning disabilities.

According to the Pupil Census, more boys than girls have learning disabilities. In 2014, 64.7% of pupils with learning disabilities were boys and 35.3% were girls. These proportions have been similar since 2008, although a slight increase in the proportion of girls can be seen. These proportions are similar to Scotland's Census, 2011, which reported 62.2% to be boys and 37.8% to be girls.

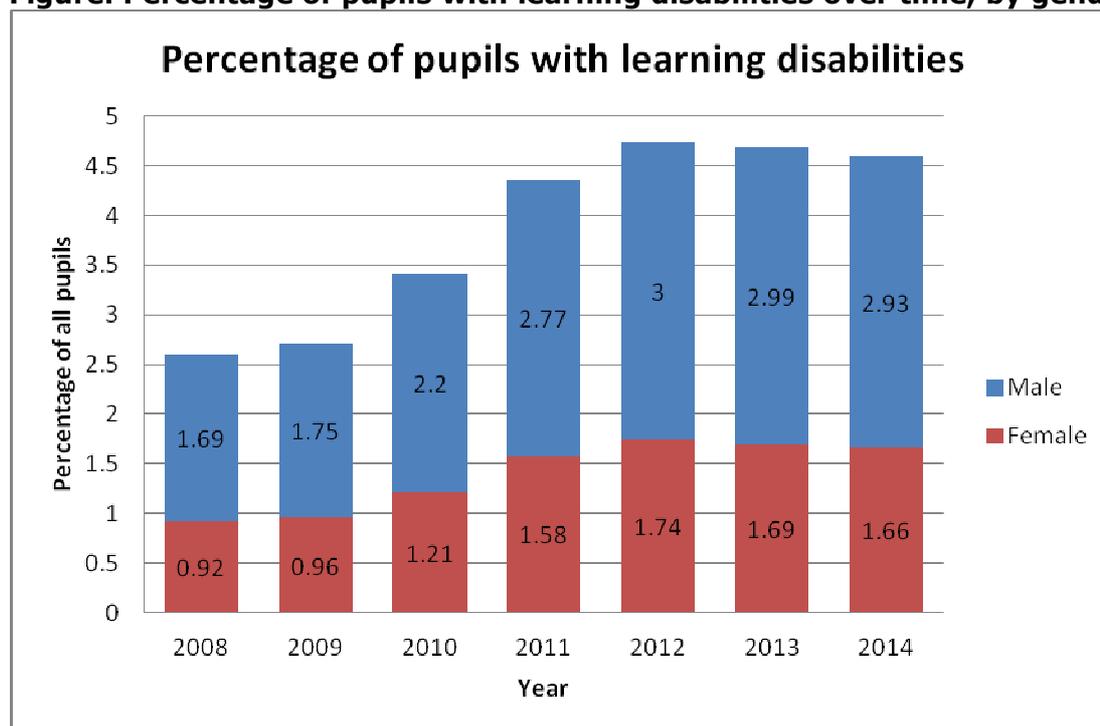
3.2 What types of school do children with learning disabilities attend?

There has been a gradual shift in the type of school that pupils with learning disabilities attend since 2008. In 2008, the majority of pupils with learning disabilities (46.2%) attended special education, while 28.1% were in primary education, and 25.7% in secondary education. By 2014, the proportion of children attending special education had fallen to 29.5%, with an increase to 41.5% in primary education, and 29.0% in secondary education (table).

Table 1. Pupils with learning disabilities over time, by gender, and school type

	2008	2009	2010	2011	2012	2013	2014
Number of pupils with LD	8,956	9,232	11,534	14,673	15,979	15,859	15,600
Prevalence (%)	1.31	1.36	1.71	2.19	2.38	2.35	2.30
Change to previous year (%)	n/a	3.08	24.94	27.22	8.90	-0.75	-1.63
Male (%)	65.52	65.39	65.29	64.51	64.26	64.76	64.72
Female (%)	34.28	34.61	34.71	35.49	35.74	35.24	35.28
Primary education (%)	28.14	30.00	36.16	42.33	43.59	42.59	41.53
Secondary education (%)	25.70	25.62	28.06	28.60	28.74	28.38	28.98
Special education (%)	46.16	44.38	35.77	29.07	27.67	29.03	29.49

Figure. Percentage of pupils with learning disabilities over time, by gender



3.3 What is Scotland’s Pupil Census?

The Pupil Census in Scotland is conducted annually in September (Scottish Government, 2014). The information is collected electronically from schools’ management information systems through the ScotXed programme. ScotXed ensures that data exchanges are effective and secure.

