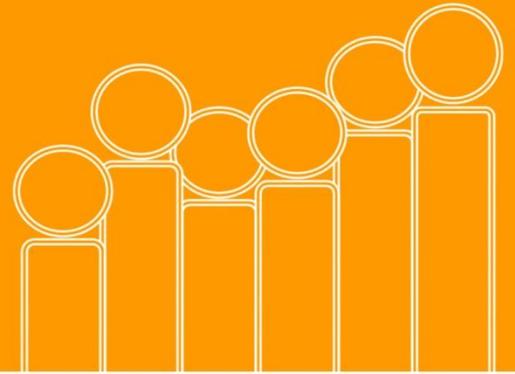




Improving Health and Lives:
Learning Disabilities Observatory

The Estimated Prevalence of Autism among Adults with Learning Disabilities in England

Eric Emerson & Susannah Baines



Supported by the Department of Health



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Background

In March 2010 the Department of Health published *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*.¹ One of the key themes of the strategy is to enable local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities. One of the tasks of the Improving Health & Lives Learning Disabilities Observatory, commissioned by the Department of Health, is to support this strategy by developing estimates of the prevalence of autism^a among adults with learning disabilities in England.

We approached this task by first reviewing the existing scientific literature that addresses:

- the prevalence of autism among adults with learning disabilities
- the prevalence of learning disabilities among children with autism.

We then applied prevalence estimates derived from these literatures to estimate the number of adults with learning disabilities in England.

Fulfilling and Rewarding Lives defines autism as ‘a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the ‘triad of impairments’. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)
- social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine).

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Many people with autism may also have other conditions such as attention deficit hyperactivity disorder (ADHD), a learning disability or dyspraxia.

Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people’.¹

^a There are a number of terms that different individuals and groups prefer to use to describe people with autism, including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. To be consistent with *Fulfilling and Rewarding Lives*, we will use the term ‘autism’ as an umbrella term for all such conditions.

The Prevalence of Autism among Adults with Learning Disabilities

To address this issue we undertook a systematic review of peer reviewed studies published since 2000 that have attempted to estimate the prevalence of autism among community-based or total population samples of adults with learning disabilities. We excluded studies based on institutionalised populations or samples solely drawn from adults in residential care due to the likely confounding relationships between entry into residential care, severity of learning disabilities and autism.² We also explored the rates of reporting of autism in hospital episode statistics and death certificates.

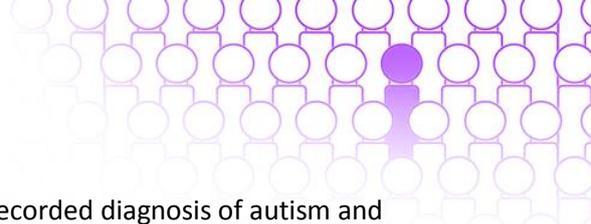
Method

Databases were searched electronically using the Lancaster University Metalib system. Concurrent searches were run in September 2010 on Academic Search Complete, Cumulative Index to Nursing and Allied Health, Embase: Excerpta Medica, Medline, PsycINFO, and Web of Sciences, using the following search terms: *autis* prevalence intellectual disabilities; autis* prevalence learning disabilities; autistic-spectrum prevalence intellectual disabilities; autistic-spectrum prevalence learning disabilities, pervasive developmental disorder intellectual disabilities; pervasive developmental disorder learning disabilities.* We also hand searched the reference lists of studies identified through this procedure to identify additional studies.

Results

Five studies met our criteria, details of which are provided below.

First Author	Year Published	Recruitment	Method of Ascertaining Autism	Sample Size of Adults with Learning Disabilities	Reported Prevalence of Autism (with 99% CI)
Bhaumik³	2010	Service-based register	Diagnosis recorded in register	1,145	19% (16-22%)
Saemundsen⁴	2010	Current users of learning disabilities services	Screened as part of research	119	21% (11-31%)
Melville⁵	2008	Adults with learning disabilities identified by GPs	Screened as part of research	1,123	8% (6-10%)
Hare⁶	2003	Current users of learning disabilities services	Carer-reported diagnosis plus carer report	1,723	10% (8-12%)
Morgan⁷	2002	Current users of learning disabilities services	Screened as part of research	571	30% (25-35%)



