

Kent Joint Strategic Needs Assessment (Kent JSNA)

Kent Adults with Learning Difficulties JSNA Chapter Summary Update 2015

Contacts: Malti Varshney and Karen Shaw

Website: www.kpho.org.uk

Adults with Learning Difficulties JSNA Chapter

Introduction

The term 'learning disability' commonly refers to a group of individuals with a history of developmental delay, a delay in or failure to acquire a level of adaptive behaviour and/or social functioning expected for their age and in whom there is evidence of significant intellectual impairment.

Generally, the severity of learning disabilities is measured by the level of intellectual impairment, known as IQ rate. However, these categories alone do not adequately reflect the type and range of impairments that people may have. The table below illustrates how learning disability is categorised and gives details of the typical needs of those who access Social Care services.

IQ score	Category of learning disabilities	Kent Social Care's Case- loads
IQ of 70-80	Borderline learning disabilities	
IQ of 50-69	Mild learning disabilities	Approximately 85% of cases: most can lead normal lives except that they may need assistance in handling difficult situations.
IQ 35-49	Moderate learning disabilities	Approximately 10% of cases: using simple language when talking but understand speech better. Can generally attend to the basic tasks of life but more complex activities, such as using money; usually require support within a special residential environment.
IQ of 20-34	Severe learning disabilities	Approximately 3-4% of cases: many are able to look after themselves with careful supervision.

Table 1

Profound multiple learning disabilities

Those diagnosed with profound and multiple learning disabilities (PMLD) have more than one disability, with the main disability being learning difficulties. They are likely to have difficulty in communicating, have mental health disorders and need carer support to assist with daily functions such as washing, dressing and eating. People with PMLD account for 1-2% of Kent adults with a learning disability caseloads.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people. However, with the right support, many people with a learning disability can lead independent lives and some may have life- long needs for health and social care.



The level of support someone needs depends on numerous factors, including the severity of their learning disability. For example, someone with a mild learning disability may only need support with things like securing employment. However, someone with a severe or profound learning disability may need full-time care and support with every aspect of their life—they may also have physical disabilities, sensory impairments and mobility difficulties (*Mencap*).

The level of intellectual impairment and other compounding conditions (such as poverty, lack of housing and unemployment) will determine the range and level of health and social care needed. The presence of some other co-existing conditions will also govern the level of support people may need.

These conditions may include:

- mental health issues
- physical disabilities (sensory impairment and mobility difficulties, for example)
- medical conditions (such as epilepsy or diabetes)
- behavioural issues (from self-injury to inappropriate social behaviours)
- preventable health conditions resulting from lifestyle factors (such as smoking, obesity and poor oral health)

This range and diversity of need represents a significant challenge to carers, families and service providers. Planning services is complex, as health, social care, education and housing must all be involved. As learning disability necessitates lifelong partnership working the quality of the interfaces between services is crucial. This is particularly true at transition points in people's lives, such as leaving full-time education. The necessity for partnership and collaboration between agencies is emphasised by the knowledge that mental and physical ill-health is often undetected or under-treated.

Key Issues and Gaps

Most population figures for the UK have been determined from service contact, often derived from case or practice registers. For the following reasons, this underestimates the true prevalence of learning disabilities and co-existing conditions.

- not all people with learning disabilities are known to the practice registers
- delay in diagnosis skews case findings so that prevalence appears higher in 15-19 year olds than in young children; case ascertainment is more complete with increasing age, as milder degrees of impairment are most likely to be identified later
- those with severe impairment, or with significant other disabilities/co-existing conditions, are more likely to use services and be registered as a service contact
- many co-existing conditions remain unrecognised/undiagnosed
- data accuracy and completeness depend on the adequacy of local interagency working and the development of local information systems.

As a consequence, more is known about people with either severe impairment or mild impairment and co-existing conditions (ie those in touch with services) than



about the much larger groups of people with relatively uncomplicated mild or borderline intellectual impairment.

The gross under reporting of learning disability incidence against estimated national prevalence may reflect a training need. Data may reflect a prime chronic disease management issue rather than learning disability. The spectrum of what constitutes learning disability and its degree of severity requires specialist diagnosis and proactive communication between clinicians. Whilst it is unlikely that a prevalence of 3% would be recorded in Kent, the current gross under reporting needs to be addressed.

Who's at Risk and Why?

The aetiology of learning disabilities can be subdivided into conditions that arise at conception (therefore whose prevention lies before conception) and those that arise during pregnancy, labour and after birth (see table below). Aetiological agents fall into three main categories: genetic, infective and environmental.

Aetiological factor	Timing of injury/exposure								
Genetic	Antenatal								
	Chromosome aberrati	ons			Se	econdary	neurological damage		
	Trisomies:			•	Dis	sorders	of:		
	p 21: Down's syndro	me		þ)	Protein	metabilism, eg		
	b 18: Edwards' synd	rom	e			phenylk	etonuria		
	 13: Patou syndrom 	ne		þ)	Lipid m	etabolism, eg Tay-		
	 Sex-linked, eg fragile 	Х				Sachs			
	syndrome			þ)	Carboh	ydrate metabolism		
				þ)	Mucopo	Diysaccaride		
						metabo	lism, eg Hurier's		
					syndrome				
				concepital hypothyroidism					
Infective	Antenatal		Perinat	te	al	oongen	Postnatal		
	Rubella – damage mo	ore				nnlex	Meningitis		
	severe, the earlier in		Tiorpoe		0	nprox	Encenhalitis		
	pregnancy contracted						Encephalopathies, eq		
	HIV						measles		
	Toxoplasma						Whooping cough -		
	Cytomegalovirus						secondary to brain		
	, ,						injury		
Environmental	 Nutritional 	• Bir	rth injury	y:			 Trauma: accidents 		
	deficiencies, eg	Tra	auma				and non-accidental		
	iodine	• Hy	Hypoxia				injury resulting in		
	Rhesus	• Hy	poglycaemia			ia	head injury		
	incompatibility						Lead		
	 Drugs/alcohol 						Nutrition		





Irradiation	

Source: Rees et al 2004

Genetic factors

In the UK the majority of cases are due to genetic factors. Non-inherited Down's syndrome causes approximately 30% of cases at birth. These fall under either chromosome aberrations most commonly Down's syndrome, or X-linked disorder (such as fragile X syndrome). Other single-gene disorders of which more than 2,000 have been identified, account for 12% of cases (Rees et al, 2004). Known genetic disorders cause only 5-10% of cases of mild learning disabilities. Although more are being recognised, other genetic disorders are caused by secondary neurological damage such as phenylketonuria.

