Learning disabilities, autism and mental health

If you only read four things:

1. 40.9% of people with a learning disability are likely to have a mental illness.²
2. Mental illness is often not diagnosed in people with learning disabilities (LD).¹
3. People with LD should have access to the same mental health support as everyone else.²
4. People with learning disabilities are five times more likely to get dementia.³

Key points

People with LD should have access to the same mental health support available to the wider population²,⁴, but specific programmes may be needed to remove inequalities in health.⁵

*Figure 1: Mental health needs of people with learning disabilities⁶*

Source: Joint Commissioning Panel for Mental Health. Mental Health Services for People with Learning Disabilities; 2013⁶

Definitions⁷

According to NICE guidance⁸, learning disabilities are defined by 3 criteria:

1. lower intellectual ability (usually an IQ of less than 70)
2. significant impairment of social or adaptive functioning
3. onset in childhood

Definitions of learning disabilities (LD) include:

- finding it hard to understand new and difficult information or finding it difficult to learn and remember new things. Some people have difficulties coping on their own and finding answers to everyday problems. These difficulties start when a person is a child and will affect them their whole life.⁷

LD are often grouped⁹:

- **mild** – may not be identified or diagnosed, so often unsupported
- **moderate** – difficulty in attempting new tasks alone, requiring individual support, often exacerbated by a lack of self-esteem and self-confidence
- **severe** – significant intellectual cognitive impairment requiring a high level of support
- **profound or multiple** - significant problems with learning, additional physical or sensory disabilities

**Associated conditions**

**Attention deficit hyperactivity disorder (ADHD)**
Characterised by hyperactivity, impulsivity and inattention, at excessive levels. Adults may have or be diagnosed with ADHD.\(^{10}\)

**Autism spectrum disorders (ASD)**
Characterised by widespread abnormalities of social interaction and communication, as well as restricted interests and repetitive behaviours\(^{11}\). The spectrum of ASD includes Pathological Demand Avoidance and Asperger syndrome\(^{12,13}\). Some people with ASD may not be diagnosed, because they have developed ways to overcome communication and social difficulties\(^{14}\).

**Challenging behaviour**
“Culturally abnormal behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities.”\(^{15}\)
May include aggression, anti-social behaviour and self-harm.

**Down’s syndrome (DS)**
A genetic condition producing a characteristic range of physical features and learning disabilities. There is some learning disability and delayed development but the extent varies.\(^{16}\)

**Diagnostic codes**
The ICD-10\(^{12}\) diagnostic codes for learning disabilities (LD), including Autistic Spectrum Disorder (ASD) and Asperger’s syndrome, are grouped under the heading “Disorders of Psychological Development” and are identified as codes F80 to F89 with ASD noted as codes F84.0 and F84.1 and Asperger’s syndrome as F84.5\(^{9}\). Down’s syndrome is coded as Q90.

ADHD and hyperkinetic disorders are grouped in F90, and conduct disorders in F91 for ICD-10\(^{12}\).

**What is the issue? Why is it important for Suffolk?**
People with learning disabilities face health and social inequalities. Some of these can be attributed to genetic factors and to poorer access to health services\(^9\).

People with learning disabilities die, on average, 15-20 years earlier than the general population\(^{17,18}\). The average life expectancy for people with Down’s syndrome is approximately 59 years\(^{19}\).

People with LD have higher rates of morbidity than the total population: a population-based study found 99.2% of participants with LD had at least one physical health condition\(^{10}\). Multiple conditions can lead to multiple prescriptions; polypharmacy can lead to adverse consequences:\(^1\):
- medication-medication interactions
- medication-condition interactions
- medication side-effects, for example beta-blockers can cause depression\(^{15}\)
- increased levels of unmet health need\(^9,11\)

There is higher prevalence of mental ill health in adults with LD than the general population:
- incidence rates are significantly higher\(^1,21\)
- more episodes “endure”\(^22\)
Mental illness in people with LD is often not recognised because:

- carers may miss changes in behaviour
- symptoms of mental illness may be attributed to LD (“diagnostic overshadowing”)
- co-morbidities may mean mental illness is missed or recognised late
- the person may find it difficult to communicate new symptoms (or medication side effects)
- supervision and support may mean common signs of mental illness do not present. If a person has carers to support washing and dressing, then failure to maintain personal hygiene or cleanliness cannot be seen; help at mealtimes can mean there isn’t weight loss

Prevalence: learning disabilities

The estimated prevalence rate for any learning disabilities in people aged 18 and over (2018) is 2.32% (13,947 people) for Suffolk, and 2.36% for England as a whole (see Table 1). Confidence intervals mean that the Suffolk percentage is similar to that for England as a whole.