The Pupil Census covers all publically funded primary, secondary and special schools in Scotland (local authority and grant-aided) (Scottish Government, 2014). Children are generally between the ages of 4.5 and 5.5 when they enter primary school in August of a given year (National Statistics, 2014). Primary school covers seven years, from P1 to P7. Pupils then move on to secondary school which covers up to 6 years, from S1 to S6. Some pupils leave school at the end of S4. While many pupils with additional support needs attend mainstream education, some pupils with more complex needs are educated in special schools. Special schools can cover both primary and secondary education and can therefore have pupils from a wide age range. Pupils who attend a ‘special unit’ attached to a mainstream school, are usually included in the figures for the mainstream school although some schools and local authorities have reported pupils from ‘special units’ separately (National Statistics, 2014).

Changes in how additional support needs are recorded have taken place over the years. Before 2006, only pupils’ ‘main difficulty’ was recorded. This means that if the pupil had learning disabilities, this would not have been recorded if they also had another difficulty which was considered their ‘main difficulty’. From 2006 onwards, all reasons for support were recorded, meaning that if the pupil had learning disabilities and/or e.g. autism spectrum disorders, alongside other difficulties, they would all be recorded in the pupil census. There was a period of two years where schools could change onto the new system, so it was not until 2008 when all schools were recording all reasons for support, rather than the main difficulty. Comparison of data before and after 2008 is therefore problematic.

Learning disabilities is defined within the Pupil Census as follows: *“Somebody with a learning disability is said also to have ‘significant impairment of intellectual functioning’ and ‘significant impairment of adaptive/social functioning’. This means that the person will have difficulties understanding, learning and remembering new things, and in generalising any learning to new situations. Because of these difficulties with learning, the person may have difficulties with a number of social tasks, for example communication, self-care, awareness of health and safety. A*

final dimension to the definition is that these impairments are present from childhood, not acquired as a result of accident or following the onset of adult illness.” (ScotXed, 2014, p. 67).

4. Scotland’s prevalence of learning disabilities within an international context

According to Scotland’s Census, 2011, 5,234 children (0.6% of all children) and 21,115 adults (0.49% of all adults) had learning disabilities.

To put Scotland’s reported prevalence of learning disabilities within an international context, we need to compare it with reports on the prevalence of learning disabilities from other countries (tables 2-4). However, measuring the prevalence of learning disabilities is a challenging task, particularly so for adult populations, and there are limitations to the work that has attempted to do this. Even the most recent studies have a wide variation in reported rates, particularly for mild learning disabilities. Most studies have been conducted with children, and few with adults in whom prevalence is less due to premature death, and acquisition of skills over time. Prevalence of mild learning disabilities is influenced by many cultural and societal factors that determine whether a mild learning impairment is likely to result in a functional disability, contributing to geographic differences. In measuring prevalence, a distinction between intellectual impairment (intellectual quotient < 70) and learning disabilities as defined in standard classificatory systems (based on intellectual quotient *and* impairments in adaptive functioning) is theoretically appealing, but in practice not usually possible. The statistical distribution of learning disabilities in a population suggests mild intellectual impairments would be in the region of 2.27% of the population. This is a statistical average and does not equate with the prevalence of learning disabilities. Additionally, intellectual quotient measurement can have a test error: DSM-5 indicates there is a margin of measurement error generally of 5 points, so advising that an intellectual quotient of 65-75 can indicate intellectual impairment. This measurement error greatly influences identified prevalence: 2.50% would be predicted to lie *within the range of* intellectual quotient 70-75 i.e. more than the proportion with intellectual quotient < 70. Additionally, the greatest deviation from the normal distribution is at its extreme ends.

The country of study, sample population, age range, definition of learning disabilities, and method of ascertainment can all have a significant impact on the identified rate. There are also cohort effects, with prevalence varying with time, such that past and more recent studies of the same age ranges may well provide different rates (e.g. effect of immunisation, improved antenatal, perinatal, and neonatal health care, detection and treatment of metabolic causes of learning disabilities, iodine, and education lowering incidence; whilst the current localized outbreak of zika virus microcephaly, survival of very low birth weight infants, and maternal smoking and alcohol use might increase incidence; and access to cardiac surgery for Down syndrome infants improving survival, and improved lifestyles and access to health care influencing lifespan). Additionally, the accepted definition changed in 1973, which significantly affects the ascertained rates. There is also the Flynn effect (overly high scores due to out-of-date test norms). Migration and clustering (e.g. congregate care and colonies) can influence spatial patterning more locally, and can be influenced by economic factors and local policy.