According to Rees et al, (2004), phenylketonuria (PKU) is the most metabolic common disorder with a birth frequency of 0.05-0.07/1,000 live births. It is a single-gene recessive disorder, which usually results in severe impairment if untreated by dietary restriction. The current screening programme should ensure that virtually no new cases with learning disabilities attributed to this cause occur in the UK.

Down's syndrome

The majority of individuals with Down's syndrome have IQs in the range 35-55; 10% have an IQ of less than 20. People with Down's syndrome have a higher incidence of medical problems than the general population; 30-45% have congenital heart disease; 6% have gastrointestinal anomalies; 1% develop childhood leukaemia; there is an increased incidence of hypothyroidism; the majority of individuals develop early-onset dementia; 70% have hearing problems; 50% have sight difficulties and many have increased levels of severe periodontal disease.

The prevalence of behavioural problems is less than that seen in other groups with severe learning disabilities, although greater than in the general population (Kerr 2004).

Prasher (1995) suggests that the following percentages of people with Down's syndrome have dementia: 2% of 30–39 year olds, 9.4% of 40–49 year olds, 36.1% of 50–59 year olds and 54.5% of 60–69 year olds. Many studies have now confirmed that age related cognitive decline and dementia affecting people with Down's syndrome occur 30-40 years earlier in life than the general population (Holland 2000).

Environmental

Some environmental factors (such as nutritional deficiencies, alcohol, drugs, exposure to irradiation and lead) may lead to increase of trauma, hypoxia and hypoglycaemia associated with learning disabilities. Alcohol studies in the USA identified a link with learning disabilities although this is not substantiated in the UK. Dietary folate (folic acid) deficiency can be associated with an increased risk of Neutral Tube Defects (NTDs).



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Non-genetic factors

Ante- and post-natal factors such as infection, non-accidental injury and accidents cause approximately 25% of severe learning disabilities. Obstetric complications and birth injury cause about another 10%. This accounts for some of the observed association between learning disabilities, epilepsy and cerebral palsy, low birth weight also being an important factor.

Infective

Infective causes are uncommon and outcome is very variable. Infection, injury and accidents account for 25% of severe learning disabilities and complications and injury at birth cause a further 10%. These factors and low birth weight may have an association between learning disabilities and epilepsy and cerebral palsy. Rubella infection in early pregnancy severely affects the development of those who survive; later infection tends to be less damaging. However, immunisations against infections (such as Rubella) contribute to the low rates of infective causes of learning disability.

Cerebral palsy

Cerebral palsy develops in approximately 2-3/1,000 live births. Estimates suggest that up to half of those with cerebral palsy will have some difficulties with intellectual functioning and between 23% and 34% will have an IQ of less than 50. In the UK, approximately 92-136/100,000 of the population has severe learning disabilities and cerebral palsy. This proportion is likely to increase with advances in neonatal medicine. The risk of cerebral palsy and severe learning disabilities increases with prematurity and low birth weight.

Physical disabilities are commonly associated with cerebral palsy. Half of those with cerebral palsy and severe learning disabilities also have epilepsy, 65% are immobile, 60% have severely limited manual dexterity and 60% have impaired vision.

Ethnicity

There is some evidence to suggest that there is an increased prevalence of severe learning disabilities in the British Asian population. For 20 years, people with learning disabilities from all ethnic minorities in the UK have experienced insufficient and inadequate services, despite sometimes desperate levels of need (Hatton 2005).

The Level of Need in the Population

In 2014-15 the recorded numbers of people with a learning disability includes all ages. As of 2014-15, Kent has 6,405 persons identified with learning disabilities in the Quality and Outcomes Framework (QOF), the rate of which is 0.42% slightly below that of England's average of 0.44%. Within Kent, the highest prevalence of learning disabilities can be identified within South Kent Coast CCG at 0.66%.

Table 3 shows the recorded prevalence in 2014-15 of LD within Kent's clinical commissioning groups. South Kent Coast and Thanet CCGs have a greater proportion of individuals know to have a learning disability.



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Table 3:

	LD Register	CCG Population	LD Prevalence (%)
		SIZE	
Ashford CCG	521	126,411	0.41
Canterbury & Coastal CCG	953	215,303	0.44
Dartford, Gravesham & Swanley CCG	661	257,242	0.26
South Kent Coast CCG	1,316	198,899	0.66
Swale CCG	456	108,243	0.42
Thanet CCG	876	143,193	0.61
West Kent CCG	1,622	475,717	0.34
Kent	6,405	1,525,008	0.42
England	252,446	56,817,654	0.44

Source: Quality & Outcomes Framework, 2014-15

Kent (excluding Medway) currently has 6,405 persons with learning disabilities identified on the QOF register. The highest number is shown in West Kent CCG area, although this is the largest geographical area and has a relatively low prevalence (0.34%). South Kent Coast CCG has a high number identified on the register and the highest rate per population (0.66%) which will make a considerable demand on resources in the South Kent Coast area. Thanet also has a high prevalence of adults with learning disabilities (0.61% of the Thanet population). There is expected to be a steady but consistent increase in the number of people with learning disabilities across all districts and CCG areas between 2014 and 2030.

Table 4 below shows the estimated prevalence of learning disability within the 18-64 population. According to the Office for National Statistics, it has been projected that there could be 22,722 persons with a learning disability within Kent by 2030.

