

KENT COUNTY COUNCIL

# Learning Disability Needs Assessment

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For Adults with Learning Disabilities in Kent

**Public Health Department, Kent County Council**

Deborah Smith, Public Health Specialist

Malti Varshney, Consultant in Public Health

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## Learning Disability Needs Assessment

### Introduction

The purpose of this Needs Assessment is to understand and determine the local needs of people with learning disabilities in Kent. The last Learning Disability Needs Assessment for Kent in 2010 identified a greater need for local data to help map and target resources against existing and future need. It also recognises that the views and experiences of people with learning disabilities should be reflected and the subsequent recommendations and guidelines from the Confidential Inquiry Report and 'Six Lives' make a refresh of the needs assessment welcome and timely. Progress and developments from the previous assessment in 2010 will be explored along with any newly identified needs, with particular emphasis on the priorities key stakeholders will need to consider.

### Scope

This Needs Assessment focuses on adults (aged 18+) with learning disabilities in Kent. The needs of children are briefly acknowledged under the first chapter, 'Giving every child the best start in life', but the breadth and complexity of their needs and services are very different to the needs of adults and would therefore demand an additional and potentially quite separate needs assessment

Where possible, all adults with learning disabilities are included in this assessment. As early chapters indicate, however, there are many people, particularly with mild learning disabilities who are not known to GPs or local authorities and obtaining their views, experiences and needs are much more difficult to quantify. Therefore, there is an incidental bias towards addressing the needs of those known to statutory services in Kent.

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.

### Methodology

Kent's Health Inequalities Action Plan (called "Mind the Gap") addresses inequalities for people in Kent, including those with learning disabilities. This needs assessment will adhere to the NICE guidance framework for undertaking Health Needs Assessments, whilst adopting Mind the Gap's 'life-course' approach that is closely aligned to the Valuing People priorities and Kent Learning Disabilities Partnership themes. These form six key chapters:

1. Give every child the best start in life
2. Maximise control
3. Meaningful employment
4. Healthy standard of living for all

5. Healthy communities and sustainable places
6. Prevent ill health

The information that feeds into the assessment will be based on the 2010 Needs Assessment and updated using reports published by Improving Health and Lives: Learning Disability observatory. Literature searches have also be undertaken to ascertain most recent findings and contributions from stakeholders (acknowledged at the front of this document) have also been included. Most importantly, the views and experiences of people with learning disabilities have helped inform this needs assessment which gives value and impetus to this work. A summary of recommendations are presented at the end of each chapter and these form the overall action plan.

To ensure the relevant commissioners have a comprehensive understanding of needs and are able to target their resources effectively, this assessment will focus on three levels:

- i) A strategic overview for Kent – to ensure that the Kent County-wide needs are identified
- ii) Clinical Commissioning Group level – to ensure that the health and primary care needs are addressed
- iii) District area level – to ensure that the social, lifestyle and environmental needs are considered.

### **Definition of Learning Disabilities**

Generally, the severity of learning disabilities is measured by the level of intellectual impairment, known as IQ rate. The Department of Health defines a ‘learning disability’ as a ‘*significantly reduced ability to understand new or complex information, to learn new skills*’ and a ‘*reduced ability to cope independently which starts before adulthood with lasting effects on development*’ (Valuing People, 2001)<sup>1</sup>. The table below illustrates how learning disability is categorised in Kent and detail of the typical needs of those who access Social Care services.

| <b><u>IQ score</u></b> | <b><u>Category of learning disabilities</u></b> | <b><u>Kent Social Care’s Case-loads</u></b>  |
|------------------------|---|--|
| 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 |

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<sup>1</sup> Department of Health. Valuing People: A New Strategy for Learning Disability for the 21st Century. 2001

|             |                                |  |
|-------------|--------------------------------|--|
| 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 (appendix 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.

### **General Needs**

Depending on the severity, adults with a learning disability will have a reduced intellectual ability and difficulty with everyday activities such as household tasks, socialising or managing money.

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*).<sup>2</sup>

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

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<sup>2</sup> Mencap: <http://www.mencap.org.uk/all-about-learning-disability/about-learning-disability/profound-and-multiple-learning-disabilities-pmld>, accessed 02 February 2014

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)

### **Causes of Learning Disabilities**

A learning disability occurs when a person's brain development is affected, either before they are born, during their birth or in early childhood.

Several factors can affect brain development, including:

- the mother becoming ill in pregnancy
- problems during the birth that stop enough oxygen getting to the brain
- the unborn baby inheriting genes, or activation of certain inherited genes, or has dominant mutated genes
- the parents passing certain genes to the unborn baby that make having a learning disability more likely (known as inherited learning disability)
- illness, such as meningitis, or injury in early childhood

Other conditions are associated with also having a learning disability, such as cerebral palsy, Down's syndrome and sometimes people with autism and/or epilepsy will have a learning disability<sup>3</sup>.

Sometimes there is no known cause for a learning disability. However, the known causes are usually categorised under three main headings:

- i) **genetic** – the majority of cases in the UK. These fall under either chromosome aberrations (most commonly Down's syndrome) or X-linked disorders (such as fragile X syndrome). Other genetic disorders are caused by secondary neurological damage such as phenylketonuria.
- ii) **infective** – 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. However, immunisations against infections (such as Rubella) contribute to the low rates of infective causes of learning disability

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<sup>3</sup><http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Whatislearningdisability.aspx>

- iii) **environmental** – some environmental factors (such as nutritional deficiencies, alcohol, drugs, exposure to irradiation and lead) may increase of trauma, hypoxia and hypoglycaemia associated with learning disabilities. Foetal Alcohol Syndrome Disorder (FASD) studies in the USA identify a link with learning disabilities although this is not substantiated in the UK. Dietary folic (folic acid) deficiency can be associated with Neural Tube Defects (NTDs).

A more detailed explanation of the causes of learning disabilities are referenced in Kent’s Learning Disability Needs Assessment (2010)<sup>4</sup>

### **Population**

Practice register data submitted as part of the Quality Outcomes Framework (QOF) is the conventional method of collecting prevalence data, however, not all people with learning disabilities are known to the practice registers so the figures provided are considered to be under-estimated. According to the register, the rate of adults (ie. 18yrs+ population) with a learning disability has risen in Kent from 0.35% (2007/8) to 0.45% (2012/3), slightly below the England average (0.47%). This could be a result of better recording or improve case finding of people with learning disabilities. The numbers of adults with a learning disability known to the Kent Local Authority is 0.38%, a slight decrease in the last three years. Not all people with learning disabilities will be known to or access Local Authority services<sup>5</sup> but some may be known to other local NHS organisations.

Table 1 shows the recorded prevalence of LD within clinical commissioning groups. South Kent Coast and Thanet CCGs have a greater proportion of patients known to have a learning disability.

**Table 1: QoF Learning Disabilities register 18+ 2012-2013 – Clinical Commissioning groups.**

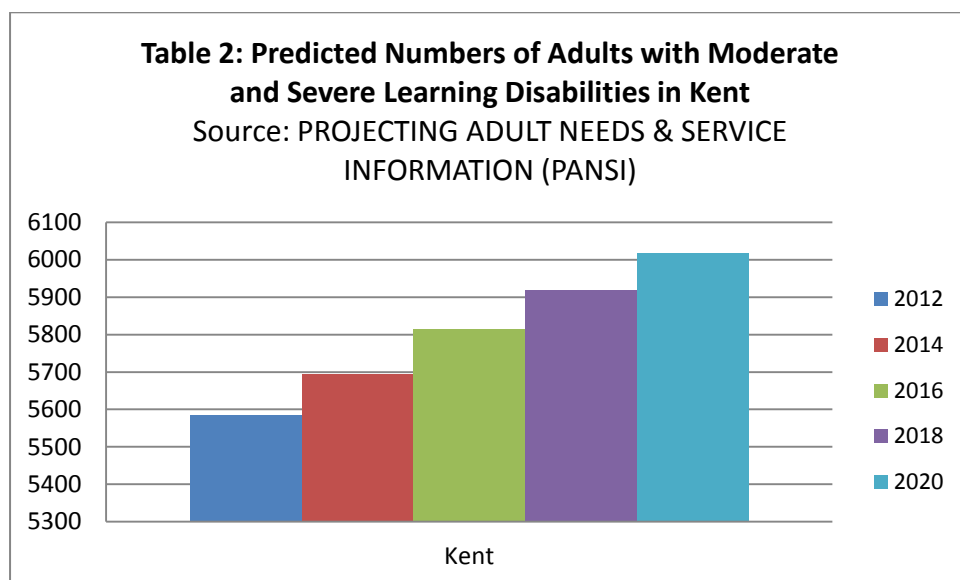
| CCG Name                                | CCG population 18+ | Learning Disabilities Register (ages 18+) | Learning Disabilities Prevalence (%) |
|---|--------------------|---|--------------------------------------|
| NHS Ashford CCG                         | 95,210             | 427                                       | 0.45                                 |
| NHS Canterbury and Coastal CCG          | 171,371            | 807                                       | 0.47                                 |
| NHS Dartford, Gravesham and Swanley CCG | 195,311            | 520                                       | 0.27                                 |
| NHS South Kent Coast CCG                | 161,233            | 1,167                                     | 0.72                                 |
| NHS Swale CCG                           | 83,531             | 399                                       | 0.48                                 |
| NHS Thanet CCG                          | 112,391            | 701                                       | 0.62                                 |
| NHS West Kent CCG                       | 367,299            | 1,330                                     | 0.36                                 |
| NHS Medway CCG                          | 219,642            | 918                                       | 0.42                                 |
| Kent                                    | 1,186,345          | 5,351                                     | 0.45                                 |
| Kent and Medway                         | 1,405,987          | 6,269                                     | 0.45                                 |
| England                                 | 44,238,483         | 206,132                                   | 0.47                                 |

Source: [www.ic.nhs.uk](http://www.ic.nhs.uk)

<sup>4</sup> Learning Disability Needs Assessment (2010), *Kent Public Health*

<sup>5</sup> Public Health England, IHAL Learning Disabilities Observatory, Kent Profile 2013