Table 1: People with any learning disability by age, Suffolk & England, estimated, 2018

<table>
<thead>
<tr>
<th></th>
<th>18-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85 and over</th>
<th>18 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>1,400</td>
<td>2,151</td>
<td>2,045</td>
<td>2,447</td>
<td>2,212</td>
<td>2,066</td>
<td>1,137</td>
<td>489</td>
<td>13,947</td>
</tr>
<tr>
<td>England</td>
<td>129,892</td>
<td>191,986</td>
<td>174,319</td>
<td>179,998</td>
<td>150,046</td>
<td>120,559</td>
<td>66,174</td>
<td>26,877</td>
<td>1,04m</td>
</tr>
<tr>
<td>Prevalence</td>
<td>2.7%</td>
<td>2.5%</td>
<td>2.5%</td>
<td>2.3%</td>
<td>2.3%</td>
<td>2.2%</td>
<td>2.0%</td>
<td>1.9%</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

Source: Projecting Older People Population Information System (POPPI) and Projecting Adult Needs and Service Information (PANSI)

Prevalence for moderate to severe learning disabilities, i.e. people likely to be receiving services, for the population aged 18 and over, is estimated as 0.47% in Suffolk (2,900) and 0.49% in England. The Suffolk estimate is significantly lower than the England figure.

Projections of people with learning disabilities

By 2030, there will be an estimated 30% increase in people with LD aged 50+ using social care services. Within this group, the number of people with LD over 80 and using social care is expected to more than double (164%).
Prevalence: ADHD

Depending on the diagnostic criteria used, prevalence of ADHD in children and young people in the UK has been estimated at 1-2% and 3-9%\(^8\). Only around 15% of children diagnosed with ADHD still have that diagnosis at 25, with a further 50% having some symptoms.\(^9\) Epidemiological studies suggest prevalence is 2-4 times greater among men\(^8\).

The Adult Psychiatric Morbidity Survey\(^10\) found 1 in 10 (9.7%) adults in England screened positive for ADHD, with similar rates for men and women (actual prevalence will be lower than screening). If these rates are applied to Suffolk populations, this would suggest approximately 60,000 people would screen for ADHD (see table 2).

Table 2: Estimated positive screening for ADHD, Suffolk, 2018\(^11,27,28\)

<table>
<thead>
<tr>
<th>Persons: age</th>
<th>CCG Registered patients (01/18)</th>
<th>ONS Population projections: 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>All 16+</td>
<td>Ipswich and East Suffolk</td>
<td>Suffolk</td>
</tr>
<tr>
<td></td>
<td>West Suffolk</td>
<td>Babergh</td>
</tr>
<tr>
<td></td>
<td>Great Yarmouth &amp; Waveney</td>
<td>Forest Heath</td>
</tr>
<tr>
<td></td>
<td>Suffolk</td>
<td>Ipswich</td>
</tr>
<tr>
<td></td>
<td>Babergh</td>
<td>Mid Suffolk</td>
</tr>
<tr>
<td></td>
<td>Forest Heath</td>
<td>St Edmundsbury</td>
</tr>
<tr>
<td></td>
<td>Ipswich</td>
<td>Suffolk Coastal</td>
</tr>
<tr>
<td></td>
<td>Suffolk Coastal</td>
<td>Waveney</td>
</tr>
<tr>
<td>32,471</td>
<td>20,173</td>
<td>69,739</td>
</tr>
<tr>
<td>19,394</td>
<td>7,218</td>
<td>5,089</td>
</tr>
<tr>
<td>59,739</td>
<td>10,675</td>
<td>10,146</td>
</tr>
</tbody>
</table>

Prevalence: Autism Spectrum Disorder (ASD)

The usual prevalence rate used for England for ASD is one per 100 people\(^29\), as shown Figure 6. This was based on the Adult Psychiatric Morbidity in England - 2007\(^30\).
A revised rate was published giving ASD prevalence of 0.8% (0.5% - 1.3% with 95% CI), based on combined data from the 2007 and 2014 surveys. This would suggest a prevalence of 4,800 people with ASD in Suffolk in 2018, rather than 5,895.

Prevalence does not appear to change significantly by age, suggesting any apparent increase in the number of children being diagnosed is due to improved identification rather than new causes.

**Prevalence: Down’s syndrome**

PANSI uses a prevalence figure of 6.25 per 10,000 population aged 18-64 based on research published in 2008 and 2005.

POPPI uses a prevalence estimate of 0.36 per 10,000 people aged 65 and over. In 2016, an updated breakdown of prevalence in older age groups were published. Using this estimate, there were no more than 14 people in Suffolk with Down’s Syndrome aged 65+, with roughly two people in each district except for Suffolk Coastal (three) and Forest Heath (one).
Local factors affecting prevalence

Estimated prevalence rates (from POPPI and PANSI) for Suffolk are based on estimates for the national population. South Asian communities (Indian, Pakistani, Bangladeshi ethnicities) have a higher prevalence of learning disabilities, possibly linked to high levels of deprivation, poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors. The proportion of Suffolk residents from South Asian communities is significantly below England (0.9% compared to England's 5.5% according to the 2011 Census), so rates from POPPI and PANSI are likely to over-estimate the number of people in Suffolk with a learning disability.