	2014	2015	2020	2025	2030
Ashford	1,735	1,745	1,806	1,845	1,864
Canterbury	2,302	2,305	2,293	2,308	2,355
Dartford	1,533	1,543	1,623	1,677	1,732
Dover	1,553	1,551	1,524	1,498	1,478
Gravesham	1,517	1,530	1,566	1,605	1,627
Maidstone	2,326	2,346	2,439	2,501	2,549
Sevenoaks	1,630	1,636	1,663	1,693	1,725
Shepway	1,519	1,522	1,534	1,531	1,526
Swale	2,017	2,035	2,105	2,162	2,209
Thanet	1,866	1,879	1,926	1,957	1,991
Tonbridge & Malling	1,749	1,761	1,828	1,866	1,895
Tunbridge Wells	1,663	1,668	1,710	1,746	1,757
Kent	21,418	21,522	22,017	22,403	22,722

Table 4: Numbers of people aged 18-64	predicted to have a learning disability,
Kent	

Source: PANSI



Parents with learning disabilities

It is estimated that 7% of adults with a learning disability in the UK are parents, most of whom have a mild or borderline learning disability. In 2014, these estimates equate to 3,080 parents in Kent; many will need additional support in accessing information about family planning, safer sex, supporting the developmental growth of their baby and reduce the risk of unintentional neglect.

Parents with learning disabilities are more likely to have children removed from their care than any other group (approximately 40%). If the parents' learning disability is mild or borderline, they may not be known to services but any difficulties in acquiring parental skills may negatively affect the safety and development of their children. In addition, other mitigating circumstances such as poor mental and physical health, poverty and lack of family support can also interfere with primary child development.

Every opportunity should be taken to encourage parents with learning disabilities into mainstream children's centres to receive support for breast-feeding, parenting, social networking and peer support. This is an issue that health visitors and child support teams may wish to support further and children's centres may need to ensure that their services are equitable and accessible for parents with learning disabilities.

Mental ill-health in adults with learning disabilities

The prevalence of psychiatric disorder and behavioural disturbance is higher in all age groups of people with learning disabilities than in the general population.

The risk factors for depression in the general population, such as stress, lack of social support and life events, are the same for older people with learning disabilities. However, older adults with learning difficulties may be further disadvantaged because of limited coping skills and experiences of discrimination, rejection, stigma and abuse (Davies 2008).

Schizophrenia – studies suggest that the prevalence of schizophrenia in those with learning disabilities may be three-four times higher than in the general population. Accurate diagnosis however, is difficult in those with severe impairment, particularly if communication is limited.

The effects of medication or misdiagnosis of depression and post-traumatic stress may be confounding factors. Greater recognition of symptoms, improved diagnosis and the monitoring of early signs can provide early support for people. These issues should be considered and included in the mental health pathway.

Dementia – as life expectancy for adults with a learning disability increases so does the prevalence of dementia among ageing adults. Dementia is almost four times more likely at the age of 65+ than the general population of that age. People with Down's syndrome are at high risk of developing dementia 30-40 years younger than the rest of the population.

Adults with a learning disability who access social care services can receive a benchmark assessment at the age of 30 to monitor the signs of the onset of dementia and include the needs of people with learning disabilities. Kent Community Learning Disability and Mental Health Teams apply a comprehensive pathway for





referring people with learning disabilities for an assessment where onset of dementia is suspected.

Adjustment reactions

People with learning disabilities may be more vulnerable to adverse life events and consequently suffer adjustment disorder more commonly than the general population. The significance of life events such as bereavement for people with learning disabilities is often not recognised.

Challenging behaviours

In some cases, people with learning disabilities may also have challenging behaviours, which is likely to increase with the type and severity of impairment. It is estimated that 10% of the learning disability population have a challenging behaviour, most of which are rated as 'other difficult/disruptive behaviour', with noncompliance being the most prevalent challenging behaviour.

Challenging behaviours are not spread evenly through the population of people with learning disabilities. There is a high prevalence of challenging behaviours in people with Autistic Spectrum Disorders (ASD), whilst people with Down's syndrome are less likely to demonstrate challenging behaviours. Some genetic conditions are associated with specific abnormal behaviour, eg Lesch-Nyhan's syndrome with self-injury, particularly of oral tissues, hypercalcaemia with hyperactivity and Prader-Willi's syndrome of over-eating. Alternatively, associated conditions, such as sensory impairment, pain or communication difficulties, may lead to changes in or challenging behaviour. This can create diagnostic difficulties. For example, visual impairment may lead to depression or challenging behaviours and be misdiagnosed as dementia or schizophrenia.

This is certainly seen as one of the main barriers to accessing universal health care services such as optometrist checks and dental care. Sometimes, a challenging behaviour can be an indication of pain, unhappiness or distress that the person with a learning disability cannot articulate in any other way. People with learning disabilities may find accessing primary health care services more conducive if professionals were given advice and guidance on how to better manage appointments and appointment times and introduce reasonable adjustments to facilitate this. Kent Community Health Trust has produced some good examples and case studies, which if along with training, can assist if made more widely available. Further demands on services are likely as numbers of people with learning disabilities are predicted to increase in Kent.



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Figure 1: Adults with learning disabilities and predicted challenging behaviours 2012-2016.

Autistic Spectrum Disorders

People who are diagnosed with an autistic spectrum condition (ASC) may not necessarily have a learning disability and may even have a higher than average IQ. Those who are diagnosed with autism and who do not also have a learning disability will be referred to specialist ASC service to meet their needs and therefore fall out of the scope of this needs assessment.

Medical conditions found more commonly in people with learning disabilities:

Chronic heart disease (CHD)

Chronic heart disease is the second highest cause of death amongst people with learning disabilities; particularly as congenital heart disease may be more common in some groups of learning disabilities (eg Down's syndrome). It is anticipated that the rates of CHD are increasing due to longevity and associated lifestyle changes (Carter and Jancar 1983; in JSNA).

Although there does not appear to be an increased incidence of hypertension in people with learning disabilities, there is a higher risk of obesity among males and females with learning disabilities (19% and 35% respectively) against 6% and 8% in the general population.

Some specific conditions, such as Down's syndrome are more affected by congenital heart disease and obesity.

Cancer

Cancer rates amongst people with a learning disability are lower than the general population although gastrointestinal cancer is likely to be twice as high in people with a learning disability than in the general population.