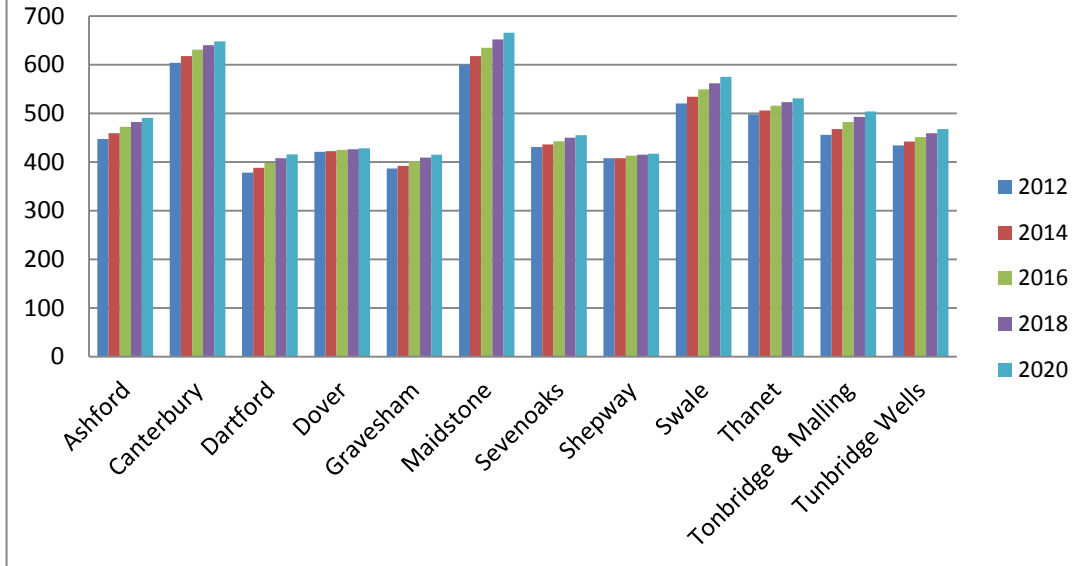
Kent (excluding Medway) currently has 5,351 adults with learning disabilities identified on the QoF register. The highest number is shown in West Kent CCG area, although this is the largest geographical area and has a relatively low prevalence (0.36% per population). South Kent Coast CCG has a high number identified on the register and the highest rate per population (0.72%) 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 (0.62% of the Thanet population). The QOF register is nationally considered to slightly underestimate the prevalence of learning disability and this is reflected in slight variations in other predictive data sources, such as **Projecting Adults Needs and Service Information (PROJECTING ADULT NEEDS & SERVICE INFORMATION (PANSI))**, however, current variations are between 5351 and 5585.



Predicted numbers of adults with a moderate or severe learning disability are expected to rise in Kent and at district level. Table 3 depicts a year on year increase to 2020 for each district, but this predictive data is not currently available at CCG level.

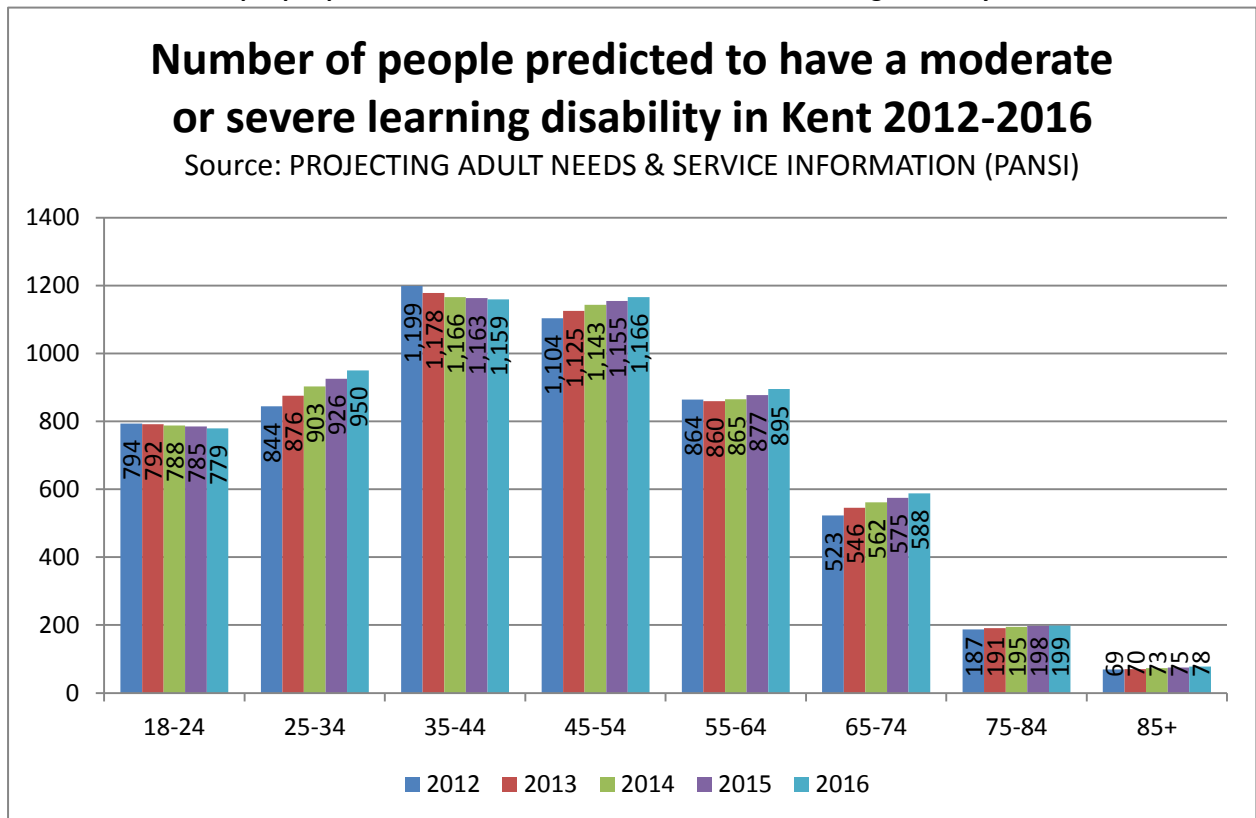
**Table 3: Number of People Predicted to have a Moderate or Severe Learning Disability in Kent 2012-2020**

Source: PROJECTING ADULT NEEDS & SERVICE INFORMATION (PANSI)



The following graph shows the projected population in Kent with a learning disability in 2012 and 2016 by age. This information can help project future health need and long term condition management.

**Table 4: Number of people predicted to have a moderate or severe learning disability in Kent 2012-2016**



The number of adults with moderate and severe learning disabilities (and therefore likely to be in receipt of services) is predicted to increase by 4.1 per cent from 2012 to 2016, resulting in an estimated 5,814 people in Kent with moderate to severe learning disabilities by 2016. (Source: Projecting Adult Needs & Service Information PANSI 2013). There is a notable and progressive increase of people with learning disabilities reaching a longer life expectancy over this duration (with an estimated 865 people over the age of 65 in 2016) although notably a slight decrease in prevalence of people in the 18-24 age category.

**Table 5: People predicted to have a moderate or severe learning disability and hence likely to be in receipt of services by age**

## Kent

### LD - Moderate or severe

People predicted to have a moderate or severe learning disability, and hence likely to be in receipt of services, by age

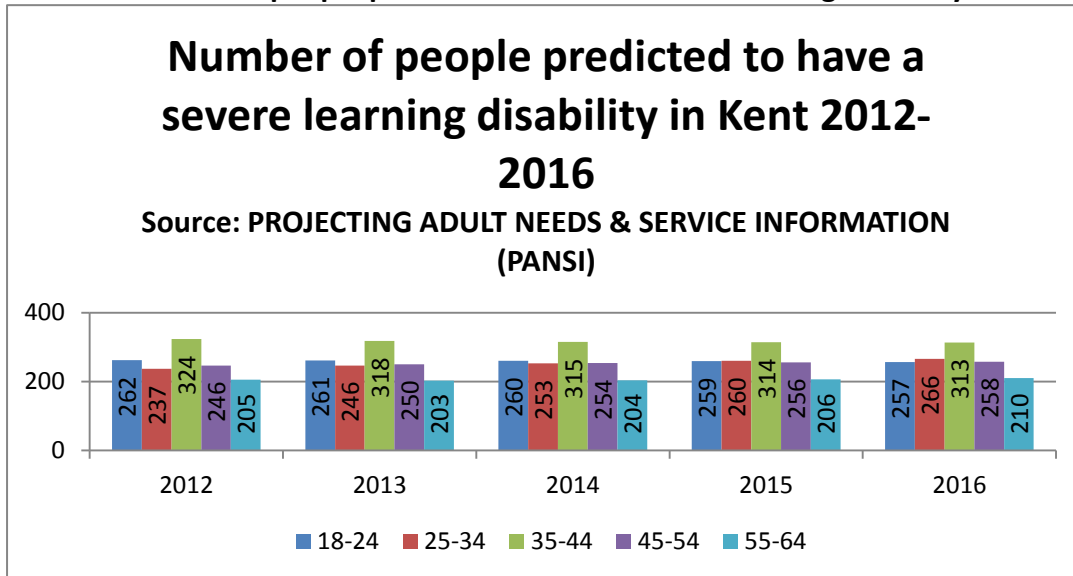
|   | 2012         | 2014         | 2016         | 2018         | 2020         |
|---|--------------|--------------|--------------|--------------|--------------|
| People aged 18-24 predicted to have a moderate or severe learning disability                        | 794          | 788          | 779          | 761          | 741          |
| People aged 25-34 predicted to have a moderate or severe learning disability                        | 844          | 903          | 950          | 995          | 1,031        |
| People aged 35-44 predicted to have a moderate or severe learning disability                        | 1,199        | 1,166        | 1,159        | 1,166        | 1,198        |
| People aged 45-54 predicted to have a moderate or severe learning disability                        | 1,104        | 1,143        | 1,166        | 1,161        | 1,131        |
| People aged 55-64 predicted to have a moderate or severe learning disability                        | 864          | 865          | 895          | 945          | 1,001        |
| People aged 65-74 predicted to have a moderate or severe learning disability                        | 523          | 562          | 588          | 597          | 599          |
| People aged 75-84 predicted to have a moderate or severe learning disability                        | 187          | 195          | 199          | 211          | 228          |
| People aged 85 and over predicted to have a moderate or severe learning disability                  | 69           | 73           | 78           | 83           | 88           |
| <b>Total population aged 18 and over predicted to have a moderate or severe learning disability</b> | <b>5,585</b> | <b>5,694</b> | <b>5,814</b> | <b>5,919</b> | <b>6,017</b> |

Figures may not sum due to rounding  
Crown copyright 2012

Source: Projecting Adult Needs & Service Information (PANSI), 2013

Of the predicted population increase for Kent, 1,304 people are likely to have severe learning disabilities in 2016 (an estimated additional 30 (2.4%) people than in 2012) and therefore is likely to make further demands on existing resources. Table 3 shows by age the expected small changes in numbers of people with severe learning disabilities across all age groups. It is expected that there will be more people in the 35-44 group than other age cohorts.

**Table 6: Number of people predicted to have a severe learning disability in Kent 2012-16**



Further consideration needs to be given to the changing demographics and effects of change in policies and legislative Acts that come into force. Recent estimates on the future need for social care among adults with learning disabilities in England show a 3.2% annual increase of those accessing services with critical & substantial and moderate needs up to the year 2030<sup>6</sup>. The predicted rate of 3.2% should however be treated cautiously as it reflects expected national growth in Special Educational Needs and ethnic communities with learning disabilities which may not be proportionate to Kent. Other societal factors such as ageing carers and their ability to continue to tend to the additional demands of people with learning disabilities who are living longer will further impact on the demand for future services.

On average, 3% of the population may have some learning disability. It is estimated that this could be 44,000 people in Kent (source:- Sensory Joint Needs Assessment, KCC 2013).