Studies between 1960-1987 were reviewed by Roelvelde et al^{4}. These older studies are probably of lesser relevance to today’s population. They found wide variation in reported rates (2-85 per 1,000)^{1}. Almost all were studies of children or lifespan studies, and some provided limited information. The Scottish *Health Needs Assessment* reviewed studies as of 2003, and found that although there is large variation in prevalence for mild learning disabilities, the range for moderate to profound learning disabilities was tighter, varying from 2.7 to 3.8 per 1,000^{4-8}. However, all but one of these studies are of children or are lifespan rather than adult studies. More recent studies are summarised in tables 2-4^{9-28}, separately for adults, then lifespan studies, then on children, given that age range affects prevalence. The considerable differences in these study methods and study findings for mild learning disabilities are such that it is not appropriate to average their results, and indeed there are likely to be some real geographic and temporal differences (tables 2-4).

Two further reports have attempted to synthesise the information on the prevalence of learning disabilities. One of these did not differentiate between children and adults and averaged out results including those at an extreme of the reported ranges. The second was more nuanced^{29}, and across all 52 studies included in a meta-analysis, the reported prevalence was 10.37/1,000 population. However, 25 of the studies did not provide their age range, a further two did not report their observation period, and prevalence varied according to age, income group of the country of origin (with higher rates from low income countries), and study design. Rates were higher for children/adolescent populations only at 18.3/1,000, and lowest in adult only populations at 4.94/1,000. Rates for all ages combined in high income countries were 9.2/1,000.

Table 2. Recent studies measuring the prevalence of learning disabilities in adults

Author	Age group	Geographic area	Sample size	Method of ascertainment	Definition of LD	Prevalence per 1,000				
						mild	moderate	severe	profound	Total
Beange & Taplin 1996 ⁽⁹⁾	20-50 years	Australia	104,584	Population based (including primary care) survey. Interviewed by a psychologist	IQ<70 on psychological testing	1.12	2.19 combined			3.31
McGrother et al 2002 ⁽¹⁰⁾	20+ years	Leicestershire, England	2,256	Population based administrative prevalence in 1991. Individual interviews by non-clinical worker of adaptive behaviour	Dependency on specialist services with adaptive behaviour problems associated with moderate, severe or profound impairment					3.6
Felce 2004 ⁽¹¹⁾	>16 years	Wales	2,360,700	Population based administrative survey	Known to local authorities as in receipt or in need of LD service					4.3
Noorbala et al 2004 ⁽¹²⁾	15+ years	Iran	35,014	Population based survey using random cluster sampling. Semi-structured interview by GP	Evident LD as assessed by GP					14.0
McConkey et al 2006 ⁽¹³⁾	19+ years	Ireland	3,961,701	Population based administrative survey using the National LD database	Known to have LD meeting ICD-10 criteria, or receiving /needing ID service	2.2	4.14 combined			6.34
Bailey, 2008 ⁽¹⁴⁾	19+ years	Northamptonshire, England	984	Identification via multiple sources, including health, social services, independent sector and voluntary organisations. Individual interviews by a psychiatrist of adaptive behaviour	Adaptive behaviour scores <12 years on the Vineland Scale	0.5	2.3 combined			2.8