In Kent, there is anecdotal evidence of bowel cancer being of significant concern for adults with learning disabilities. The reasons for this are still unclear, but one of the reasons could be due to poor diet and lack of physical activity.

Women with learning disabilities are much less likely to undergo cervical smear tests than the general population as they do not understand the purpose of the test. Women with learning disabilities are also much less likely to engage in breast cancer examinations or receive invitations to mammography than the general population.

Support in attending screening appointments and assistance with follow up is offered by the Community Learning Disability team.

Respiratory disease

Respiratory disease is the leading cause of death for people with learning disabilities (46%-52%; Carter and Jancar 1983; Hollins et al 1998; Puri et al, 1995) and is much higher than for the general population (15%-17%).

The organisation PAMIS (Profound and Multiple Impairment Service), reports that people with multiple learning disabilities are more susceptible to respiratory conditions, particularly pneumonia, although the symptoms are often not spotted soon enough.

A leaflet raising awareness and advice of the symptoms has been produced to identify and address concerns at an early stage and this can be promoted more widely among adults with learning disabilities and their carers.

http://www.pamis.org.uk/cms/files/leaflets/respiratory_leaflet.pdf

Dysphagia

The prevalence of dysphagia is also high among adults with learning disabilities, 40% of whom suffer from recurrent respiratory tract infections. Difficulties with eating, drinking and swallowing can also result in higher incidence of asphyxia, dehydration and poor nutrition.

In Kent, as standard good practice, there is an initial health baseline test as part of the social services assessment. Those at risk of dysphagia are referred to the speech and language team for a 'swallowing' assessment to reduce their risk of choking.

Endocrine disorders

Endocrine disorders are associated with increased or decreased levels of endocrine hormone which can be caused by a range of genetic disorders, disease, injury to or tumour of an endocrine gland, or failure of a gland to release hormones. The endocrine system influences the likelihood of developing, diabetes, thyroid disease, growth disorders and sexual dysfunction. Diabetes is the most common endocrine disorder diagnosed in the UK¹.



¹ <u>http://www.webmd.boots.com/diabetes/guide/endocrine-disorders?page=2</u> accessed 19/5/14

Some endocrine disorders are relatively common among some people with learning disabilities. Hypothyroidism has a 9%-19% prevalence rate in children with Down's syndrome and marginally higher prevalence rate (22%) reported in adults with Downs's syndrome in institutional settings although these rates are not statistically significant². Best practice advice is an annual thyroid function test.

This is particularly important as differential diagnosis for onset of dementia. Children with profound learning disabilities are also at greater risk of experiencing growth hormone deficiency². Other conditions at risk of endocrine disorders are Turner's syndrome, Kleinfleter's syndrome, Noonan and William syndromes. People with Prader-Willi syndrome may be at risk of hypothalamic-pituitary dysfunction and DiGeorges syndrome with a parathyroid insufficiency². Monitoring of some disorders such as hypothyroidism is collected through the QOF data (Thyroid 1 and Thyroid 2) but is not routinely analysed separately for people with learning disabilities.

A 1997 study of health checks for people with learning disabilities demonstrated the value of health checks in revealing previously undiagnosed endocrine problems - six per cent of the 74 people studies³.

Epilepsy

People with learning disabilities are at a higher risk of having epilepsy compared to the rest of the population. The presence of epilepsy is up to 20 times higher for people with learning disabilities against a national average of 0.4% for the general population (Emerson, E et al, 2012).

The prevalence and severity is likely to increase with the severity and type of learning disability. Seizures can be multiple and resistant to drug treatment. Uncontrolled epilepsy can be life threatening and yet diagnosing epilepsy in people with learning disabilities is sometimes problematic, especially when accompanied by communication difficulties. The effects of learning disabilities may also mask the side-effects of anti-epileptic medication.

The risk of active epilepsy in the general population is 0.5%. For those with an IQ of 50-70 it is approximately 4%, for those with an IQ of 20-50 it is 30%, and 50% of those with an IQ of less than 20 have had at least one seizure. Epilepsy is more likely in cases of intellectual impairment associated with peri/post-natal brain injury.

It is estimated that 13% of preventable deaths are caused by epilepsy and are also a main concern for non-psychiatric ambulatory care sensitive conditions (ACSCs). A recent study found that epilepsy and convulsions account for more than 40% of all emergency admissions for ACSCs for people with learning disabilities.

Falls and mobility

Falling is a common cause of physical injury and impaired quality of life for people with learning disabilities. About 2% of the population have a learning disability and according to Finlayson et al (2010) their risk of falling is perhaps three times higher





² Emerson, E et al Health Inequalities & People with Learning Disabilities in the UK: 2012, Ihal, p.5

² Emerson, E et al Health Inequalities & People with Learning Disabilities in the UK: 2011, Ihal, p.9

³ Robertson, J et al *Health Checks for People with Learning Disabilties: A Systematic Review of Evidence, Ihal, p.10*

than in the general population. Of all those with severe learning disabilities, 15% have difficulty walking and 10% are unable to walk. In Denmark, Australia, Canada and the USA, higher rates of falls among individuals with learning disabilities have been noted.

Research shows that people who are non-ambulatory or wheelchair users also have a high incidence of falls. In one study 67% of regular wheelchair users experienced a fall over a 33 month period (Wagemans and Cluitmans, 2006). The significance of these points out the potential hazards associated with wheelchair use and the risks of everyday procedures such as transfers. People who usually use a wheelchair for mobility may be at increased risk of falling when walking. Health practitioners can play an important role by identifying those who are at most risk, implementing management strategies and educating others such as the carers and family members.

Dental health

There is very little research on dental care and oral hygiene for people with learning disabilities, but comprehensive studies in Oldham in 2001 concluded that adults living in the community had significantly higher levels of untreated decay than those in residential settings. The higher risk factor is accounted for by the greater control of dietary choices and personal responsibility for seeking dental treatment, which is more likely to be when problems become severe or urgent.

Adults with a learning disability are more unlikely to have a dentist and be reluctant to accept treatment. Those in residential care were statistically likely to have more teeth missing but have greater access to dental care services. In addition, delivery of dental treatment and services can be problematic and difficult to manage when adults with learning disabilities also pose challenging behaviours.