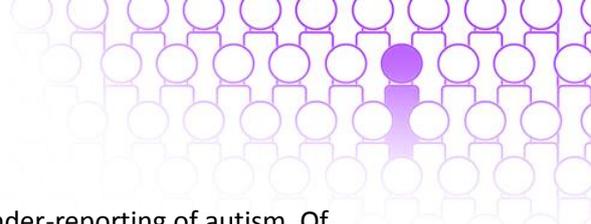
Bhaumik and colleagues examined links between a register-based recorded diagnosis of autism and carer reported autistic traits amongst the 1,145 adults on the Leicestershire Learning Disability Register.³ While 19% of adults on the register had a recorded diagnosis of autism, autistic traits were identified in 69% adults with 30% showing two or more autistic traits. The presence of two or more autistic traits most efficiently predicted diagnosis. These results raise the possibility of under ascertainment of autism, possibly as a result of the attribution of autistic traits to learning disabilities, rather than autism. The use of a service-based learning disability register as a sampling frame will have resulted in the under-sampling of adults with mild or moderate learning disabilities who may not be known to specialised learning disabilities services.

Saemundsen and colleagues initially screened individuals using the Childhood Autism Rating Scale and the Autism Diagnostic Interview-Revised (ADI-R) to ascertain the prevalence of autism in a sample of 119 adults with severe learning disabilities.⁴ Recruitment rate for the attained sample was 46% of eligible participants. Recruitment rates were higher among adults living in residential facilities or group homes.

Melville and colleagues investigated the prevalence and incidence of mental ill-health in adults with learning disabilities with and without autism.^{5,8} The sample was based on individuals identified by GPs as having learning disabilities. Of these, 8% were identified as having autism as a result of comprehensive psychiatric assessment undertaken by a consultant clinician.

Hare and colleagues undertook an audit of an urban population of adults with learning disabilities distributed through a variety of services including community learning disability teams, independent housing providers, supported housing, day services, schools and colleges serving a post-16 population and providers for those placed out of district.⁶ Postal questionnaires were used to ascertain the number of people with a recorded diagnosis of autism or suspected by carers of having autism. This was then compared with the number of individuals known to health and social care services as having learning disabilities living in the borough. The authors suggest the estimated prevalence of autism (10%) is an underestimate on the basis of people with severe learning disabilities being less likely to have their autistic traits recognised as such. Of the 10% of people identified, only 33% had a formally recorded diagnosis of autism.

Morgan and colleagues used the Pervasive Developmental Disorder – Mental Retardation Scale to screen for the presence of autism among a predominantly urban convenience sample of adults with learning disabilities.⁷ A disproportionate number of the 30% of adults identified as having autism had severe learning disabilities (57%).



Our analysis of hospital episode statistics suggested considerable under-reporting of autism. Of people admitted to hospital in 2008/09, 0.25% (0.24% to 0.25%) of those under 18 had a diagnosis of autism and 0.31% (0.31% to 0.32%) a diagnosis of autism or Asperger syndrome. For adults aged 18 to 64, corresponding figures were 0.032% (0.031% to 0.034%) and 0.051% (0.049% to 0.053%), and for those aged 65 and older, 0.002% (0.001% to 0.003%) and 0.004% (0.003% to 0.005%). The proportions of people diagnosed as having 'mental retardation' or 'learning disability' were 0.47% (0.46% to 0.48%), 0.384% (0.379% to 0.390%) and 0.153% (0.148% to 0.158%) for the three age groups respectively.

As the proportion of people recognised as having an autistic spectrum condition fell with age, the proportion of these also recognised as having learning disability rose. So that for children and young people, 18.2% (17.0% to 19.5%) of those with autism were also diagnosed as having a learning disability, whilst of those with autism or Asperger syndrome 15.1% (14.1% to 16.2%) were. Corresponding figures for the older age groups were 46.0% (43.5% to 48.6%) and 32.6% (30.7% to 34.6%) for those aged 18 to 64, and 52.1% (38.3% to 65.5%) and 31.2% (22.7% to 41.2%) for those aged 65 and older.

Data from death certificates suggested even poorer levels of recognition of autistic spectrum conditions. In the five years from 2004 to 2008 inclusive, in England, only 54 deaths out of 2,362,095 (0.0023%) included a code for autism or Asperger syndrome.

In both cases, these data tell us more about levels of recognition of autism and Asperger syndrome than about their actual prevalence.