ADHD is thought to be under-recognised in women and girls; instead they may be more likely to be diagnosed with another neurodevelopmental condition, or mental illness.

The England Adult Psychiatric Morbidity Survey found that people in the following groups are more likely to screen for ADHD:

- younger adults
- those living alone (aged under 60)
- people with no qualifications (also higher rates of ASD)
- the unemployed
- the economically inactive, especially those receiving disability-related out-of-work benefits

Factors affecting projected figures

The population of Suffolk (18 and over) is projected to increase by 2.5% (15,000) from 2018 to around 622,000 in 2035. The total number of people (18 and over) with a learning disability (including mild learning disabilities) is predicted to increase by 3.1% (440) in the same period. However, this could be higher if survival rates for pre-term babies continue to improve, diagnostic criteria change or healthcare increases life expectancy for adults with LD.

Numbers supported locally

3,849 (0.5%) Suffolk people (any age) registered with a GP have a recorded learning disability (2016/17 data), significantly higher than England as a whole (0.5%).

<table>
<thead>
<tr>
<th>CCG / Area</th>
<th>Practices</th>
<th>Total List Size</th>
<th>LD Register</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Value</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td></td>
</tr>
<tr>
<td>Ipswich &amp; East Suffolk</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>Great Yarmouth &amp; Waveney</td>
<td>0.5</td>
<td>0.5</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>West Suffolk</td>
<td>0.5</td>
<td>0.4</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
<td></td>
</tr>
</tbody>
</table>
1,625 adults aged 18 to 64, and 170 people over 64, with LD are recorded as receiving long-term support from Suffolk County Council (2016/17)\(^{24}\). This is 4.2 people per thousand, not significantly different from the England figure of 3.9 per thousand.

* Note

Some of the following charts use experimental statistics published by NHS Digital at CCG level on the health and care of people with learning disabilities. Aggregated data for the three CCGs that cover Suffolk (Great Yarmouth and Waveney, Ipswich and East Suffolk, West Suffolk) is used, as data cannot be taken from practices that use SystmOne, so information is only available for 23% of registered patients in the three CCGs. For England the proportion is better, at 57%. These charts should not be used for precise counts, but to compare trends and broad differences to identify where there might be unmet need needing further investigation.

**Figure 10***: Patients recorded on GP’s learning disability register by CCG & age, end of year 2016-17\(^{40}\)


**Learning disabilities: Unmet need**

In Suffolk, a third of people of working age who have a moderate to severe learning disability may not be receiving services which could improve their health or quality of life, such as tier 1 to 3 social care or supported access to healthcare\(^9\):

<table>
<thead>
<tr>
<th>Count</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2,332</td>
<td>POPPI estimate 18 to 64-year-olds with moderate to severe learning disability(^{14})</td>
</tr>
<tr>
<td>1,625</td>
<td>Recorded service users (18-64) who received long-term support during the year with primary support reason of learning disability(^{24})</td>
</tr>
<tr>
<td>707 (30%)</td>
<td>Gap between estimated and recorded prevalence</td>
</tr>
</tbody>
</table>

If the projections for any learning disability are used, then as much as 80-85% of the LD population does not receive specialist LD support in Suffolk.
The Department of Health estimated that up to a quarter of people with LD who are living with older family carers only become known to services when there is a crisis.26

Figure 11: People aged 18-64 predicted to have a moderate or severe learning disability and be living with a parent, by Suffolk district, 201814,23

This would suggest that there may be up to 200 people with LD in Suffolk who are not known to services.

There appears to be a high level of unmet need for ADHD. Of the 9.7% screening for ADHD in England, 3.7% believed they had the disorder, only 2.3% had been diagnosed by a professional, and 0.5% were taking medication for ADHD.11

Prevalence: mental illness and learning disabilities
Mental ill-health is common among people with learning disabilities. NICE quotes England prevalence of mental illness among adults with LD of 40.9%1,22, compared to a lifetime prevalence of around 25% in the general population1. This figure includes “problem behaviours” and reduces to 28.3% if they are excluded. The prevalence of mental illness in adults with moderate to severe LD is estimated at 43.8%5.

Figure 12*: Standardised prevalence ratio (SPR) of conditions in patients with learning disabilities, 3 CCGs covering Suffolk 40

The types of mental illness most commonly experienced by people with LD are: depression, anxiety disorders, autism, and schizophrenia. People with LD have been found to be up to two to five times more likely to report distress, depression, anxiety, or suicidal thoughts than the general population, and have higher rates of consultations with health professionals about mental health.\textsuperscript{1,15,26,41,42}

Some types of mental illness are more common in people with learning disabilities than in other people: schizophrenia, bipolar disorder, dementia, ADHD, and pica (eating items that are not typically thought of as food and have no significant nutritional value).\textsuperscript{11,15}

The most frequent diagnoses (by clinician) from the Glasgow study\textsuperscript{22} were:

- 22.5\% problem behaviour
- 7.5\% ASD
- 6.6\% affective disorder (incl. 4.1\% depression)
- 4.4\% psychotic disorder (incl. 3.3\% schizophrenia)
- 3.8\% anxiety disorder (incl. 1.7\% generalised anxiety disorder, 0.7\% agoraphobia)
- 11.8\% of participants had more than one mental disorder

Personality disorders may be more common in people with LD, with a suggested prevalence of 1\%\textsuperscript{22}, however they can be difficult to diagnose and may be incorrectly attributed to people with autism\textsuperscript{15}.