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<sup>6</sup> Emerson, E & Hatton, C Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update, IHAL, 2011

**Table 7: Estimated prevalence of people with a learning disability in Kent**

*Estimated prevalence of people with a learning disability in the population, who may require support from KCC*

|                     | Prevalence of LD in Population (3%) |               |               |               |               |
|---------------------|-------------------------------------|---------------|---------------|---------------|---------------|
|                     | 2011                                | 2016          | 2021          | 2026          | 2031          |
| Ashford             | 3,550                               | 4,010         | 4,490         | 4,970         | 5,100         |
| Canterbury          | 4,520                               | 4,740         | 4,880         | 5,040         | 5,210         |
| Dartford            | 2,930                               | 3,230         | 3,620         | 3,910         | 4,070         |
| Dover               | 3,350                               | 3,530         | 3,780         | 4,020         | 4,040         |
| Gravesham           | 3,050                               | 3,100         | 3,150         | 3,210         | 3,250         |
| Maidstone           | 4,670                               | 4,780         | 4,830         | 4,880         | 5,030         |
| Sevenoaks           | 3,460                               | 3,450         | 3,470         | 3,460         | 3,470         |
| Shepway             | 3,250                               | 3,290         | 3,360         | 3,420         | 3,480         |
| Swale               | 4,090                               | 4,200         | 4,330         | 4,440         | 4,550         |
| Thanet              | 4,030                               | 4,100         | 4,170         | 4,210         | 4,250         |
| Tonbridge & Malling | 3,630                               | 3,720         | 3,820         | 3,910         | 4,010         |
| Tunbridge Wells     | 3,460                               | 3,430         | 3,470         | 3,480         | 3,500         |
| <b>Kent</b>         | <b>44,000</b>                       | <b>45,590</b> | <b>47,500</b> | <b>49,000</b> | <b>50,000</b> |

### **Kent's Key Statistics:**

- On average, 3% of the population may have some learning disability. It is estimated that this could be 44,000 people in Kent (*source:- Sensory Joint Needs Assessment, KCC 2013*)
- There are 5,351 adults with learning disabilities on GP Registers in Kent
- The number of adults with moderate and severe learning disabilities is expected to rise by 4.2% (from 5,638 to 5,814) from 2013-2016, of which 1,304 people are likely to have a severe learning disability in 2016.
- In line with the above, discounting inflation, rising costs and potential changes to policy and criteria, this is likely to have a 4.2% increase on service expenditure and resources between 2013 and 2016 (2.4% projected increase in people with a severe learning disability will also need to be factored in).
- There are around 4,222 adults with learning disabilities on caseloads within Kent Local Authority
- The average life expectancy of adults with learning disabilities in Kent is 55 years. This is 26 years less than the Kent population average (*Source: KMPHO Health and social care mapping, Key Killers – Kent*)

## Objective 1. Give every child the best start in life

*Addressing the broad needs of parents with learning disabilities and their children and exploring prevalence in children to plan for the future*

*The primary focus of this needs assessment is on Adults with Learning Disabilities. However, the prevalence and needs of disabilities in early years should be acknowledged and recognized. The Joint Strategic Needs Assessment for Children in Kent, 2010, reflects the specific needs and services in more detail than the scope of this needs assessment allows. This chapter provides a condensed overview of the current position for children with learning disabilities in Kent to plan resources to cope with predicted future demand. This section also identifies the broad needs of parents with learning disabilities. There is potential for partnership working to explore the needs of children with a learning disability in much further depth.*

### Parents with Learning Disabilities

It is estimated that 7% of adults with a learning disability in the UK are parents, most of which have a mild or borderline learning disability<sup>7</sup>. 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 the general population and in particular, parents with learning disabilities into mainstream children centre 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 centres may need to ensure that their services are equitable and accessible for parents with learning disabilities. Basic awareness training to recognize those that may have additional and specific needs can be offered.

### Children with Learning Disabilities

Most of the causes of learning disabilities in the UK are genetic, but still 30% of causes for severe learning disabilities are unknown.<sup>8</sup> The Royal College of Nursing attributes the rise in incidence of children and adults with learning disabilities to improved pre-term neonatal

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<sup>7</sup> Best Beginnings <http://www.bestbeginnings.org.uk/parents-with-learning-disabilities> (accessed January 2014)

<sup>8</sup> Stevens, A (ed) et al, *Health Care Needs Assessment*, V2, Oxon, Radcliffe, 2004, p.453

survival, growing substance misuse rates and more advanced diagnosis of conditions such as Attention Deficit Hyperactive Disorder (ADHD), Autism Spectrum Condition (ASC) and Foetal Alcohol Spectrum Disorder (FASD)<sup>9</sup>. Studies in the US strongly suggest that maternal alcohol consumption is one of the main causes of learning disabilities although some European data does not uphold this claim. However, the dangers of alcohol consumption in pregnancy cannot be ignored and should be considered as part of public health campaign messages.

Sometimes, low birth weight can increase the risks of children having learning disabilities, especially for premature babies born earlier than 26 weeks where there is an increased risk for atypical motor, cognitive and behavioural development. It is reported that one in six babies are born with extremely low birth weight, but due to advanced medicine, survival rates have increased. This, and overall improved early detection and intervention, may account for the increase in children diagnosed with learning disabilities, especially those with severe disabilities or profound and multiple learning disabilities (PMLD). Studies conducted in 2006 showed that children diagnosed with PMLD had increased by 75% in the previous five years, compounding the need for health care, social services and carer support planning for the future.<sup>10</sup>

### **Needs of Children with Learning Disabilities**

The 'Kent Parent Partnership' supports parents who have children with disabilities and special educational needs; providing information, advice, advocacy and support through an online telephone service and drop-in centre. The Partnership also offers training and mediation and support for schools. School Nurses provide an essential role to ensure that the health and social needs of children with learning disabilities are integrated and effective. When schools nursing services are re-commissioned in 2014, the new service specification should reflect the expressed needs of children with learning disabilities and their parents.

The Local Authority can provide additional support and advice for children with learning disabilities appropriate to their needs through a Statutory Assessment as part of the Special Educational Needs (SEN) Code of Practice, but the clear distinction between learning difficulties and learning disabilities needs to be acknowledged. Kent applies the following definition<sup>11</sup>:

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<sup>9</sup> Royal College of Nursing, 2011: Learning from the past-setting out the future, RCN, London

<sup>10</sup> Dawkins, 2009, in JSNA, 2010, P.23

<sup>11</sup> KCC ASC Factsheet

- **Learning Disability** – is a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual's situation include complex needs or high support needs
- **Learning Difficulty** is often used in educational settings and refers to individuals who have specific problems with learning as a result of either medical, emotional or language problems e.g. dyslexia. Children and Young people requiring special education needs (SEN) are often described as having a learning difficulty

### Prevalence of Children with Learning Disabilities

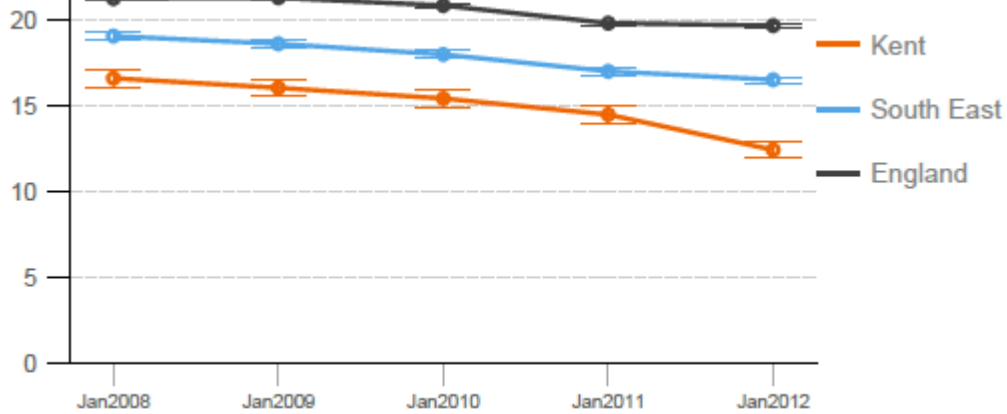
There has been a steady decrease in numbers of children with moderate learning disabilities being known to schools in Kent between 2008-2012. The current rate of 12.42 per 1,000 is much lower than the national average (19.65 per 1,000). The trend in Kent for children with severe learning (3.51 per 1,000 children), is close to the national average. If this trend continues, this would suggest that there would be a reduced demand on services and resources needed to support children and adults with moderate and severe learning disabilities.

However, despite the general trend for children with learning disabilities known to schools declining, the numbers of children with profound and multiple learning disabilities (albeit small; 1.23 per 1,000) are increasing. Between 2008 and 2012 there has been a 28.5% increase of known children with PMLD with an estimated prevalence of 288 children rising to 317 of known children by 2016 if this trend remains consistent. This will have a significant impact on the demand for future resources.

### Health Inequalities

90% of children with moderate learning disabilities attend mainstream schools. Children with special educational needs associated with learning disabilities have poorer educational attainment than their peers and are more likely to be excluded from school. Prevalence is more common in boys and children from poorer families and among Traveller and Romany children. Pakistani, Bangladeshi, Black African and Caribbean children are also more likely to have severe and profound multiple learning disabilities. Deprivation and poor housing is especially prevalent in families where children have moderate and severe learning disabilities.

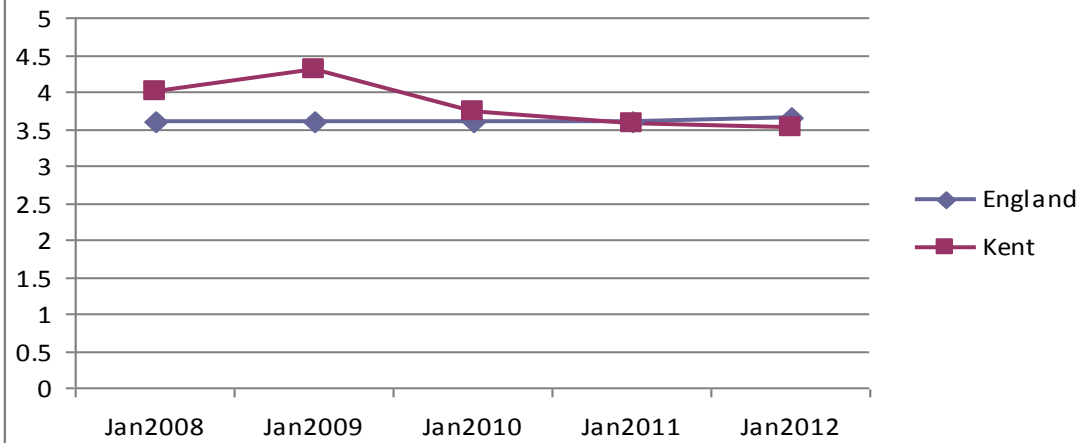
**Table 8: Children with moderate learning disability known to schools  
Per 1000 children, 2008-2012**