Summary

Few studies have attempted to ascertain the prevalence of autism among non-institutionalised samples of adults with learning disabilities. Those that have are characterised by a range of methodological problems including: the use of small and probably non-representative samples of adult users of learning disabilities services;^{4,7} reliance on recorded diagnosis to identify the presence of autism;^{3,5,6} and under sampling of adults with mild and moderate learning disabilities who do not use specialised health and social care services for adults with learning disabilities.³⁻⁷ However, all studies report markedly higher rates than have been reported among the general adult population in the 2007 general household psychiatric morbidity survey (1%).⁹

In addition, these five studies have reported prevalence rates somewhat lower than reported by studies based on samples of adults with learning disabilities in residential care (23-50%),^{10,11} or among users of mental health services for people with learning disabilities (38%).¹² As noted above, this is likely to reflect the increased probability of people with learning disabilities and autism entering residential care as a result of the association between autism and the prevalence of challenging behaviours.¹³

Finally, it is notable that studies that have screened for autism have reported higher rates than those that have relied on pre-existing recorded diagnoses. This difference is consistent with concerns regarding the under-identification of autism among adults with learning disabilities.



Given these concerns it appears reasonable to assume that the true prevalence of autism among adults with learning disabilities is likely to lie at the upper end of these existing estimates. **For our current purposes we propose to employ two prevalence rates: a lower estimate of 20% (close to the median rate across studies) and an upper estimate of 30% (the higher rate reported by studies on community-based samples of adult users of specialised learning disabilities services).**

The Prevalence of Learning Disabilities among Children with Autism

Given the small number of well-constructed studies that have investigated the prevalence of autism among adults with learning disabilities, we also reviewed the existing literature on the prevalence of learning disabilities among children with autism.^b

We did not undertake a systematic review of this area for two reasons. First, within the time frame we needed to work to and the resources available, it was not possible to undertake a systematic review of such an extensive body of literature. Second, a number of high quality reviews of this area have been published over the past decade.¹⁴⁻²⁰ Instead, we reviewed these reviews and supplemented them with a review of epidemiological studies published since 2000. These additional studies were identified by a combination of: (1) literature searches undertaken in September 2010 using the databases Medline and PsycINFO; (2) consultation with recognised experts in the field.

The Prevalence of Autism

Most estimates of the current prevalence of autism lie in the range of 30-160 per 10,000 children.^{14-18 21 22} Reported prevalence rates have increased over time. The current consensus suggests that these rises are the result of: (1) improved methods for the detection of autism; (2) a broadening of the concept of autism, especially in relation to children with near normal or normal non-verbal intelligence.^{14 16-19} It remains unclear whether there have been any changes in underlying prevalence rates.^{16 17 19}

Two recent well-constructed studies undertaken in England have reported estimates at the upper end of this range.^{21 22} **As a result, we have derived two estimates of the overall prevalence of autism for use in subsequent modelling: an upper estimate of 150 per 10,000 (1.5%) and a lower estimate of 100 per 10,000 (1%).**

The upper estimate is slightly lower than the highest recent estimate reported (by Baron-Cohen and colleagues in a recent study in Cambridgeshire).²² The lower estimate is slightly lower than recently reported by Baird and colleagues in a recent study in South London,²¹ but slightly higher than recorded by DfE among 7-15 year old children in maintained schools and non-maintained special schools in England.²³

^b The vast majority of epidemiological research on autism has focused on children. As a result, we restricted our review to children with autism.

The Prevalence of Learning Disabilities among Children with Autism

Estimates of the prevalence of learning disabilities among children with autism in more recent well-constructed studies range from 15-84%.^{14-18 20 21 24-33} The following table summarises prevalence rates of learning disabilities among children with autism in studies published since 2000.

Study	Country	Size of Screened Population	% with Learning Disabilities
Baird 2000 ³²	UK	16,235	40%
Kielinen 2000 ³⁰	Finland	152,732	50%
Bertrand 2001 ²⁹	USA	8,896	63%
Fombonne 2001 ³¹	UK	10,438	44%
Magnusson 2001 ³⁴	Iceland	43,153	84%
Chakrabarti 2001 ²⁷	UK	15,500	71%
Croen 2002 ³⁵	USA	4,950,333	37%
Chakrabarti 2005 ²⁸	UK	63,859	67%
Baird 2006 ²¹	UK	56,946	55%
Williams 2008 ³³	UK	14,062	15%

The average reported prevalence of learning disabilities across these studies is 52.6%. The median reported prevalence of learning disabilities across these studies is 52.5%.

It is possible to calculate a *weighted* average to take account of the substantial differences in sample size. This gives more weight to larger studies (in proportion to their sample sizes). The weighted average reported prevalence of learning disabilities across these studies is 38.4%. However, it has been independently suggested that the rates reported by Croen and colleagues (by far the largest study) are likely to be underestimates due to the methods used.¹⁵ Doubt has also been cast on the extremely low rates reported by Williams and colleagues.²⁴ If the Croen study is excluded, the weighted average prevalence rate is 56.7%. If the Croen and Williams studies are excluded, the weighted average prevalence rate is 58.3%.