Schizophrenia has been found to be three times as common among people with LD than in the general population, and as presenting at a younger age\textsuperscript{15}. It is important that claims of victimisation are considered seriously, rather than assumed to be delusions or paranoia, as stigma and bullying is common\textsuperscript{15,41}.

\textit{Figure 13: Patients with LD and a diagnosis of depression, 2016-17 Suffolk CCGs\textsuperscript{40}}


\textit{Figure 13a: 3 Suffolk CCGs\textsuperscript{40}}

\textit{Figure 13b: England\textsuperscript{40}}

*NB – experimental NHS statistics taken from data for 23\% of patients in the CCGs

\textit{NB different scales for y axis (percentage)}


\textit{Figure 14: Patients with a diagnosis of severe mental illness, 2016-17\textsuperscript{40}}

Prevalence for patients with a recorded learning disability: 7.4\% (8.1\% England). Prevalence for patients with no recorded learning disability: 0.8\% (0.9\% England).
Learning disabilities and mental health

NICE notes that symptoms of ADHD overlap with other disorders such as ASD, personality disorders, depression, anxiety and bipolar disorder, and that ADHD can co-exist with other disorders, including:

- children: mood (including anxiety and depression), conduct, learning and anxiety disorders
- adults: personality disorders, bipolar disorder, obsessive-compulsive disorder

The 2014 Adult Psychiatric Morbidity Survey showed adults who screened positive for ADHD were three times more likely than the wider population to be receiving psychological therapies or psychotropic medication (34.3% compared to 10.8%), and more likely to be using health or community care services. They are also more likely to have requested a particular treatment which they did not subsequently get.

**ASD, learning disabilities and mental health**

The National Autistic Society estimates that roughly half of autistic people may have a learning disability. Around a third of people with a learning disability may be autistic, according to The National Autistic Society, although others suggest 7.5% of adults with LD may also have ASD. Autism is markedly more prevalent the greater the degree of learning disabilities.

A 2008 survey of 1,400 people, carried out by the National Autistic Society, found that over a third of adults with autism experience severe mental health problems. However, the 2014 Adult Psychiatric Morbidity Survey reported people with ASD appear to be no more likely than other adults to make use of treatment or services for mental or emotional problems. In fact, people with autism may be less likely to use health services for a mental health reason than those without autism (3.7% compared to 11.6%). A population-based study found no significant prevalence of mental ill-health between people with autism and LD and people with LD, once matched for age, gender, ability, and DS.

Prevalence of mental illness in people with Down’s syndrome

A study of people in Glasgow established point prevalence amongst those with Down’s syndrome of mental ill-health of any type, excluding specific phobias, as 23.7% (as assessed by psychiatrist or using Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning
Disabilities/Mental Retardation). This is significantly lower than prevalence amongst all people with LD (40.9%).

The most prevalent types of mental illness were:

- problem behaviours - 10.2%
- organic disorders (dementia) - 7.0%
- affective disorders (depressive) - 2.7%
- anxiety disorders -2.7%

None of the participants were identified as having a psychotic disorder, mania, attention deficit hyperactivity, or an organic disorder that wasn’t dementia.

Dementia and people with learning disabilities

Age-related dementia is more common in people with LD, and at a younger age than the wider population:

- 5.1 times higher prevalence in people with LD (having controlled for age and sex)
- 2-3 times higher prevalence in people with LD aged over 60
- nearly 70% of people with Down’s syndrome are likely to develop dementia by 70
- over 80% of people with Down’s syndrome and dementia develop epilepsy

People with LD are more likely to experience some risk factors associated with dementia: diabetes, obesity, inactivity, depression, and may not receive sufficient support on lifestyle factors such as diet and exercise. People with Down’s syndrome are more likely to develop dementia, and at younger ages.

Figure 15: Comparison of dementia prevalence rates by age, national
Figure 16: Patients with a diagnosis of dementia, 2016-17
Prevalence of dementia is shown as 1.3% (England 1.4%) in people with a learning disability, against 0.9% (England 0.7%) in people with no LD.