Sensory impairments

Hearing – the reported prevalence of hearing impairment is in the range 22-68%, depending on the population studied. About 7% are deaf or partially deaf. There are a number of different causes, eg congenital problems, recurrent infections or impacted earwax. Hearing deteriorates at a faster rate in people with Down's syndrome than in the general population or in other people with learning disabilities.

Seventy per cent of people with Down's syndrome are likely to have hearing impairments and their hearing loss is likely to deteriorate faster than other adults with learning disabilities. It is estimated that there are approximately 1,701 people with Down's syndrome in Kent with hearing problems.

Sight – up to 30% of people with learning disabilities may have significant impairment of sight, whilst 10% are blind or partially sighted. However, identified rates in Kent known to the local authority are significantly lower (reaching only 0.9% and 1.2% respectively).

Kent's Sensory Joint Needs Assessment recognizes the need for a systematic approach to early detection and treatment to improve health outcomes and makes recommendations for improved awareness training among people with learning





disabilities, their carers, professionals and service providers. It also seeks to improve accessibility into eye and ear health care services which will be facilitated through a proposed integrated health and social care sensory team for people with learning disabilities.

Studies conducted by the Centre for Disability Research at Lancaster University suggest that an estimated 579,000 adults with learning disabilities (including 122,000 known to the statutory services) have refractive error17. This means that nearly six out of 10 people with learning disabilities need glasses and many sight problems are going undetected and untreated.

People with Down's syndrome are more susceptible to sight and hearing loss. It is estimated that 50% of those with Down's syndrome will have a sight difficulties such as mild to moderate visual loss such as squints or long or short sightedness (estimates for Kent: 1,222 people).

Despite the increase risk of sight and hearing impairments, people with learning disabilities or their carers do not always know they have sight or hearing problems and the impairments can go undetected for years. National research estimates 60% of people with learning disabilities need glasses, but the table below illustrates the relatively low numbers of people registered with sight impairments.

Kent Population#	People with LD in Kent est.#	People with LD known to KCC#	No. people with Downs Syndrome in Kent+		
1,480,200	44,000	5,010	2,243		
Est. Nos Down's syndrome in Kent with sight difficulties+	Est. Nos Down's syndrome in Kent with hearing problems~	Est. Nos. LD reg blind / partially sighted*	Est. Nos LD significant sight impairment**	Actual people with LD reg. blind/severe sight impairment+	Act people with LD reg. partial sight/sight impairment+
1,122	1,570	500	1,503	63	49

Table 5: Adults with Learning Disability and Sensory Impairment

Taken from: Sensory Joint Needs Assessment, Kent County Council, 2013 pp.16–18, p33.

Some adults with learning disabilities are likely to have dual sensory impairments.

Communication

It is widely recognised that people with learning disabilities can find it harder to access health services and treatment for general health problems and when they do, health professionals do not dedicate enough time to appointments. In many cases it is also considered that the health needs, communication and characteristics of people with learning disabilities are poorly understood. Communication difficulties



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experienced by many people with learning disabilities are one of the key barriers, potentially resulting in failure to make 'reasonable adjustments'.

Current Services in Relation to Need

Health promotion

Providers of universal health and wellbeing services will be expected to deliver their services equitably across the community but there is often no mandate to make further reasonable adjustments to ensure that their services are accessible and amenable to people with learning disabilities.

The Community Learning Disabilities Team and other specialist workers can be utilised to provide some training and support to key service providers. Currently, Learning Disability Awareness training is being rolled out systematically to Kent Community Health Trust teams.

Stop smoking services

Adults with learning disabilities are less likely to smoke than the general adult population; smoking rates among adolescents with mild learning disabilities are higher than their peers in the general population. In addition, adults with learning disabilities and who also have asthma are twice more likely to smoke than those with learning disabilities who do not have asthma, leading to higher risk of respiratory conditions.

Drugs and alcohol

People with learning disabilities are less likely to use drugs or drink alcohol compared to the general population, however, alcohol is more likely to be used, particularly for males (Emerson and Baines, 2010). Good practice would suggest that alcohol services should be delivered in a way that people with learning disabilities can be aware of and access them effectively.

Weight management

A number of studies suggest that, depending on their condition, people with learning disabilities are more likely to be obese or underweight than in the general population. Recent research indicates that more than 90% of people in supported accommodation do not eat a healthy diet and 80% are likely to have very low levels of physical activity, particularly if they have severe learning disabilities.

As poor diet can increase the risk of diabetes, it is important that information on healthy eating and physical activity is promoted to those with learning disabilities and their carers and that support is also provided to assist with positive lifestyle changes. A Nutritionist specialising in learning disabilities located in the West Kent Community Learning Disabilities Team helps facilitate this support.

Sexual health

Recent research has indicated that people with learning disabilities are more likely to have poor access to sex and relationship education (SRE) and many are not empowered to make their own choices, with health professionals and/or carers making choices on their behalf. It is important that there is a clear understanding,



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awareness and good practice of 'Capacity to Consent' under the Mental Capacity Act (2005).

Sexual health link nurses in the Community Learning Disabilities Teams provide information and support on some of the main identified areas of sexual health needs:

- menstruation-poor understanding and self-management
- relationships–lack of awareness of consent, rights and risks of pregnancy or by referring to services for information on:
 - Contraception–lack of use of barrier methods and poor level of knowledge of types of contraception available
 - Infection control-increased likelihood amongst men with learning disabilities
 - Other good examples of joint working and training on sexual health for people with learning disabilities through Integrated Community Learning Disabilities Teams that are accessible and commensurate for people with learning disabilities are:
 - CASH (Contraceptive and Sexual Health Services)
 - GUM services (Genitourinary Medicine including HIV services)
 - EHC (Emergency Hormone Contraception) schemes through pharmacies
 - School-based sexual health clinics (there is only one of these in a Kent based SEN school)
 - C-Card (condom registration and access points)
 - Outreach work
 - Termination of pregnancy service
 - Contraception including long acting reversible contraception via GPs.