Source: Ihal, Kent Profiles 2013

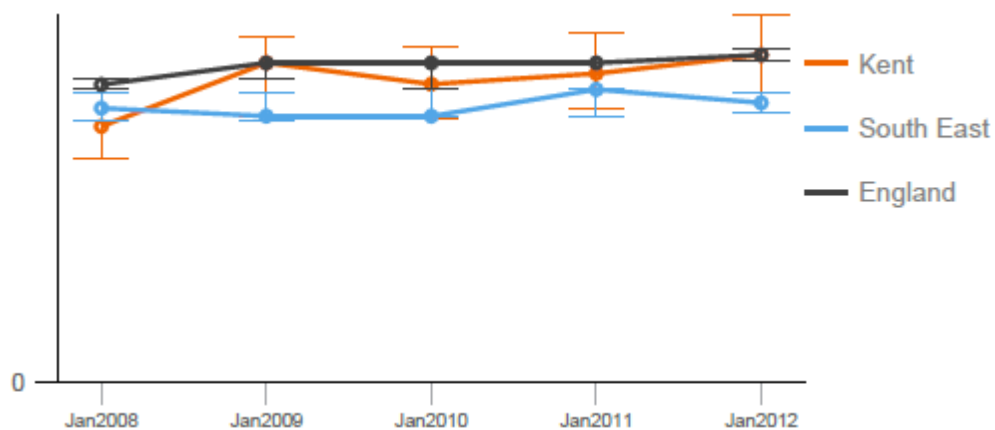
**Table 9:**

**Children with severe learning disability known to schools  
per 1000 children, 2008-20112**



Source: Ihal, Kent Profiles 2013

**Table 10: Children with profound multiple learning disability known to schools  
Per 1000 children, 2008-2012 (source: Ihal, Kent Profiles, 2013)**



Children with special educational needs are recorded through the School Census. Kent is also piloting the Total Child programme which is included in Mind the Gap (Kent's Health Inequalities Action Plan) and seeks to record comprehensive information about children and their progress, behaviour and emotional wellbeing. The information is monitored by teachers, the children's families and other multi-disciplinary professionals. Considering most children with moderate learning disabilities attend mainstream schools, this programme has the potential to support them and identify individual needs through school life<sup>12</sup>.

### **Recommendations:**

Ensure that parenting support for parents with learning disabilities is promoted and delivered effectively at Childrens Centres

Offer training to Children Centres to recognize the needs of and raise awareness of parents with learning disabilities

Children Centres to identify and promote support offered to children with learning disabilities

Ensure that the needs of children with learning disabilities are reflected in School Nursing service specification in new commissioning arrangements.

Deliver Public Health campaigns on use of alcohol and smoking in pregnancy to reduce risk of premature births and low birth weight

Promote the implementation of systematic and holistic assessments of individual children and the whole school population to identify children who would benefit from early help and to target resources according to a robust understanding of need.

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<sup>12</sup> Emerson et al, Health Inequalities and People with Learning Disabilities in the UK 2011, IHAL.

## 2. Enable all children, young people & adults to maximize their capabilities and have control over their lives

*This section is all about increasing personal independence and empowering people to have control over their own lives*

‘Valuing People Now in Kent’ is Kent’s Partnership strategy for Learning Disability in Kent for 2012-15. The four main national principles are all designed to improve the control people with learning disabilities have over their lives. These are:

- **Rights**
- **Independent living**
- **Control**
- **Inclusion**

Kent’s strategy for delivering “Valuing People Now” will be delivered through 10 different commitments (or actions); all of which are included in this assessment.

### Valuing People Now Actions

1. Personalisation
2. Support for Carers
3. Safeguarding
4. Health
5. Transition
6. Accommodation solutions
7. Employment
8. Including Everyone
9. Partnerships
10. Measuring outcomes

The performance outcomes and feedback from users and carers are identified through the Kent Learning Disability Partnership Board and local delivery groups that feed into this Board also indicate how well services do to support independent living, health and empower people with learning disabilities to maximise the control they have on their lives.

### Advocacy

Strong advocacy can help empower people to make decisions and take control over their lives. Although some advocacy services have been commissioned, there is still a need for local based self-advocacy groups to provide peer support on a wide range of issues. Effective advocacy groups could provide the additional learning skills and confidence needed to participate in the community which could also lead to voluntary work. Improved skills and confidence in this area could reduce the need for support workers accompanying people with learning disabilities in some cases.

### Support for Carers

There are approximately 128,000 unpaid carers in Kent who care and support family members or friends<sup>13</sup>. Supporting Carers to look after their own health and wellbeing is important although some people do not recognize themselves as carers, especially if they look after parents, children or other family members. Three major Voluntary support services (Carers First, Carers Support and Voluntary Action Maidstone) across Kent are commissioned to support carers, offering general information and advice as well as benefits advice, befriending, advocacy, support with physical and emotional wellbeing as well as support participation in work, leisure training and education.

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<sup>13</sup> Carers in Kent. A Review by a Select Committee appointed by the Adult Social Care Policy and Overview Committee, Kent County Council, 2007

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.

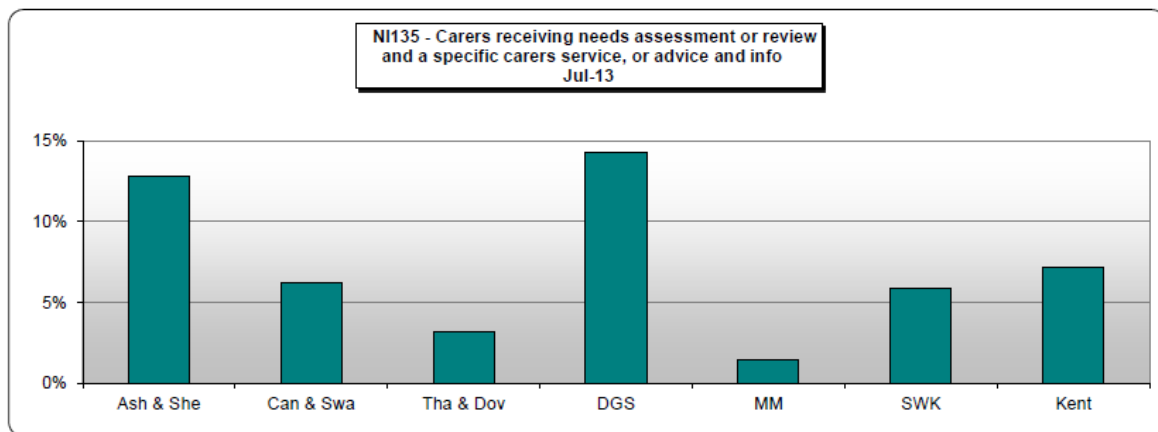
[http://www.kent.gov.uk/adult\\_social\\_services/your\\_social\\_services/services\\_and\\_support/carers.aspx](http://www.kent.gov.uk/adult_social_services/your_social_services/services_and_support/carers.aspx) .

The Kent Carers Emergency Card provides reassurance to carers by detailing emergency plans and response should they not be available when the person they are caring for needs them urgently. Carers assessments are essential to support the health and emotional wellbeing of carers which can reduce the likelihood of people with learning



disability entering residential care. Although there is no national target set, just over 7% of Carers in Kent received an assessment from social care services in July 2013. A higher percentage of assessments are routinely undertaken in Dartford Gravesham and Swanley area (14.3%) and also in Ashford/Shepway area and relatively few in Thanet & Dover and Maidstone & Malling areas (1.5%). This variation of assessments could be explored further to ensure more carers have the opportunity to benefit from assessments and support, particularly because prevalence of learning disability in these areas is comparatively higher (Table 1).

**Table 11: Carers receiving needs assessment or review in Kent**



Source: Kent County Council LD Performance Report, August 2013

Kent's Short Break scheme also facilitates and supports respite care in a choice of 5 Kent-based venues; 4 situated in East Kent and 1 in West Kent. There are another two places (The Birches and Rusthall) available in West Kent but these have a limited number of beds and hours of support available. The Direct Payment scheme enables people with a learning

disability to organize other private or voluntary sector short break services that may better meet their needs, although the demands for respite care and short breaks are considered to exceed supply<sup>11</sup>. Kent Local Authority are currently undertaking a consultation exercise to scope and better understand the local needs.

### **Short Breaks**

Short breaks provide an opportunity for carers to have a break from caring and gives the person with a learning disability the opportunity to try new things and become more independent. They can include daytime, evening and overnight breaks and can take place in the home, a residential or community based setting or a holiday.

Short breaks are viewed as valuable and essential to people with a learning disability and their carers. They have told us that a wider choice of short break options would be good for the future.

We recognise and value carers as being fundamental for strong families and able communities. We want the support to be right for individuals' needs. This will help carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to have a full life.

*Kent County Council*

## **Young Adults**

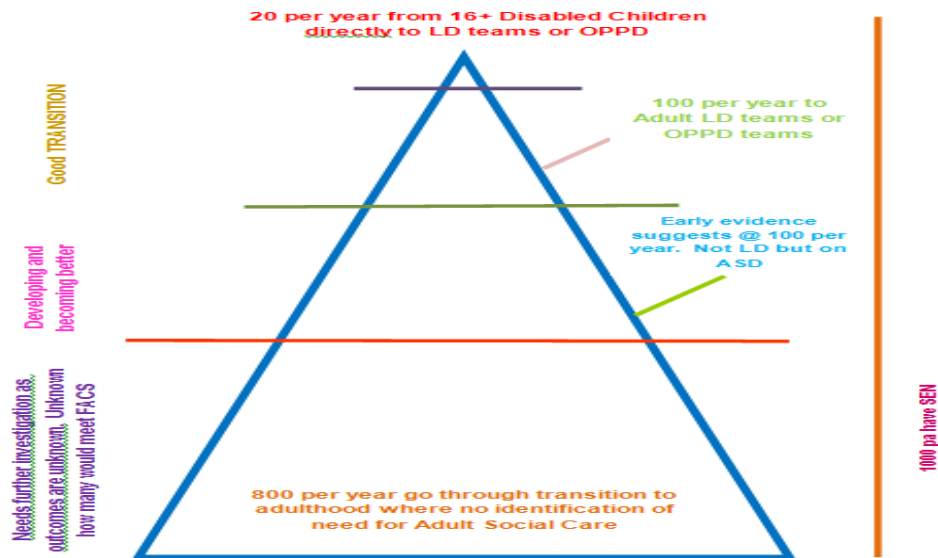
### **Transition**

The Kent Learning Disability Partnership Board govern a specific partnership group dedicated to becoming an adult. The 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 6 areas across Kent. However, District Partnership Groups have reported difficulties in engaging with schools to navigate the educational aspect of the transition system. Social Care Services work closely with Education, Learning & Skills (ELS) teams and with people with learning disabilities between the ages of 14 and 19. Despite this, the general view of some service users is that services need to be joined up more effectively. The Transition pathway includes a set of progressive health protocols agreed by Kent's social care services and NHS commissioners accessed through a single common referral process (Appendix). The Transition Triangle below is used to plan

resources and services for present and future need, but clearly more integrated work is needed to ensure a smooth transition for young people, especially across education services. The 'Becoming an Adult' partnership have participated in a workshop to identify how young people with learning disabilities feel about transition services. Initial responses indicate that some services are inclusive and others are not. Carers views are being sought as part of the second phase of this partnership work. The views from both phases should inform future transition services.