*NB – experimental NHS statistics taken from data for 23% of patients in the CCGs
NB different scales for y axis (percentage)


Figure 17: Patients with Down’s syndrome and a diagnosis of dementia, 2016-17

*NB – experimental NHS statistics taken from data for 23% of patients in the CCGs
NB different scales for y axis (percentage)

Factors increasing the risk of mental illness in people with learning disabilities

Risk factors found in the general and LD population

The following factors are independently associated with the prevalence of mental ill-health in the general population and in people with learning disabilities:

- a higher number of preceding life events\(^1,2,22\)
- having a higher number of preceding consultations with physician\(^2,22,41\)
- being female\(^2,22,41\)
- being a smoker\(^2\) (does not affect incidence\(^21\))
- urinary incontinence\(^22\) (also increases incidence\(^21\))
- genetic links - for example, a family history of schizophrenia still means an individual with LD is more likely to develop the condition\(^1\)

The incidence of mental illness among people with LD is, like the wider population, also associated with adult abuse, and preceding life events.\(^15,21\) Life events may include: physical illness, bereavement and loss (through death or changes in staffing), change of routines, transitions (between services for children and adults, moving home, leaving school), trauma.\(^15\)

Bullying, harassment and stigma, which are often experienced by people with learning disabilities are associated with mental ill health.\(^1,15,26\) Adults with ASD are often isolated, bullied and socially excluded.\(^11\)

Endocrine disease and ischaemic heart disease were found to increase the risk of problem behaviours in people with LD. This appears to be similar to the general population: hyperthyroidism can lead to psychosis, restlessness and irritability; obesity is associated with mental ill-health and aggression; myocardial infarction is associated with depression.\(^20\) There may be increased risk of delirium due to the higher incidence of infections, and higher risk of reaction to medication, particularly for patients with metabolic disorders.\(^15\)

Neurological conditions, which are common in people with learning disabilities, may also increase the prevalence of mental health problems. Epilepsy has been associated with an increase in the risk of mental illness in the general population\(^15\). Epilepsy is more common in people with learning disabilities, with a prevalence of about 22%, or 40% (excluding people with mild learning disabilities), which may increase mental illness\(^1\). However a population-based study found no association between mental health and epilepsy in people with LD\(^21,22\).

An analysis of Down’s syndrome patients in Glasgow which considered personal, lifestyle and support, and health and disability risk factors (including ability level and whether the person had lived in a long-stay hospital), found that only urinary incontinence was a significant risk factor for mental ill health.\(^46\)

Obsessive Compulsive Disorder (OCD) may be more prevalent among people with LD, but it can be difficult to differentiate between compulsion and tics or mannerisms, and to discern whether an action is a compulsion or a pleasurable activity.\(^15\)

Risk factors found only in the LD population

Greater degrees of learning disabilities are associated with more physical health problems and more mental health problems, although this depends in part on the specific type of mental health problem.\(^1\)
Some prevalence factors are only associated with mental ill-health (excluding ASD and specific phobias) among people with learning disabilities:\textsuperscript{22}
- living with paid carer support (i.e. not living with one’s family)
- having severe to profound intellectual disabilities
- not having severe physical disabilities

It is unclear whether the type of living support is cause or effect: do the reasons that an individual requires paid carer support also mean that s/he is more likely to experience mental ill-health, or does paid carer support lead to increased mental illness (for example, through repeated broken relationships when staff move to other positions)?\textsuperscript{1}

Genetic causes of mental illness in people with LD (“behavioural phenotype”) increase prevalence:\textsuperscript{1}
- dementia in middle-aged and older adults with Down’s syndrome
- affective psychosis, and over-eating\textsuperscript{15}, in Prader–Willi syndrome
- anxiety and autism
- severe self-harm in Lesch-Nyhan syndrome\textsuperscript{15}
- depression in phenylketonuria

Polypharmacy has been implicated in mental health problems in people with learning disabilities.\textsuperscript{1}

Poor mental health in people with LD may be caused by allostatic load, i.e. the demands on the body from adapting to their adverse psychosocial situation. There is some supporting evidence that people with LD have higher levels of inflammation.\textsuperscript{1}

Increased age (from 15-21 to 30-44 years old) has been associated with increased depression and suicidal thoughts in people with LD, whereas studies in people without LD show a peak in the twenties.\textsuperscript{41}

Factors protecting against mental illness in people with learning disabilities
Mental illness appears to be less prevalent in adults with Down’s syndrome than other types of LD. Protection appears to be biological.\textsuperscript{46}

Family support, disability identity and self-advocacy are reported to significantly predict psychological well-being in people with learning disabilities.\textsuperscript{42}

Impaired mobility is a protective factor in prevalence and incidence of mental illness amongst people with LD, unlike in the wider population.\textsuperscript{21,22}

Unlike the general population\textsuperscript{49}, some chronic physical conditions appear to protect against mental ill-health in people with LD:
- respiratory disease reduced the risk of problem behaviours and mental ill-health
- musculoskeletal disease reduced the risk of mental ill-health\textsuperscript{20}

The anti-inflammatory drugs used to treat musculoskeletal problems may account for its protective factors, as inflammation can induce symptoms of depression, and anti-inflammatory drugs may have antidepressant effects.\textsuperscript{20}

Suicide attempts and self-harm appear to be less frequent and less severe than in the general population\textsuperscript{15}. However, it is estimated that around half people with autism will engage in “self-injurious behaviour” at some point in their life\textsuperscript{50}, and this is often categorised separately to self-harm\textsuperscript{51,52}. NICE guidance recommends that people with mild learning disabilities who self-harm should use mainstream services, and people with moderate or severe LD should be assessed by LD specialists\textsuperscript{53}
People with Learning Disabilities are less likely to take psychotropic drugs and therefore induced psychosis is less common. Anorexia nervosa and bulimia nervosa are also found to be less prevalent.