Given the variation in prevalence rates, we have derived two estimates of the overall prevalence of learning disabilities among children with autism for use in subsequent modelling: an upper estimate of 67% and a lower estimate of 40%. These are equivalent to the upper and lower terciles of the reported prevalence estimates (i.e., one third of estimates are lower than the lower estimate, one third higher than the upper estimate).

The Prevalence of Autism among Children with Learning Disabilities

It is possible to combine our estimates of the prevalence of autism and the prevalence of learning disabilities among children with autism with estimates of the prevalence of learning disabilities to derive estimates of the prevalence of autism among children with learning disabilities. To do this we have used two estimates of the prevalence of learning disabilities among children, an upper estimate of 3.4% and a lower estimate of 1.4%. Both of these were derived from analyses of data for 7-15 year old children in the Department for Education's Spring 2010 School Census. The 7-15 age range was selected as the identification of SEN associated with learning disabilities rises sharply up to age 7 and then declines sharply once children reach school leaving age.²³ The upper estimate is the percentage of children at School Action Plus or with a Statement of Special Educational Need (SEN) with a primary SEN associated with learning disabilities. The lower estimate is the percentage of children with a Statement of Special Educational Need (SEN) with a primary or secondary SEN associated with learning disabilities. These estimates are consistent with the results of epidemiological studies of the prevalence of learning disabilities in children.^{36 37}

Combining these estimates of the prevalence of learning disabilities, the prevalence of autism and the prevalence of learning disabilities among children with autism gives eight separate estimates of the prevalence of autism among children with learning disabilities. For example, in a population of 100,000 children, we estimate that 3,400 will have learning disabilities (upper estimate) and 1,500 will have autism (upper estimate). Among these 1,500 children we estimate that 1,005 will also have learning disabilities (upper estimate). Thus, the estimated percentage of children with learning disabilities who also have autism is $1,005/3,400$ or 30%. These estimates range from 12%-72%, with an average of 34%. The lowest estimate results from combining the lower estimate of the prevalence of autism, the lower estimate of the prevalence of learning disabilities among children with autism and the upper estimate of the prevalence of learning disabilities. The highest estimate results from combining the upper estimate of the prevalence of autism, the upper estimate of the prevalence of learning disabilities among children with autism and with the lower estimate of the prevalence of learning disabilities.

Estimating the Prevalence of Autism among Adults with Learning Disabilities in England

The Number of Adults with Learning Disabilities in England

Three approaches can be taken to estimating the numbers of adults with learning disabilities in England. These are based on:

- the number of people using learning disabilities services;
- the number of people known to learning disabilities services; and
- the number of people with learning disabilities in the population.

It is possible to identify the number of adults who use some specific services for people with learning disabilities. The most comprehensive information of this kind is collected annually from Councils with Social Service Responsibilities in relation to the number of adults who have received social care services in any given year. Provisional data for 2009/10 indicates that 141,715 adults in England aged 18+ received specific social care services designated for people with learning disabilities.^c

These are, however, poor estimates of the actual number of adults with learning disabilities in England. First, people may use services intermittently. That is, they may be known to Councils with Social Service Responsibilities as people with learning disabilities, but may not have received a designated service in that particular year. Data from PCTs suggest that 145,130 adults with learning disabilities were 'known to Councils with Adult Social Services Responsibilities' in 2009/10.³⁸ Previously we have estimated that 177,000 adults are likely to be known to adult social care services as people with learning disabilities.³⁹

Second, it is clear that the majority of adults with learning disabilities simply do not use learning disabilities services. In England, for example, the administrative prevalence of learning disability (i.e., the number of people known to services as people with learning disabilities) drops precipitously from 3-4% among children in the education system,²³ to 0.6% among adults aged 20-29.⁴⁰ It is highly implausible that such reductions in prevalence can be accounted for by either reduced life expectancy or sudden improvements in intellectual functioning. Rather, it is likely that they reflect the impact of a combination of factors which include: (1) a decrease in health/disability surveillance in post-education health and social care agencies; (2) the rationing of specialised social care supports to adults with learning disabilities; (3) the stigma associated with learning disability leading to unwillingness to use specialised services or self-identify as having learning disabilities; and (4) the less disabling impact of the intellectual impairments associated with learning disabilities in non-educational settings. Previously we have estimated that 828,000 adults in England are likely to have learning disabilities.³⁹