It is anticipated that the new SEN legislation due for release in 2014 will address transitional issues, particularly around ensuring that services are streamlined into a single assessment framework and multi-agency support is increased to young people up to the age of 24. The Public Health team aim to work with the Becoming an Adult Partnership group and the County Council's Learning Disabilities Transition teams to ascertain what people in Kent feel works well and where services could be improved and be more accessible.

### 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.

Person Centred Plans (or Support Plans) are an inclusive way for people with learning disabilities to access a range of service and activities that meet their own personal needs. 94.2% of service users with learning disabilities in Kent have support plans<sup>14</sup> which offer a range of opportunities from day care services to accessing personal assistants.

Service Users also have greater purchasing power of their support plans, paying for packages through Direct Payment schemes or more flexible schemes with agreed outcomes via Self-directed support. Currently, 1094<sup>15</sup> people are in receipt of Direct Payments to purchase their own day care and personal care packages. Kent is also performing above 80% of clients on Self Directed support (NI130) progressing to a target of 100%<sup>12</sup> for a wider range of leisure activities. Many of these can be purchased through the Kent card. Difficulty in accessing information on direct payments could be a barrier to take-up. The South West Kent toolkit for Direct Payments could be promoted more widely across Kent and District Partnership groups are involved in further communication and media work.

### 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). There are 702 individual day care places and the diverse nature of these activities means that clients/users have a greater say on how they spend their day. Although specific outcomes are recorded on individual care plans, there is not currently a system to collectively record and report on the way direct payments are being spent and the value for money they may provide. This is consequential of policies that encourage mainstreaming and integrating into universal services. Due consideration would need to be given to the time and resources required to set up data systems that can usefully record the way in which direct payments are being utilized and their outcomes.

The traditional Day Care services are currently being redesigned under the Good Day Programme with the aim to mainstream popular and familiar activities and introduce people to new community activities such as gardening, music and movement and open mic events. The new Good Day Programmes are available across Kent, promoted on the County Council website and have had positive feedback. The transition of new day care activities are still in development and will be evaluated in due course. Further details of the local opportunities offered are available on the Kent County Council website.

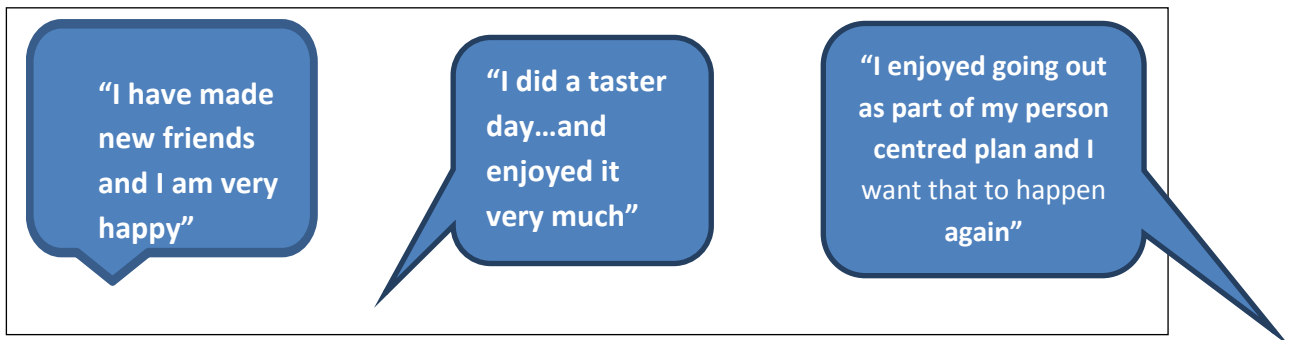
[http://kent.gov.uk/adult\\_social\\_services/your\\_social\\_services/services\\_and\\_support/learning\\_disability/good\\_day\\_programme/whats\\_happening\\_in\\_your\\_area.aspx](http://kent.gov.uk/adult_social_services/your_social_services/services_and_support/learning_disability/good_day_programme/whats_happening_in_your_area.aspx)

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<sup>14</sup> KCC Activity report August 2013

<sup>15</sup> KCC Performance Report August 2013

## Feedback from users of the Good Day Programme:



## Domiciliary Care

There are only a small number of people with learning disabilities in receipt of Local Authority domiciliary care which is superseded by Supported Independence service where appropriate. Further information on this can be explored, especially to identify future need and demand for future resources.

The Enablement pilot programme favours assisting and supporting adults with learning disabilities to help them undertake daily living skills for themselves, where possible. This actively promotes independence and provides the skills to enable and empower people to manage their own lives. The pilot is delivered by two skilled workers per team (one in Dartford, Gravesham & Swanley and the other in Thanet) and, if successful, will be expanded across other areas in Kent. There are currently 587 adults with a learning disability being supported through the Enablement pilot. Further evaluation will be available as the programme is rolled out across Kent.

## **Recommendations:**

- **Consider monitoring systems to record value for money and outcomes of direct payment activities**
- **Increase numbers of carers in receipt of a carers assessment**
- **Explore and monitor outcomes and performance of transitional services for people with learning disabilities through the Becoming an Adult Partnership group.**

### **3. Create fair employment & good work for all**

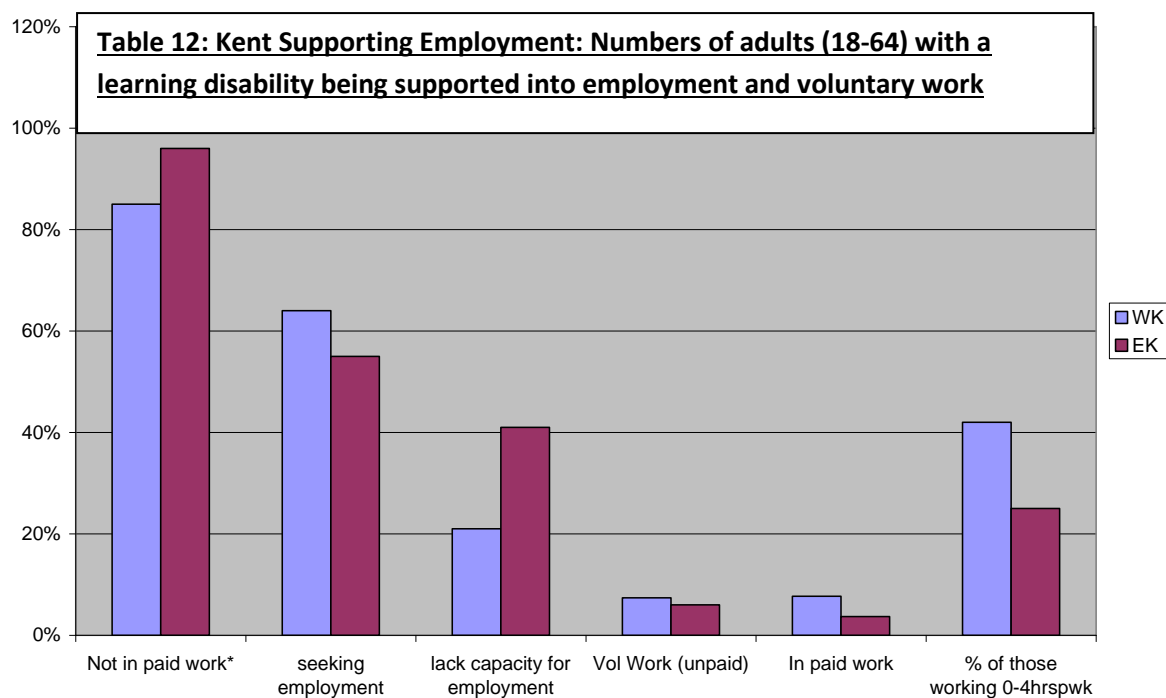
Ensuring people with learning disabilities have opportunities to work and meaningful employment.

#### Employment

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 latest data 2011/12 shows a 1.1% decrease in Kent in the last year of the number of people with Learning Disabilities in paid work.

Regionally, the South East (9.2%) is performing much better than the England average (6%), but Kent's performance of 5.1% is slightly worse than the England average and considerably worse than the rest of the region<sup>4</sup>. Part of the reason for this is considered to be due to the high numbers of people supported in unpaid voluntary work and paid employment of less than 4 hours per week in Kent. Despite less than 4 hours suiting some people, these figures are not counted or acknowledged within national performance monitoring and are therefore, discarded. In Kent, for instance, 35% of adults with learning disabilities in paid employment work less than 4 hours per week and 6.6% of those engaged with Kent Supporting Employment are in unpaid voluntary work. Approximately one third are assessed as lacking capacity for employment in Kent and who, after rigorous assessment, are deemed to be unlikely to find employment or voluntary work. Therefore, there is more collaborative work needed to increase the number of people with learning disabilities in paid employment. Many of the outcomes not included in national data collection may be in accordance with the needs and best interests of the individuals themselves. In addition, in Kent, people with Learning Disabilities who enter permanent employment and no longer require social care services have their case files closed. This practice is not consistent with many other Local Authorities and misrepresents Kent's performance on the national indicator set in comparison with national trends. Further information is available to highlight Kent's employment activity for people with Learning Disabilities with caseloads remaining open.

One of the successful employment programmes, 'The Bright Futures scheme' delivered by Kent Supporting Employment in collaboration with East Kent College has gained national recognition for the pioneering work of supporting young people with moderate or severe learning disabilities through an internship at the East Kent Hospitals University Foundation Trust. The scheme has contributed to permanent employment and has reported to have shown trust-wide benefits in employment retention as well as patient-care benefits.



\* does not include those in unpaid voluntary work

Ref: Kent Supporting Employment, KCC, September 2013

### Not in Education, Employment or Training (NEETS)

In 2011, the Childrens JSNA reported that 28% of the 7,790 young people in Kent aged 16–24 who were 'Not in Education, Employment or Training' had a learning disability and/or other disability. This is the highest proportion of NEETs of all the 10 priority groups. Further analysis can identify the collaborative work needed to reduce the number of NEETs among adults with a learning disability.

Kent’s What I Do delivery group is dedicated to improving the lives of people with learning disabilities by supporting education, activities and employment opportunities. It has been engaged in an adult education survey in 2013 to help plan courses and activities local people with learning disabilities would wish to access in Kent. In addition, the group undertook a workshop in 2012 to identify what would make a good day for them. The responses are predominantly featuring access to meaningful work, volunteering, supported employment, further study and training and flexible social activities. It is recommended that having identified these activities, further support is offered to achieve these outcomes where relevant and possible. Current work for these groups includes mystery shopping areas of the employment system (such as Job Centres) to provide valuable feedback on the specific needs of people with learning disabilities. This work is on-going.