Factors not found to affect mental illness in people with learning disabilities

There was no association between mental ill-health prevalence or incidence amongst people with and the following factors (unlike the general population):  
- living in a more deprived area  *
- having no daytime occupation
- epilepsy
- Marital status did not affect prevalence.

* The impact of other measures of social disadvantage is unclear, with some studies finding mental ill health in children and young people with LD is associated with income poverty, households with no employment, lone parent family or poor family functioning, and others finding no relationship.

In the general adult population, there is an increasing likelihood of mental ill health as the number of physical co-morbidities increase. A study of a thousand adults in Scotland found this is not the case in people with LD (regressions were adjusted for level of LD), possibly because so many people with LD have co-existing physical conditions.

Impairments to hearing or communication, or previous residence in an institution were not associated with increased prevalence of mental ill-health.

Incidence: mental ill-health and learning disabilities

Incidence of mental ill-health in people with LD is higher than the general population. NICE reports the 2-year incidence of mental ill-health amongst people with LD as 16.3%, with a ratio of 1.87 (95% CI 1.51-2.28) compared to the wider population. This is 12.6% if behavioural problems are excluded. Ranked incidence by clinical diagnosis:

- 8.3% affective disorder
- 4.6% problem behaviour
- 1.7% anxiety disorder
- 1.5% organic disorder
- 1.4% psychotic disorder
- 0.5% first episode psychosis, Standardised Incidence Ratio 10

The standardised incidence ratio for dementia is 4.98 in people with LD (excluding DS) aged 65 and over, higher than the age-matched general population at.

There is a slightly lower incidence of problem behaviour for people with LD and autism, however their recovery rate is significantly lower than for people with LD as a whole.

A study showed the two-year incidence of mental illness (clinician-assessed) for people with Down’s syndrome is 14.9%. The most common types of new episodes were:

- 5.2% affective (all depressive episodes)
- 5.2% organic disorders (of the seven instances, 6 were onset of dementia, 1 was delirium)
- 3.7% problem behaviour

Incidence of mental illness was not statistically significant between people with LD and people with DS, due to the wide confidence intervals from the small cohort size.
The impact

ADHD

The 2014 Adult Psychiatric Morbidity Survey showed adults who screened positive for ADHD were three times more likely than those below the threshold (34.3% compared to 10.8%) to be receiving psychological therapies or psychotropic medication:

- psychological therapies (10.1% v 2.2%)
- medication (31.5% v 9.4%)
- using health services (37.4% v 10%)
- using community care (19.6% v 11)

Adults with ADHD are more likely to have behavioural problems such as substance misuse or antisocial behaviour. Adults with ADHD tend to have increased criminal convictions, traffic accidents and mortality, as well as fewer qualifications, poor work performance and poor interpersonal relationships. A quarter (26%) of prisoners have ADHD, and 12% of people with substance misuse disorders.

A recent study (systematic review, meta-analysis and population-based study) has found a significant (dataset pooled adjusted OR= 1.53, CI 1.41-1.65, population study after adjustment for all covariates: 1.45, CI 1.41-1.48) association between asthma and ADHD.

Challenging behaviour: mental ill-health or physical condition?

People with LD are less likely to receive health checks or screening. Health checks are effective in identifying unmet needs in people with learning disabilities. In a trial:

- 51% to 94% of patients were found to have previously undetected health conditions (including dementia)
- 2.2 to 5.2 previously undetected or unmanaged health needs were identified per patient

A study of people with learning disabilities referred to a clinic for challenging behaviour found 75% had one or more undiagnosed or undertreated health problems. These included:

- epilepsy (46%) - in 4% of the total sample, seizures were the challenging behaviour
- hypothyroidism (13%)
- gastro-oesophageal reflux (10%)
- severe closed head trauma (9%)
- chronic pain (9%)
- recurrent urinary tract infections can also precipitate mental illness (delirium)

In many cases, the person’s challenging behaviour stopped once their health condition was treated.

Health checks

54% of Suffolk adults with a learning disability had a health check in 2016/17, in line with the England figure of 48.9%. West Suffolk and Ipswich and East Suffolk CCGs have a target of 75% by 2020.

The learning disabilities health check scheme is a GP enhanced service (ES). GP surgeries do not have to provide this service, but are rewarded if they do as, as it is intended to reduce demand on secondary care.