Housing and communities

It is important that people with learning disabilities have the opportunity to live in their own accommodation, either as a tenant within the rental market or as a home owner. Too few people with learning disabilities have a choice as to where they live or with whom and too few people with learning disabilities have homes of their own with rights as tenants or homeowners compared to the general population.

A housing needs assessment is currently being undertaken by the accommodation and solutions team at Kent Adult Social Care. This will include an audit of existing provision and seek to ensure that resources are best used to meet the accommodation needs of people in the future.

Initial analysis reveals that within Kent currently two thirds of adults with a learning disability live in a care home and further assessment will determine whether this is currently the best or preferred option. This also shows that only 1% currently live in a nursing home, although this is expected to rise as people with learning disabilities continue to live longer. There are currently only 100 people with learning disabilities in shared accommodation and nearly one third of people living at home with parents or family.

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The community support map below identifies current support services that promote independent living in KCC housing stock and for people with disabilities living in their own home. Future activity will be decided upon through the accommodation needs assessment mentioned above.



Figure 2

Figure 3:



Supported living

Kent Supporting People support 23,000 people across Kent in temporary housing and floating support services (2011). The aim is to help vulnerable people cope with some of the problems and issues that may put them at risk of homelessness through



short term limited support to access independent living as well as targeted support to adults with learning disabilities not in receipt of care packages (ie people with mild to moderate learning disabilities) and through the developing peer support services.

In 2009-10, Supporting People spent £4.7m (14% of its annual budget) on supporting adults with learning disabilities. Some of the higher financial demands on Supporting People are from people with learning disabilities in the Maidstone area. One of the main considerations for the future of the Supporting People service is the need for other appropriate partners to manage the demand of the more intensive support packages for people with learning disabilities that the service is currently experiencing.

Kent Public Health are involved with Supporting People to understand how best to support effective service models for people and to support their health and wellbeing. Some of the ways in which Public Health might offer support are:

- access to healthcare
- mental health and wellbeing
- breast-feeding support
- stop smoking services
- falls.

Promoting independence and personalisation

Promoting independence is supported through the Valuing People Personalisation agenda. This offers flexible support in a range of settings with clients/users having a greater say in how they spend their day and access interests, hobbies and personal support.

The activities or outcomes are agreed by the client/user's care manager within a person centred plan and monitored through regular service package reviews. Many of these are mainstream activities provided by the public, private or voluntary sector and give people with learning disabilities greater control in managing the types of activities and interest relevant to their lives.

Day care

Day care support is provided through a range of settings, many of which have moved away from traditional day care centres and more towards personalised day and leisure pursuits within mainstream settings (such as leisure centres).

Education and employment

It is important to continue to develop employment opportunities for people with learning disabilities. The most reliable data for recording numbers of people with learning disabilities in employment is supplied by Improving Health and Lives (IHAL), but only includes people with learning disabilities who are known to councils with Adult Social Services Responsibilities (CASSRs).

The table below summarises the number of adults with a learning disability recorded in paid employment at the time of their latest assessment.



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Table 6:

	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14
Adults with learning disabilities in paid employment.	360	200	205	175	220	215
Number of adults (18-64) known to local authority with client type 'learning disability'.	3820	3520	3470	3390	3445	3355

Source: Public Health England, 2015

The above data show that in 2011-12, there was a slight decrease in Kent. However, this increased by 45 people in 2012-13 (6.4%) and a very slight decrease in 2013-14 of the number of people with learning disabilities in paid work.

Regionally, as of 2013-14, the South East (8.1%) is performing much better than the England average (6.7%), but Kent's performance of 6.4% is slightly similar to the England average. One of the reasons for Kent not performing as well within the South East could be due to the high numbers of people supported in unpaid voluntary work and paid employment of less than four hours per week in Kent, figures for which are not recorded.

In Kent, 38% of adults with learning disabilities are in receipt of direct payments compared to 29% regionally and 30% nationally. Direct payments are one way of receiving financial support from social care instead of providing people directly with a service. This encourages a person with a learning disability to be more independent by using the money to pay for the support to meet his or her everyday needs. These payments cannot pay for services for which the NHS is responsible to provide or for services provided by the council or permanent residential care. Below are a few examples of what direct payments can be used to purchase:





- household tasks such as cooking, housework or gardening
- personal care
- guiding and communication support
- transport such as taxis
- leisure activities such as socialising, sports, classes or groups
- holidays, short breaks or a link family
- equipment such as computer equipment, specialist homeware, mobile phones
- minor home adaptations (eg a handrail).

The table below summarises the number of adults with a learning disability recorded to be receiving non-residential social care through direct payments or self-directed budget.

Figure 5:



Table 7:

	2005	2006	2007	2008	2009	2010	2011	2012	2013
	/06	/07	/08	/09	/10	/11	/12	/13	/14
Adults with									
learning									
disabilities	120	310	360	540	705	730	945	1110	1265
receiving direct									
payments.									
Number of adults									
(18-64) receiving	2625	2030	2825	2720	2670	2480	3100	3010	3320
non-residential	2025	2930	2020	2120	2070	2400	5100	3010	3320
social care.									

Source: Public Health England, 2015





The data show that there was a sharp increase in 2012/13 to a steady increase by 2013/14 in comparison to England's average which appears to be a constant and steady growth since 2010/11 to 2013/14 and the same regionally.



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Transition

The Kent Learning Disability Partnership Board governs a specific partnership group dedicated to becoming an adult called 'Becoming an Adult'. he aim of the group is to discuss issues about people with learning disabilities being in charge of their own lives and being empowered to make plans for their future.

Kent County Council's transition protocols provide information and guidance for families and young people with learning disabilities as they move to adulthood. The protocols have been updated into an Easy Read version and are available as an interactive web-based information site.

Transition services for people with learning disabilities in Kent aim to be seamless and effective, supported by a dedicated Community Learning Disability Team (CLDT) dealing with all aspects of transition care located in six areas across Kent.

Annual health checks/health action plan

Annual health checks for people with learning disabilities are designed to promote good health and provide early diagnosis of the onset of disease conditions. They were introduced as part of the reasonable adjustments within primary care to reduce the risk of early morbidity for adults with learning disabilities.