### **Recommendations:**

- **Kent Supporting Employment to provide:**
  - **Demonstrate that education, employment and volunteering placements are commensurate to the individual's expressed needs.**
  - **More support to those seeking employment to assist them into work**
- **Work with other KCC partners to promote and increase the number of training and apprenticeship schemes in Kent**
- **Produce a measurable action plan to ensure that the outcomes from the What I do workshop are being delivered**

#### 4. Ensure a healthy standard of living for all

Making sure that people with disabilities have access to good quality lifestyle opportunities.

The benefits of a healthy lifestyle are well recorded, but there are some cohorts that are less likely to access health promotion advice or services and it is important that people with learning disabilities receive equal access and opportunities to take care and responsibility of their own health where possible. In Fair Society, Healthy Lives health inequalities report, Marmot suggests:

*People with physical and learning disabilities are more likely to suffer discrimination, poor access to some health services and worse employment prospects as a result of their disabilities, all of which impact negatively on their health.*  
(Marmot, 2010)<sup>16</sup>

Health Promotion messages are often publicised to the general public and within communities, with the onus of self-responsibility and control to manage our own lifestyle behaviours. At times, the public can access professionals and volunteers, such as Health Navigators, Health Trainers and Personal Trainers to support better management and personal behaviour change. Where these are not appropriate to meet the additional needs of adults with learning disabilities, Enablement workers (in designated pilot areas), Health Care Assistants and Community Nurses in the integrated Community Learning Disabilities Teams can provide the individual support to signpost and actively refer to support services available. Health promotion delivered via these teams works well at an individual level and although delivery to groups of adults with learning disabilities are frequently offered, take up tends to be varied across Kent. Dartford, for example, operates a well-supported men's group but Maidstone uptake has been low in the past, with difficulties in securing accessible and appropriate local venues. As the varying demands of the Community Learning Disabilities Teams increase, they may need further assistance and additional resources to support the preventative and proactive health agenda.

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. Recognising that people with learning disabilities may need additional support and that providers may lack the necessary training to make 'reasonable adjustments' or to understand the additional and specific needs of people with learning disabilities, the skills within the Community Learning Disabilities Team and other specialist workers can be utilized to provide training and support to key service providers. Currently, Learning Disability Awareness Training is being rolled out systematically to Kent Community

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<sup>16</sup> Marmot, M: *Fair Society, Healthy Lives*, 2010 p.40

Health Trust teams. The brief awareness training includes recommendations for reasonable adjustments and providing there are the resources to support demand, can be promulgated more widely across the service sector.

It is recommended that public health, social care and primary care commissioners specifically demand that providers ensure that their services are accessible and effective for meeting the needs of people with learning disabilities and that the measure of success be built into the service specification, monitoring and evaluation systems. This would be particularly (but not exclusively) applied to the following services:

- Stop Smoking Services

Although 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<sup>21</sup>. 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. Stop Smoking Services need to be accessible and appropriate to people with learning disabilities and also be promoted better to this cohort.

- 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 by 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. Although there is no specific training among commissioned agencies for delivering drug and alcohol services in Kent, data methods are in place to identify people with learning disabilities and every attempt is made to ensure that specific needs are recognised to deliver support effectively. Commissioned providers have identified a nominal number of people with learning disabilities who access their services, but successful outcomes are not clear and the agencies would welcome training that can promote and identify appropriate adjustments to existing services to make them more inclusive of people with learning disabilities should they need to access them.

- 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<sup>10</sup>. 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. Work is underway to ensure there is equity in dietetics services supported by the CLDT Teams across Kent.

Many generic exercise programmes and activities, such as Kent's Healthy Club initiative (part of the National Change for Life campaign) currently do not promote or target their services to people with learning disabilities but do operate a user-friendly website. With additional, flexible support and more robust monitoring systems, Healthy Club could be promoted to people with learning disabilities and to relevant voluntary sector agencies and Social Care Management teams for signposting purposes.

- Dental care

Reports suggest that one third of adults with learning disabilities have unhealthy teeth and gums due to poor oral hygiene and untreated decay. There is very little research on dental care and oral hygiene for people with learning disabilities, but comprehensive studies in Oldham in 2001<sup>17</sup> conclude 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, although reluctance to accept treatment was the greatest barrier to care reported by residential care managers.<sup>16</sup> In addition, delivery of dental treatment and services can be problematic and difficult to manage when adults with learning disabilities also pose challenging behaviours. Dental services in Kent provide health promotion advice in residential and nursing care homes and are piloting training in the care home setting in the Medway area. The service recognizes the need for robust epidemiological data on patients with a disability which is currently unavailable and for ways to target people with mild learning disabilities whose disabilities are not recorded on patient records. Some of the challenges the dental service faces is to promote effective health promotion messages to those with learning disabilities in the community to improve oral hygiene and to understand where Reasonable Adjustments can be made to ensure treatment is accepted and not refused. Training on the specific needs of this client

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<sup>17</sup> Tiller & Wilson et al., Oral health status and dental service use of adults with learning disabilities, in *Community Dental Health*, Vol.18,pt3, 2001

group can be offered to dental teams and dental working groups to assist in meeting these challenges.

- Mental health

For people with learning disabilities, the risk factors of discrimination, lack of social support, stress and lack of coping skills and resilience can further exasperate poor mental health, resulting in anxiety and depression. The prevalence of schizophrenia is likely to be 3-4 times higher in people with learning disabilities and is likely to be harder to diagnose than in the general population. The effects of medication or misdiagnosis of depression and post-traumatic stress may be confounding factors<sup>18</sup>. 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.

Kent sets a good, pro-active example for adults with learning disabilities at risk of dementia who access social care. Statistically, adults with Downs Syndrome over the age of 50 can have a 70% risk of displaying clinical signs of dementia<sup>23</sup>. Kent Social Care arrange a baseline assessment for all adults with learning disabilities known to them from the age of 30 years old, to ascertain and monitor early signs of dementia. As life expectancy and predicted prevalence continues to rise, services will need to ensure that there are the resources and capacity to cope with future demand.

- 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, awareness and good practice of 'Capacity to Consent' under the Mental Capacity Act (2005). This requires regular and consistent training for professionals and clear information provided to adults with a learning disability and their carer. The Department of Health's National Framework for Sexual Health Improvement in England (2013) states that effective commissioning and health promotion services should include the needs of people with learning disabilities<sup>19</sup>. It also declares that as part of good practice, public and patient feedback should be applied to ensure that services are meeting the needs of the local population and that staff working in sexual health services should be trained to meet recognised national professional guidelines (eg. the British Association for Sexual Health and HIV (BASHH)). This

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<sup>18</sup> Stevens, A (ed) et al, *Health Care Needs Assessment*, V2, Oxon, Radcliffe, 2004

<sup>19</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW\\_ACCESSIBLE.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/142592/9287-2900714-TSO-SexualHealthPolicyNW_ACCESSIBLE.pdf)

criteria should be included in the specification for tendering new sexual health services.

Sexual Health Link Nurses in the Community Learning Disabilities Teams provide information and support on some of the main identified<sup>20</sup> 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

There has also found to be low take up of cervical screening among women with learning disabilities and increased rates of sexually transmitted infections among males, which could also be addressed through greater take up of annual health checks<sup>26</sup>

Other good examples of joint working and training on sexual health for people with Learning Disabilities through Integrated Community Learning Disabilities Teams can be extended to some of the mainstream sexual health services to ensure that they are accessible and commensurate for people with learning disabilities; namely:

- 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

Appropriate training for staff in universal sexual health services is necessary to provide adequate support for people with learning disabilities, including capacity to consent.

### Challenging behaviours

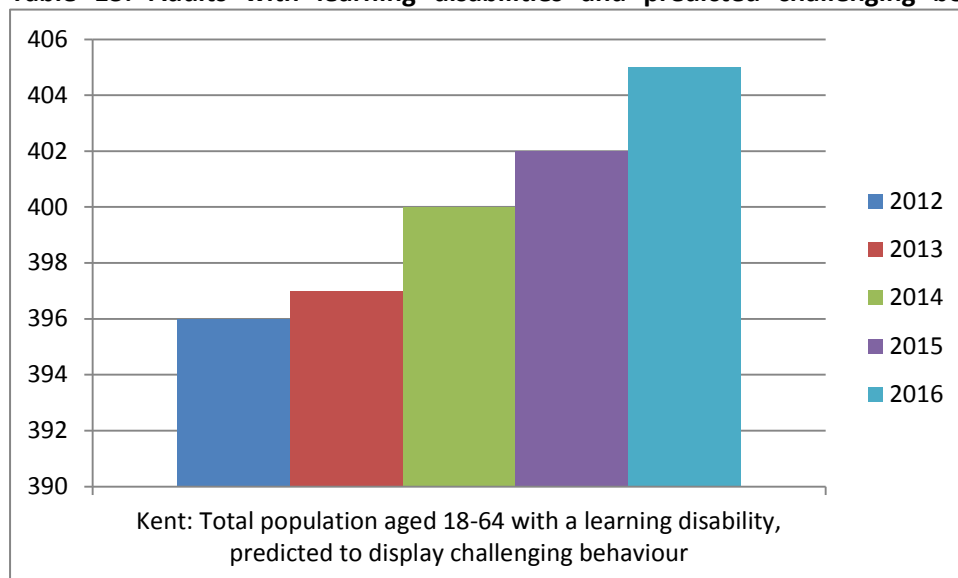
In some cases, people with learning disabilities may also have challenging behaviours, which is likely to increase with the type and severity of impairment. It is estimated that 10% of the learning disability population have a challenging behaviour, most of which are rated as

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<sup>20</sup> Jeffreys, Wendy, Learning Disabilities and sexual Health 2013

'other difficult/disruptive behaviour'<sup>21</sup>, with non-compliance being the most prevalent challenging behaviour. 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 have 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.

**Table 13: Adults with learning disabilities and predicted challenging behaviours 2012-2016**



Source: *PROJECTING ADULT NEEDS & SERVICE INFORMATION (PANSI) 2013*

### **Sensory Impairment**

People with a learning disability are at an increased risk of sensory impairment such as sight and hearing loss. 30% of people with learning disabilities are likely to have some visual impairment and 10% are registered blind or partially sighted<sup>17</sup>. However, the Sensory Joint Needs Assessment only identifies 2.1% of people with a learning disability registered as blind or with a sight or partial sight impairment in Kent. This raises a potential 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.

<sup>21</sup> Emerson, E & Baines, S Health Inequalities and people with Learning Disabilities in the UK: 2010, IHAL, 2010

National studies conducted by the Centre for Disability Research at Lancaster University suggests that an estimated 579,000 adults with learning disabilities (including 122,000 known to the statutory services) have refractive error<sup>17</sup>. This means that nearly six out of 10 people with learning disabilities need glasses and many sight problems are going undetected and untreated. It is anticipated that the proposed integrated health and social care sensory team will be able to assist with some of the barriers to accessing sight and hearing tests including the implementation of Reasonable Adjustments.

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 (estimates for Kent: 1,222 people) and 70% have hearing problems (estimating 1701 people) in Kent<sup>22</sup>. Additional measures may be required to ensure that people with Downs Syndrome and other conditions at risk of hearing and sight loss can receive targeted support. 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<sup>17</sup> but Table 14 below illustrates the relatively low numbers of people registered with sight impairments.