LD health check scheme data is published quarterly. There are known issues with the data, including data quality:
- the ES register of all patients aged 14 years or over with learning disabilities (LDHC001 (register)) is submitted manually (other data in the set is submitted automatically)
- the register is intended to comprise patients on a practice’s QOF learning disabilities register as well as any other patients registered at the GP practice and known to social services, so figures will not match with figures used in QOF
- different local authorities’ social services departments will have different guidelines on recording people with learning disabilities, and therefore figures should not be compared outside local authority areas. (this means that differences between Great Yarmouth & Waveney CCG and the other two CCGs covering Suffolk may be due to different rules on recording in social services)

Figures 18 and 19 use data from the ES register (LDHC001(register)) and from LDHC001(checks) which is used to calculate reward payments to GPs\(^5\). At the end of quarter 4 2017-18, 3,111 people over 13 were recorded on this register in Suffolk.

*Figure 18: People (14+) on the learning disabilities enhanced service register (LDHC001 register)*\(^5\)

*Figure 19: Learning disability health checks carried out p.a. (LDHC001 checks)*\(^5\)
Table 4: % eligible patients receiving screening, Suffolk CCGs, 2016/17

<table>
<thead>
<tr>
<th>Screening type</th>
<th>% eligible patients with a learning disability</th>
<th>% eligible patients without a learning disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Suffolk</td>
<td>England</td>
</tr>
<tr>
<td>Breast (aged 50-69, within 5 years)</td>
<td>71.1%</td>
<td>50.2%</td>
</tr>
<tr>
<td>Colorectal (aged 60-69, within 5 years)</td>
<td>90.6%</td>
<td>79.5%</td>
</tr>
<tr>
<td>Cervical (aged 25-64, within 5 years)</td>
<td>37.3%</td>
<td>30.4%</td>
</tr>
</tbody>
</table>


What are we doing?

Improving Access to Psychological Therapies (IAPT)

Figure 20: Number of referrals finishing a course of treatment in the year who have reliably improved, 2016-17, by Suffolk CCG

20a With behavioural & emotional disabilities

20b With Learning Disability*

*memory or ability to concentrate, learn or understand

Transforming care

Suffolk County Council, the CCGs and NSFT continue to work together to develop the Transforming Care work programme, to support people with learning disabilities or autism, and challenging behaviour or mental health problems. ‘Transforming Care: A national response to Winterbourne View Hospital and the Concordat: Programme of Action’ (Department of Health, 2012), and showed that there were failures across the health system in providing the best outcomes for people with learning disabilities or autism, who also have mental health needs or challenging behaviour.

The Assuring Transformation data collection supports work to ensure people are not in hospital unnecessarily. It records inpatients of any age who have a Learning Disability or Autism (whether or not they are recorded on a LD register) and are in a Mental Health or Learning Disability specialist bed. This may mean they are being treated for mental illness or because they have (had) challenging behaviour.

The differences in inpatient figures between the Mental Health Data Set (MHDS) and the Assuring Transformation data set are being investigated by NHS Digital. For example, for England in March 2018, there was a difference of 1,080 recorded LD and autism inpatients between the Assuring
Transformation data and MHDS\textsuperscript{41}. Figure 21 should therefore be read with care, particularly as numbers are also rounded. It is of interest that, although performance appears to have improved over time for Great Yarmouth and Waveney, and for Ipswich and East Suffolk CCGs, trends for West Suffolk are less clear. However, East and West Suffolk recently reported that they are achieving their agreed target in the reduction in the number of people with learning disabilities in specialist hospital placements\textsuperscript{49}.

*Figure 21: Assuring Transformation data – inpatients by originating CCG, 2016-May 2018*

Notes:
- Numbers less than 5 have been replaced by '*' and other values have been rounded to the nearest 5 to minimise disclosure risks associated with small numbers. Rows will therefore not always add up to the total.
- The latest changes to inpatient counts have been included.

Due to these unexplained discrepancies in the national data, and interest in the impact of mental and physical co-morbidities, the Public Health Knowledge and Intelligence Team also analysed annual hospital episode data. Figure 22 shows the number of admissions with a primary diagnosis of LD (including autism, but not Down’s syndrome), while figure 23 shows admissions where any of the first five diagnosis codes were LD (including autism, but not Down’s syndrome). The gradual increase in numbers in figure 23 may have peaked in 2015/16 but could merit further investigation to ensure that all aspects of health for people with LD are dealt with equitably and fairly.
Other services

Services for people with LD are commissioned by Suffolk County Council’s social services directorates and the NHS (the three Suffolk Clinical Commissioning Groups (CCGs)).

The SCC strategy for implementation of Supporting Lives, Connecting Communities and personalisation is designed to provide services more effectively and efficiently while putting control of choice in the hands of LD service users. Uptake of direct payments is considered a way of measuring progress against this objective, and in 2015/16 uptake in Suffolk was in line with the England average (27.0% compared to 28.6%).