LD: learning disabilities

Table 3. Recent studies measuring life span prevalence of learning disabilities

Author	Age group	Geographic area	Sample size	Method of ascertainment	Definition of LD	Prevalence per 1,000				
						mild	moderate	severe	profound	Total
Larson et al 2001 ⁽¹⁵⁾	Lifespan	USA	202,560	Non-institutionalized population, household survey. National Health Interview Survey 1987-1994 with follow-up disability interview for possible cases	Mental retardation reported as the primary cause of limitations in basic activities or for seeking services					7.8
Arvio & Sillanpaa 2003 ⁽¹⁶⁾	Lifespan	Finland	341,227	Population based administrative survey in 1995	IQ<70 and using LD services	3	0.7	0.6 combined		4.3
Fujiura 2003 ⁽¹⁷⁾	Lifespan	USA	202,560	Non-institutionalized population, household survey. National Health Interview Survey 1994/1995 with follow-up disability interview for possible cases	Mental retardation reported, or if mild intellectual disability, generalised learning difficulty or specific learning disability was associated with activity limitation or need for formal support					12.7
White et al 2005 ⁽¹⁸⁾	Lifespan	Australia	37,580	Population based household survey in 1998. Individual computer assisted interviews with non-medical interviewers	ICD-10 definition of LD					12.5
Van Schroyen et al 2006 ⁽¹⁹⁾	Lifespan	Netherlands	1,142,679	Population based administrative survey including primary care. Case files of identified persons examined for evidence of LD	IQ<70-75, manifest before 18 years plus related limitations in two or more skill areas					6.4-7.0
Westerinen et al 2006 ⁽²⁰⁾	Lifespan	Finland	36,053	Data combined from eight national registers using social security codes	ICD-10 definition of LD derived in routine practice					7.0
Wullink et al 2007 ⁽²¹⁾	Lifespan	Netherlands	15,987,075	Two methods of extrapolation from GP research database and LD care service records	IQ<70-75 and impaired adaptive behaviour (= definite LD), or person attended a special					6.4-7.0 5.4-6.0

					school/uses specialist LD services/or an adult unsuccessful at primary school (= unconfirmed LD)	
Allgar et al 2008 ⁽²²⁾	Lifespan	Leeds, England	218,551	Administrative survey including primary care	Significantly reduced ability to understand new and complex information and a reduced capacity to cope independently (including autism and cerebral palsy)	6.4

LD: learning disabilities

Table 4. Recent studies measuring prevalence of learning disabilities in children

Author	Age group	Geographic area	Sample size	Method of ascertainment	Definition of LD	Prevalence per 1,000				
						mild	moderate	severe	profound	Total
Stromme & Valvatne, 1998 ⁽⁵⁾	Median age 10.8 years	Norway	30,037	Birth cohort 1980-1985. Ascertainment via educational and health services for children with LD, followed by psychometric evaluation	IQ<70 (various tests used; not a standard battery)	3.5	1.5	0.4	0.8	6.2
Croen et al 2001 ⁽²³⁾	4-12 years	USA	4,590,333	Birth cohort 1887-1994. Identification via Developmental Service register	Physician or psychologist established significantly subaverage intellectual functioning, concurrent with related limitations in at least 2 adaptive skills areas					5.2
Bradley et al 2002 ⁽⁶⁾	14-20 years	Canada	225	Population based survey in 1994. Identification via service registers followed by psychological assessment	IQ<75 on Weschler Adult Intelligence Scale-revised, or Weschler Intelligence Scale for Children-Revised or Palmer scale of Mental Tests	3.5	3.6 combined			7.2
Christianson et al 2002 ⁽²⁴⁾	2-9 years	South Africa (rural)	6,692	Population based survey in 1993-1996. All households screened using the Ten Questions Questionnaire followed by paediatric neurodevelopmental assessment	GIQ<80 measured by the Griffiths Scale of Developmental Assessment	29.1	6.4 combined			35.6
Heikura et al 2003 ⁽⁷⁾	11.5 years	Finland	9,351	Birth cohort 1985-1986. Individual assessments	IQ<70 on most recently administered psychometric test or developmental assessment (various tools used)	7.5	1.7	0.75	1.3	11.2

Leonard et al 2003 ⁽²⁵⁾	<16 years	Australia	240,358	Birth cohort 1983-1992. Identified by record linkage of multiple sources	IQ<70 on testing, or has a condition known to be associated with LD or clearly documented as having LD	10.6 combined	1.4 combined	14.3 (2.3 were unspecified)
El-Hazmi et al 2003 ⁽²⁶⁾	<18 years	Saudi Arabia	60,630	Population based survey. Specially designed screening questionnaire followed by clinical assessment and psychological testing	IQ<70 on Weschler Intelligence Scale for Children or Stanford Binet Intelligence Test	2.6	6.3 combined	8.9
Gustavson 2005 ⁽²⁷⁾	6-10 years	Pakistan	1,476	Birth cohort 1984-1986. Individual paediatric, psychology and social work assessment.	IQ<69 (assessment tools unspecified)	62	11 combined	73
Eapen et al 2006 ⁽²⁸⁾	3 years	United Arab Emirates	694	Population based survey. Denver Developmental Screening Test followed by clinical diagnostic interview	Functional limitations in two or more adaptive skill areas as determined by clinical assessment			24.4

LD: learning disabilities

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