**Table 14: Adults with Learning Disability and Sensory Impairment**

|   |   |  |   |   |  |
|---|---|--|---|---|--|
| Kent Population#  | People with LD in Kent est.#                            | People with LD on Kent CCG LD registers                        | No. people with Downs Syndrome in Kent+                       |   |  |
| <b>1,480,200</b>  | <b>44,000</b>   | <b>5,351</b>   | <b>2,243</b>  |   |  |
| 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 (based on 10% prev) | Est. Nos LD significant sight impairment (based on 30% prev.) | Nos. people with LD reg. blind/severe sight impairment+ | Nos. people with LD reg. partial sight/sight impairment+ |
| <b>1,122</b>  | <b>1,570</b>  | <b>535</b>   | <b>1,605</b>  | <b>63</b>   | <b>49</b>  |

# Kent Adult Accommodation strategy +Sensory JNA 2013 pp.16-18 ~Sensory JNA 2013 p.33

<sup>22</sup> Sensory Joint Needs Assessment, Kent County Council, 2013

The RNIB and SeeAbility<sup>23</sup> have produced four key public health messages from the research to raise awareness about sight difficulties in the population of people with learning disabilities. It is recommended that these are published and promoted widely to people with learning disabilities and their carers:

1. People with learning disabilities are more likely to have serious sight problem than other people.
2. People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with a learning disability they know can see perfectly well.
3. 6 in 10 people with learning disabilities need glasses and often need support to get used to them.
4. People with learning disabilities need to have a sight test every two years, sometimes more often. Regular sight tests and wearing glasses helps people stay healthy and get the most from life.

Hearing is also an issue for people with learning disabilities. 7% of people with learning disabilities are deaf or partially deaf and between 22-68% of people have a hearing impairment<sup>3</sup>. The broad variation highlights the disparity and under diagnosis of hearing impairment which needs to be addressed. Recent calculations estimate 9,620 people with learning disabilities in Kent have some deafness<sup>24</sup>. Many of the causes for hearing loss can range from congenital defects, recurrent infections and impacted ear wax<sup>17</sup>. According to RNID, Hearing difficulties can lead to social isolation and low self-esteem and they also report that GPs fail to refer 45% of people reported having a hearing problem<sup>25</sup>. This could be escalated for adults with learning disabilities who have communication problems. 70% of people with Downs 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 1,570 people with Downs Syndrome in Kent with hearing problems.<sup>26</sup>

Some adults with Learning Disabilities are likely to have dual sensory impairments although the numbers of these are not yet known.

Further recommendations conclude that opticians and hearing services are aware of these facts and are able to apply 'Reasonable Adjustments' to ensure that they can appropriately support people with learning disabilities to access the services and resources they need.

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<sup>23</sup> RNIB

[http://www.rnib.org.uk/aboutus/Research/reports/prevention/Pages/learning\\_disability\\_VI.aspx](http://www.rnib.org.uk/aboutus/Research/reports/prevention/Pages/learning_disability_VI.aspx) )

<sup>24</sup> Sensory Needs Assessment, Kent County Council, 2013, p.50

<sup>25</sup> Sensory Needs Assessment, Kent County Council, 2013, p.38

<sup>26</sup> Sensory Needs Assessment, Kent County Council, 2013, p.35

The Reasonable Adjustment database includes Kent's guidance resources for opticians performing eye tests to people with learning disabilities (see Appendix) but a systematic approach is needed to ensure that effective practices are routinely provided. For those with disabilities who are known to Kent social care services, access to services and support can be promoted by the Sensory Team (a sensory Nurse and two assistants in West Kent) who also works closely with Kent Association for the Blind (KAB) and deaf services. The Sensory and Autism Service has made 7 key recommendations to the County Council that will increase training and sensory awareness to the community and professionals to improve early detection of sight and hearing problems and improve accessibility to and experience of services. It is proposed that this is delivered through a newly developed integrated Health and Social Care Sensory/Learning Disability Team.<sup>27</sup>

### Recommendations:

- 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):
  - Stop Smoking Services
  - Drug and Alcohol Services
  - Sexual Health Services
  - Weight Management, Healthy Eating and Leisure/exercise services
  - Dental Care
  - Mental Health Services
- Deliver a 'Best Practice' Charter for delivering health promotion to people with learning disabilities to ensure that health promotion messages are accessible, easily understood, supported, 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.
- More out of hours crisis support is needed to manage challenging behaviours
- Address recommendations for people with learning disabilities from the Sensory Needs Assessment and relevant papers.

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<sup>27</sup> Palmer, B Update on the Sensory Strategy Learning Disability Sub-Group paper to KCC LDMH Integrated Divisional Management Team – 5 December 2013

## 5. Create and Develop Healthy and Sustainable Places and Communities - making the community a healthy place to be

Valuing People Now recognises the importance of empowering people with learning disabilities to feel safe in society, free from abuse and hate crime. National guidance on fighting Hate Crime addresses how to define and respond to different types of hate crime, such as assault, abusive graffiti or hate-mail. This is formed under the Home Office's 'Free from Fear' agenda, stating: 'The government is committed to ensuring that everyone has the freedom to live free from fear of hostility or harassment.'<sup>28</sup> In addition, Mate Crime can be considered an aspect of Hate Crime (ARCUK, 2012) but differs in that it may not cause people to live in fear. This is because the nature of the crime lures the victim into a belief that what is happening is acceptable. The Kent Partnership Board recognises that Mate crime is a particular risk for people with Learning Disabilities and the Keeping Safe Delivery group are working to raise awareness of the issue.

Newly implemented data systems require local authorities to record the incidences of safeguarding alerts and investigations. Nationally, the information states that 93% of alerts for adults with learning disabilities are between the ages of 18-64 and the most common alleged perpetrator was a member of social care staff (24%), followed by another vulnerable adult (22%) and then another family member (15%).

In comparison to the Regional trends, Kent has shown an increase in the number of rates of referral of abuse to vulnerable people by almost 36% to 125 people per 1,000 population from 2010/11 to 2011/12<sup>4</sup>. It should be acknowledged that this could be a result of improved reporting rather than a rise in incidents of abuse.

The University of Glamorgan and the Big Lottery Fund have produced a research project including people with a learning disability to a focus on the specific needs and key messages to tackle abuse (Appendix). There could be potential for Kent Keep Them Safe delivery group to adopt a similar methodology for a Kent wide campaign.

### 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. 94.2% of adults with a learning disability accessing Kent social care services have support plans in place (July, 2013<sup>12</sup>). 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

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<sup>28</sup> A Guide to Fighting Hate Crime, *Home Office*, 2011

assessment rating. Information on eligibility and accessibility is available from Kent County Council.

<https://shareweb.kent.gov.uk/Documents/adult-Social-Services/leaflets-and-brochures/sds-factsheet-support-planning.pdf>

Further consideration will need to be given to population forecast predictions and emerging policy and legislation to determine impact and demand on future social care resources and services. .

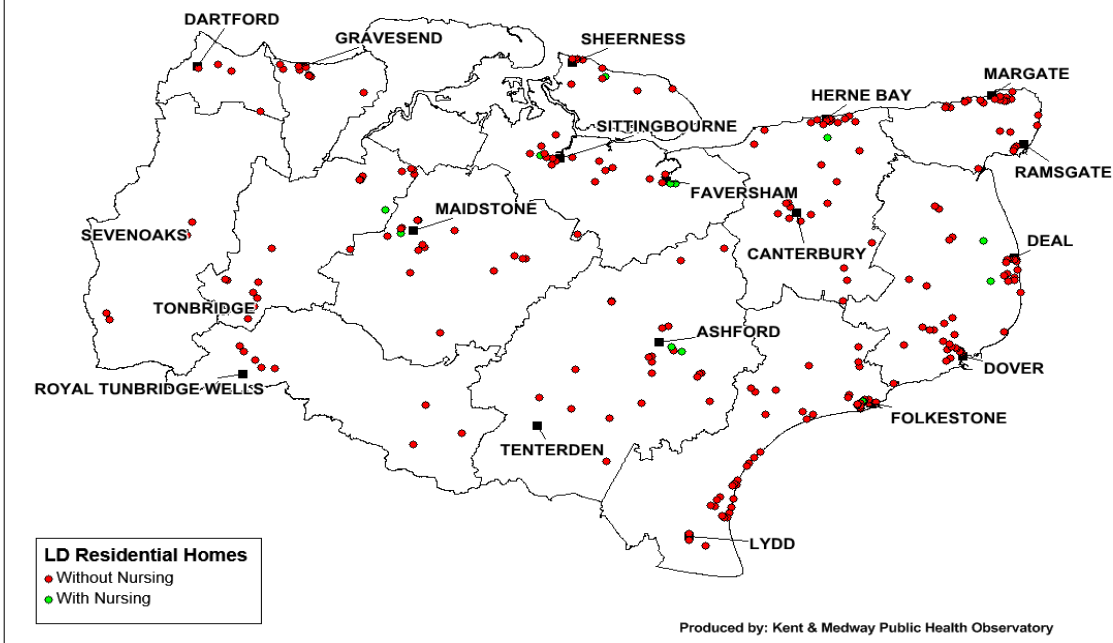
### Housing and communities

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 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. 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 limited supported accommodation units at present and further analysis of the market is being undertaken to understand how these can be best utilized and fit for future client groups. 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. Market forces are also a consideration in this phase of the assessment as well as identifying void rates and out of county placements. A Health Impact Assessment will be undertaken to identify opportunities for partners to work together to maximise potential for health outcomes.