Uptakes for health checks are low with eligibility being dependent on GP surgeries being registered for Directed Enhanced Services, which requires adults with learning disabilities being known to local authority social services and is further complicated by non-Kent residents being placed in Kent local authority services. The data below suggests that more health checks need to be undertaken as there is strong evidence of their benefit in identifying unmet health needs. The percentage of eligible adults with a learning disability having a GP health check in Kent is 41.6% which is lower than the England average of 44.2%.

A number of measures such as more flexible and longer appointment times, information on what health checks are, and their significance and having a doctor well known to the person with learning disabilities has helped improve the uptake of health checks in Kent.

The figure below shows that in 2013-14, there were 2,314 learning disability health checks delivered in Kent in comparison to the registered population of 5,569 persons aged 18 and over on the QOF register. Across England, the uptake of learning disability health checks has increased between 2008-09 and 2013-14 and although there is an increase in Kent, there have been fluctuations between 2009-10 and 2012-13.



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Table 8:

		2011/12			2012/13	2013/14			
	HC	QOF	%	HC	QOF	%	HC	QOF	%
Kent	1730	4999	33.2	1587	5351	29.7	2314	5569	41.6
England	86023	188819	43.3	92329	206132	44.8	94647	214352	44.2

Health action plans are prepared for all adults with learning disabilities who access the Community Learning Disabilities Team. The plans are held by the team and can help identify and support individual health needs and monitor progress against them. There are opportunities for a routine and measured approach to health promotion that can reduce the risks of poor health (such as healthy eating, diet, exercise) and to ensure that GPs contribute to the plans by encouraging health checks and recording and monitoring treatment and health outcomes. This could be explored further to assist with increasing numbers of eligible health checks and improving general health and wellbeing.

Screening programmes for learning disability

A number of national screening programmes are also being promoted specifically to people with learning disabilities, although nationally take up is low. Local data is currently unavailable to ascertain uptake in Kent. Easy Read guides on breast screening, for example, clearly explains the national screening service available which all women aged 40-70 should be able to access. However, it is important that the guides are made readily available at the time of invitation and that staff that



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provide screening services are aware and supportive of the needs of women with learning disabilities. This may command further awareness training for staff.

Other easy guide screening leaflets are available on the national Reasonable Adjustments database and all health topics should be available as an example of good practice.

- Easy guide to breast screening
- Easy guide to cervical screening
- Easy guide to bowel cancer screening
- Easy guide to colonoscopy.

http://www.improvinghealthandlives.org.uk/adjustments/

The Easy Read guide: Good Health Care for All: What can I expect from the NHS?⁴ offers a better understanding of NHS processes and terminology for people with learning disabilities. This resource has the potential to be shared more widely at the point of accessing healthcare. The Community Learning Disabilities Team provide access to the easy guides for people with learning disabilities when required and where necessary to improve the experience and can also accompany people on hospital visits to ensure reasonable adjustment advice is provided.

Support services

Social care service needs are met by Kent Adult Social Care through a support plan which the client/user can complete to identify their specific support needs. Social Care services are accessed through the Fair Access to Care (FACs) criteria which accepts adults with learning disabilities on the assessed care needs rather than IQ assessment rating. Information on eligibility and accessibility is available from Kent County Council.

https://shareweb.kent.gov.uk/Documents/adult-Social-Services/leaflets-andbrochures/sds-factsheet-support-planning.pdf

Support for carers

Kent commissions three major voluntary support services (Carers First, Carers Support and Voluntary Action Maidstone) to support carers. These services offer general information and advice on benefits, befriending, advocacy, and support with physical and emotional wellbeing as well as supporting participation in work, leisure, training and education.

Other resources for carers include a Carers Assessment, Kent Carers Emergency Card, Caring with Confidence training programmes and respite services and are signposted from the Kent County Council website. <u>http://www.kent.gov.uk/social-care-and-health/care-and-support/how-to-get-help</u>

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⁴ Foundation for People with Learning Disabilities, Good Health Care for All: What can I expect from the NHS?

Projected service use and outcomes

Source: PANSI, prepared by KPHO (ZC), November 2015

Ja

There is expected to be a steady but consistent increase in the number of people with learning disabilities across all districts and CCG areas between 2012 and 2020. It has been projected that there could be approximately 5,216 persons with a moderate or severe learning disability within the Kent districts in 2030. Of these, 1,380 people will have a severe learning disability and 419 are predicted to display challenging behaviours. These are shown below within their specific criteria.



Figures 7, 8 and 9: Predicted numbers of adults with moderate or severe learning disabilities in Kent



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Districts

Within the Kent districts, the number of people predicted to have a moderate or severe learning disability by 2013 shows Maidstone (585) and Canterbury (542) with the highest predicted numbers in comparison to other districts.



Figure 10:

The graph below shows predicted numbers for only severe learning disability by districts between the years 2014 to 2030 based on ages 18–64 only. Although currently in 2015, Maidstone is slightly lower than Canterbury, the prediction for 2030 indicates that people ages 18–64 with severe learning disability in Maidstone will be slightly higher than Canterbury. Interestingly, Dover is the only district predicted to be lower in 2030.

Figure 11:





Age Groups

Figure 12 shows the number of people predicted to have a moderate or severe learning disability in Kent by age group 2014–2030. There is an increase across the age groups, however, the age band 35–44 shows where a greater increase is expected by 2030 in comparison to the others. The age band 25–34 indicates that the numbers will remain the same by 2030 despite the fluctuations between 2014 and 2030. Ages 45–54 would have decreased by 2030 also.



Figure 12:

Children with learning disabilities

There is evidence that the number of children with profound multiple learning disabilities is continuing to increase because more premature babies are surviving, medical science is prolonging lives that would have been lost in infancy and people with profound multiple learning disabilities are living longer.