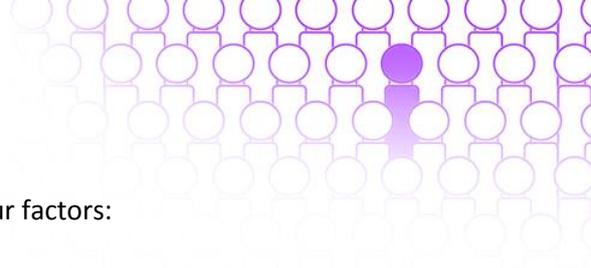
^c <http://www.ic.nhs.uk/pubs/carestats0910asr>

The Number of Adults with Learning Disabilities and Autism in England

From our systematic review of the relevant adult literature we extracted two estimates for the prevalence of autism in adults with learning disabilities: a lower estimate of 20% (close to the median rate across studies) and an upper estimate of 30% (the higher rate reported by studies on community-based samples of adult users of specialised learning disabilities services). Our analysis of more recent epidemiological studies of autism in children suggested that 34% children with learning disabilities also have autism. As a result of these child-based estimates, we have slightly increased our upper estimate of the prevalence of autism among adults with learning disabilities from 30% to 33%.

The following table applies these estimates to our estimates of the number of adults with learning disabilities in England and to a hypothetical population of 100,000 adults. We have not, however, applied the upper estimate of the prevalence of autism to the estimate of adults in the population who have learning disabilities as people with less severe learning disabilities are less likely to have autism,⁷ and are also less likely to use learning disabilities services.

Estimates of the Number of Adults with Learning Disabilities and Autism		
	Lower Estimate	Upper Estimate
In England		
Adults using learning disabilities social care services for people with learning disabilities (142,000)	28,000	46,200
Adults likely to be known to specialised health and social care services for people with learning disabilities (177,000)	35,000	57,750
Adults in the population who have learning disabilities (828,000)	166,000	n/a
In a population of 100,000 adults with a demographic profile similar to that of England		
Adults using learning disabilities social care services for people with learning disabilities (344)	69	114
Adults likely to be known to specialised health and social care services for people with learning disabilities (429)	86	142
Adults in the population who have learning disabilities (2,006)	401	n/a



These estimates will vary across local areas as a result of at least four factors:

- the age profile of the adult population
- the ethnic composition of the adult population
- the socio-economic profile of the adult population
- patterns of ‘migration’ of people with learning disabilities and people with learning disabilities and autism

Due to the reduced life expectancy of people with learning disabilities,⁴¹ learning disabilities are significantly more prevalent in younger adult age groups.^{40 42} As a result, areas with younger demographic profiles would be expected to have increased number of adults with learning disabilities and autism.

Severe learning disabilities are more common among Pakistani and Bangladeshi children.²³ As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism.

Learning disabilities are more common in poorer households and less severe learning disabilities are also more common in poorer communities.^{23 36 37} As a result, more socially deprived areas would be expected to have an increased number of adults with learning disabilities and autism. However, this effect may not be particularly pronounced as autism is less common among people with less severe learning disabilities.

Patterns of the provision of residential support services have led to considerable levels of ‘migration’ of adults with learning disabilities. First, the closure of long-stay hospitals for people with learning disabilities led, in many regions of England, to people being relocated to areas with which they had no natural ties. Second, one in three adults with learning disabilities in supported accommodation services who are supported by Councils with Social Services Responsibilities are placed in services lying outside of the area from which they originate.⁴³ This figure rises to 65% among Inner London Boroughs.^d

^d <http://nascis.ic.nhs.uk/Portal/Tools.aspx>

Conclusions

We estimate that between 20% and 33% of adults known to Councils with Social Services Responsibilities as people with learning disabilities also have autism. Across England, this suggests that between 35,000 and 58,000 adults who are likely users of social care services have both learning disabilities and autism. The number of adults in the population who have both learning disabilities and autism (including those who do not use specialised social care services) is likely to be much higher.

These estimates will vary across local areas as a result of at least four factors:

- the age profile of the adult population
- the ethnic composition of the adult population
- the socio-economic profile of the adult population
- patterns of 'migration' of people with learning disabilities and people with learning disabilities and autism.

Our estimates are derived from two main sources. First a very small number of studies of varying quality that have directly investigated the prevalence of autism among adults with learning disabilities. Second, a larger number of studies (of generally better quality) that have investigated the prevalence of learning disabilities among children with autism. These two approaches give broadly similar results.

Department of Health funded research that is currently underway (led by Professor Traolach Brugha at the University of Leicester) will provide additional important information on this issue.

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