---

*Figure 22: Suffolk hospital admissions with primary diagnosis of disorders of psychological development (ICD-10: F80-F89), 2010/1-2017/8*

*Note: numbers under 6 are suppressed.*

*Source: Hospital Episode Statistics Data Interrogation System*

*Figure 23: Suffolk hospital admissions with any diagnosis (first five diagnosis codes) of disorders of psychological development (ICD-10: F80-F89)*

*Source: Hospital Episode Statistics Data Interrogation System*

---

Other services

Services for people with LD are commissioned by Suffolk County Council’s social services directorates and the NHS (the three Suffolk Clinical Commissioning Groups (CCGs)).

The SCC strategy for implementation of Supporting Lives, Connecting Communities and personalisation is designed to provide services more effectively and efficiently while putting control of choice in the hands of LD service users. Uptake of direct payments is considered a way of measuring progress against this objective, and in 2015/16 uptake in Suffolk was in line with the England average (27.0% compared to 28.6%).
Figure 24a: Prescribed items (count) for CNS stimulants and drugs used for ADHD, by CCG, May 2018

Figure 24b: Prescribed items (cost) for CNS stimulants and drugs used for ADHD, by CCG, May 2018

Note: the Suffolk CCGs are highlighted. Link to the latest data. Prescriptions can be for people of any age, one person can be prescribed more than one item, someone with ADHD might not receive a prescription item every month.

In the month, West Suffolk prescribed 468 items, Ipswich and East Suffolk 662, Great Yarmouth and Waveney 883.

What else could we do?

Pilot integration work is planned between Suffolk County Council’s Learning Disabilities Teams and the Norfolk and Suffolk Foundation Trust (NSFT) Neurodevelopment Teams which will explore co-location, sharing of data and intelligence, shared workforce development to best integrate the
customer journey and improve outcomes. The project is expected to launch an early adopter site early in 2018.

People with learning disabilities should access to mainstream mental health services, including dementia support, wherever possible. However, risk assessments should consider how vulnerable the person with LD may be in general mental health services, and whether other patients may be at risk from the person with LD’s behaviour.

The Learning Disabilities Mortality Review (LeDeR) recommends that all people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator.

**Treatment**

Antipsychotics are the most frequently used drugs for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. NICE recommend they should be used only after treating comorbid mental and physical conditions, and if psychosocial interventions have been of insufficient benefit.

Mental illnesses caused by a genetic factor may still be effectively treated using psychosocial approaches or medication.

Physiological differences in some genetic syndromes may require different medical treatments:

- low blood pressure in Down’s syndrome,
- differing immunology causing high rates of thyroid and similar disorders
- differing dementia aetiology compared with typical Alzheimer disease

Treatment should be designed for each individual where there are co-morbidities. Regular medication reviews and use of minimal effective doses will reduce the impact of polypharmacy.

The government recommend that IAPT (Increasing Access to Psychological Therapies) must be available to people with LD. There is also evidence that group cognitive-behavioural therapies are effective for people with mild LD.

**Recommendations**

Taken from the recommendations in Maidrag M, Diley I, Ghurtskaia J. *People with Learning Disabilities in Suffolk (Age 14 and over)*:

- reduce unmet need (the gap between estimated prevalence and registered population) through improved identification and recording of people with LD. These people could benefit from Tier 1 to 3 social care support or supported access to healthcare
- continue to improve access to healthcare services such as annual health checks and health screening programmes
- develop a centralised source for service provider information
- improve access to information about available services and offers and the level of care quality, would support both the process of personalisation and commissioners’ ability to monitor provider performance

**Useful links**

**Department of Health**


NICE – National Institute for Health and Care Excellence

- NICE. *Autism Spectrum Disorder in Adults: Diagnosis and Management - Guidance and Guidelines.* NICE; 2016. [https://www.nice.org.uk/guidance/C142](https://www.nice.org.uk/guidance/C142)

- NICE. *Care and Support of People Growing Older with Learning Disabilities - Guidance and Guidelines.* NICE; 2018. [https://www.nice.org.uk/guidance/NG96](https://www.nice.org.uk/guidance/NG96)


- NICE. *Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management Guidance and Guidelines.* NICE; 2016. [https://www.nice.org.uk/guidance/NG54](https://www.nice.org.uk/guidance/NG54)

Public Health England


Related Suffolk Mental Health Needs Assessment topics


- Transgender and non-binary people and mental health

Related Suffolk JSNA topics


References


10. NICE. *Attention deficit hyperactivity disorder: diagnosis and management Guidance and guidelines NG87*. (NICE, 2018).


23. Institute of Public Care. PANSI - Projecting Adult Needs and Service Information.


39. Public Health England. Learning Disability Profiles. Available at:


48. NICE. *Care and support of people growing older with learning disabilities | Guidance and guidelines | NICE.* (NICE, 2018).


62. NHS Digital, 1 Trevelyan Square, Boar Lane, Leeds, LS1 6AE, United Kingdom. Hospital Episode Statistics.


65. NICE. Learning disabilities: challenging behaviour | Guidance and guidelines | NICE. (NICE, 2015).