In 2013-14, there were 2,541 children identified to have moderate learning disabilities across Kent. The proportion of children with moderate learning disabilities in relation to all pupils has decreased between 2009-10 and 2013-14 in Kent. This trend can be observed consistently across the South East and England in the diagram below:



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Figure 13: Children with mild learning disabilities known to schools. Pupils with mild learning difficulties at school action plus or stamen level as primary special educational need, in spring term census, as a proportion of all pupils



Table 9:

	2009/10			2010/11			2011/12			2012/13			2013/14		
	MLD	All pupils	%												
Kent	3586	230571	1.6	3371	232963	1.4	2904	233895	1.2	2374	235320	1.0	2541	238613	1.1
South East	24390	1300700	1.9	23180	1313560	1.8	21505	1322470	1.6	19275	1336155	1.4	18595	1350345	1.4
England	168580	8064300	2.1	160750	8123865	2.0	149520	8178200	1.8	138350	8249810	1.7	129830	8331385	1.6

The figure below shows that in 2013-14, there were 789 children identified to have severe learning disabilities in Kent which equates to 0.33%. The proportion of children with severe learning disabilities in relation to all pupils shows a decrease between 2009-10 and 2013-14. However, across England this shows an increasing trend.



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Figure 14:



Table10:

	2009/10			2010/11			2011/12			2012/13			2013/14		
	SLD	All pupils	%												
Kent	865	230571	0.38	831	232963	0.36	820	233895	0.35	770	235320	0.33	789	238613	0.33
South East	4350	1300700	0.33	4435	1313560	0.34	4345	1322470	0.33	4380	1336155	0.33	4515	1350345	0.33
England	28770	8064300	0.36	29270	8123865	0.36	29935	8178200	0.37	30440	8249810	0.37	31040	8331385	0.37

In 2013-14, there were 283 children identified to have profound and multiple learning disabilities across Kent. The proportion of children with profound and multiple learning disabilities in relation to all pupils shows a slightly increasing trend between 2009-10 and 2013-14 in Kent. This trend can be observed consistently across the South East and England.







	2009/10			2010/11			2011/12			2012/13			2013/14		
	PLD	All pupils	%												
Kent	260	230571	0.11	271	232963	0.12	288	233895	0.12	285	235320	0.12	283	238613	0.12
South East	1360	1300700	0.10	1410	1313560	0.11	1390	1322470	0.11	1400	1336155	0.10	1405	1350345	0.10
England	9480	8064300	0.12	9895	8123865	0.12	10255	8178200	0.13	10525	8249810	0.13	10590	8331385	0.13

Evidence of What Works

Adults with learning disabilities must be recognised as individuals and treated as having the same citizenship rights as the rest of the population.

This means that:

- people with learning disabilities have the same right of access to NHS and other services as the rest of the population
- although learning disabilities may lead to the need for additional and/or specialist support and services, generic services should be fully accessible
- people with learning disabilities should be entitled to help if required, to access services
- individuals should be seen as having health *and* social care needs, not health *or* social care needs.

'Parenting with support' is an emerging model of supporting adults with learning disabilities to parent while ensuring the needs of the baby and later the child are consistently and adequately met. This emerging practice is currently being championed by some professionals who are in direct contact with parents with learning disabilities. Local champions are working to raise awareness of the support needs of such parents in order to demonstrate that when services work together, adults with learning disabilities can be 'good parents'.

This model of long-term pro-active, flexible protective support for families headed by a parent or parents with learning disabilities is strongly supported by legislation promoting the child's right to grow up in their natural family and by recent good practice guidance for working with parents with learning disabilities (DfES/DH 2007).

Recommendations for Commissioning

Parents with learning disabilities

- 1. Ensure that parenting support for parents with learning disabilities is promoted and delivered effectively at Children's Centres.
- 2. Offer training to Children's Centres to recognize the needs of and raise awareness of parents with learning disabilities.
- 3. Deliver Public Health messages in Easy Read format on all campaigns aimed at people with learning disabilities (eg campaigns on the use of alcohol and smoking in pregnancy to reduce risk of premature births and low birth weight, bowl screening and breast screening campaigns).





Enabling young people and adults to have control over their lives

- 4. Explore and monitor outcomes and performance of transitional services for people with learning disabilities through the Becoming an Adult Partnership group.
- 5. Undertake full analysis of carers' support in next iteration of needs assessment.
- 6. An analysis of the direct payment and monitoring outcomes in the next needs assessment.

Create fair employment

- 7. Explore the development of pathways working collaboratively with KCC partners, CCGs and relevant stakeholders to support and encourage local solutions to remove barriers and increase employment of people with learning disabilities.
- 8. Consider building on the work of the NHS' Five Year Forward View as a progressive employer for people with learning disabilities.

Ensure a healthy standard of living

- 9. Review the following service specifications to offer awareness training and make recommendations for reasonable adjustments to ensure that quality services can be delivered to people with Learning Disabilities (this will also include the promotion and monitoring outcomes of services):
 - a. Stop smoking services
 - b. Drug and alcohol services
 - c. Sexual health services
 - d. Weight management, healthy eating and leisure/exercise services
 - e. Dental care
 - f. Mental health services
 - g. Deliver a Gold Standard Charter of delivering health promotion to people with learning disabilities to ensure that health promotion messages are accessible, easily understood, supported, and monitored and outcome measured. This will include the offer of training on the subjects above and will also be targeted to carers who can support health promotion messages.
 - h. More out of hours crisis support is needed to manage challenging behaviors
 - i. Address recommendations for people with learning disabilities from the Sensory Needs Assessment and relevant papers.

Impact of ill health prevention

- 10. Explore national best-practice initiatives to support improved access to health care, specifically working with Community of Practice and other relevant stakeholders.
- 11. Commissioners to develop an action plan for increasing numbers of people with learning disabilities receiving a health check.
- 12. Maximise opportunities to use health action plans as part of health care planning and delivery.
- 13. Explore the development and implementation of health care pathways to reduce emergency hospital admissions.
- 14. Promote healthy eating and exercise programmes to support effective weight management.



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Key Contacts

Malti Varshney – Consultant in Public Health, KCC <u>Malti.Varshney@kent.gov.uk</u> Karen Shaw – Public Health Programme Manager, KCC <u>Karen.Shaw@kent.gov.uk</u>

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