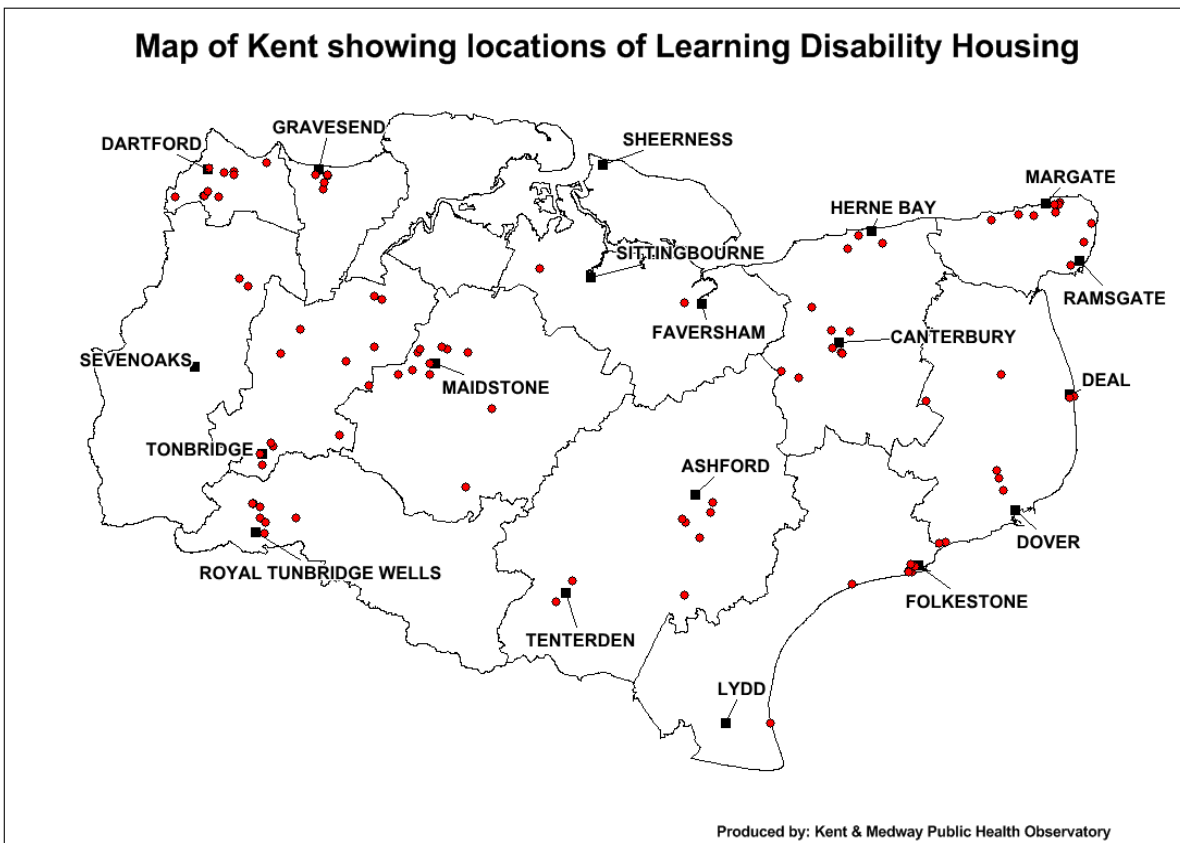
### Independent living

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.

### Map of Kent showing locations of Learning Disability Residential Homes



### Map of Kent showing locations of Learning Disability Housing



The Learning Disability Observatory has also published residential and accommodation profile of people with learning disabilities from 2010/11.

**Table 15:**

| Type of Accommodation          | % of adults with Learning Disabilities in accommodation: | Numbers of adults with Learning Disabilities in accommodation | % of adults with Learning Disabilities in accommodation |
|--------------------------------|--|---|---|
|                                | nationally 2010/11                                       | in Kent 2011/12   | in Kent 2011/12   |
| Registered Care Home           | 16.9%  | 1210  | 24.1%   |
| Supported Accommodation        | 12.7%  | 840   | 16.8%   |
| Adult Placement                | 1.9%   | 110   | 2.2%  |
| Registered Nursing home        | 0.9%   | 10  | 0.2%  |
| Long stay residential hospital | 0.8%   | 0   | 0.0%  |
| Sheltered Housing              | 0.5% (extra care)  | 2950  | 58.9%   |

*Refs: Emerson et. al, People with Learning Disabilities in England 2011, DH, 2011*

*Kent County Council Draft Strategy (v9) Accommodation Solutions for the Adult Social Care Clients in Kent 2013*

### Supporting People

Kent Supporting People support 23,000 people across Kent in temporary housing and floating support services<sup>29</sup> (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 time limited support to access independent living, 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. Some of the main considerations for the future of Supporting People services 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.

Supporting people are currently undertaking an 'appreciative inquiry' approach to a needs assessment of their service. This area of work engages stakeholders and users to build on the aspects of the supporting people service that works well and ensures that future services are fit for purpose to meet the changing needs of people in Kent.

<sup>29</sup> Kent Supporting People Strategy 2011-2015

The outcomes of the needs assessment will also address some of the barriers and specific emerging needs of vulnerable people, such as managing the rising number of under 18 year olds needing temporary accommodation or with family mediation to help them return home safely and the additional support required by older people suffering from dementia.

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 can offer support may be:

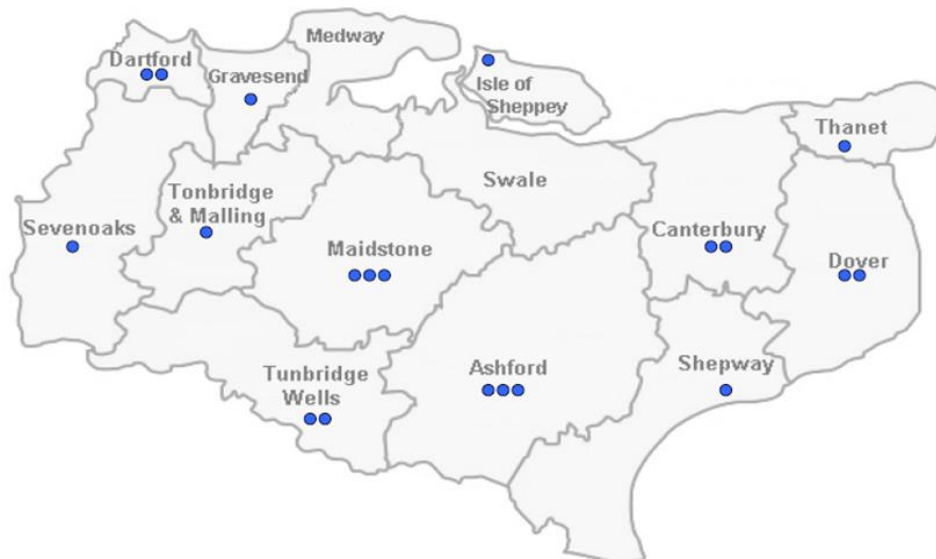
- Access to Healthcare
- Mental health and wellbeing
- Breast-feeding support
- Stop smoking services
- Falls prevention
- NHS Health Checks

There will be a clearer idea on the collaborative working once the needs assessment has been written and a Health Impact Assessment will be undertaken to increase opportunities for better health outcomes for people with learning disabilities.

### Changing Places

In response to meeting identified needs within the community, Kent has also adopted the Changing Places campaign where many public toilets have been modified with the space and equipment to make accessing toilet facilities easier for people with learning disabilities. Better access means removing some of the barriers that prevent adults with learning disabilities and their carers from going out, keeping mobile and being active. There are currently 20 Changing Places across the county with the potential for more to be available in the future. The Delivery Partnership groups are currently undertaking a survey to identify whether Changing Places are fit for purpose and easily accessible. Sites for Changing Places in Kent are illustrated on the map below, but for more details about locations and facilities, the County Council has issued a leaflet (appendix) and links to the Changing Places website ([www.kent.gov.uk](http://www.kent.gov.uk)). The outcomes of the partnership group survey should be considered before new sites are located and awareness should be raised to Carers and voluntary sector groups.

## Changing Places Locations



### **Recommendations**

**Maximise health outcomes through a Health Impact Assessment and Action Plan for Supporting People and Accommodation Solutions needs assessments.**

**Develop a Strategy and/or campaign to reduce abuse and hate crime**

## 6. Strengthen the role and impact of ill health Prevention

### Reducing the risk of ill health and premature mortality

It is widely recognized 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.

Some of the main organisational barriers to accessing healthcare services, are namely:

- 'scarcity of services [which is considered to refer to specialist mental health services for people with learning disabilities]
- Physical barriers to access
- Failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities
- Variability in the availability of interpreters for people from minority ethnic communities
- 'Diagnostic overshadowing' (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities)
- Disablist attitudes among healthcare staff'
- Consent being sought by carer rather than take the time to gain consent from the person with the learning disability<sup>21</sup>

Many people and carers also feel that their views and opinions are ignored by health care professionals. There are, however, good examples of best practice adopted by some health care services which include<sup>30</sup>:

- Specialist Learning Disability role in putting into Public Health teams (Bristol PCT)
- Medical records system signals when someone has a communication need (Torbay Hospital and East Kent Hospitals Foundation Trust and KCHT).

Many of these examples could be explored to improve health care systems in Kent.

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<sup>30</sup> *Michael, Sir Jonathan: Healthcare for All: A report of the independent inquiry into access to healthcare for people with learning disabilities, 2008*

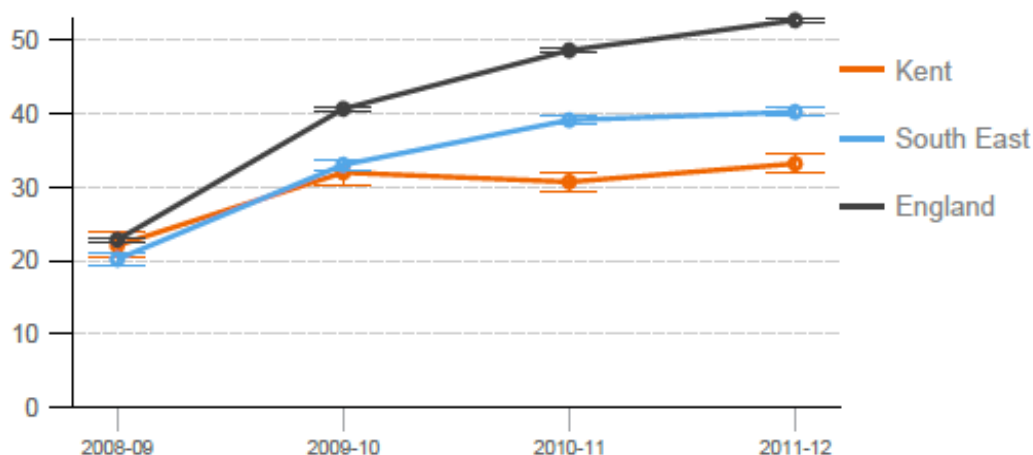
## Health Checks

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 agenda for primary care to reduce the risk of early morbidity for adults with learning disabilities. However, the take up rate of Health Check is low. According to the Improving Health and Lives observatory:

*“The provision of health checks is probably the most important Reasonable Adjustments that can be made by PCTs through GPs to ensure that people with learning disabilities receive a reasonable acceptable standard of primary medical care<sup>31</sup>”*

Eligibility for Health Check is dependent on GP surgeries registered for Directed Enhanced Services, adults with learning disabilities being known to local authority social services and is complicated further 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 role to identify unmet health needs. The number of eligible adults with a learning disability having a GP health check in Kent is 33.19%; performing significantly lower than the England average of 52.7% and lower than the regional average of 40.2%. Kent has seen less than a 3% increase in the last year following a negative trend the previous year between 2009-10 and 2010-11. A number of measures such as more flexible and longer appointment times, information on what health checks are and their significance and having a GP well known to the person with learning disabilities well has helped improve uptake. It is recommended that collaborative support is needed to improve the number of health checks in Kent.

**Table 16:** Proportion of eligible adults with a learning disability having a GP health check in Kent  
*Source: IHAL Kent profiles 2013*



<sup>31</sup> Glover, et al., The Uptake of Health Checks for Adults with Learning Disabilities: 2008/9 to 2011/12, IHAL

| Period  | England South East<br>Average | Kent  | Received<br>health checks | Not received<br>health checks |
|---------|-------------------------------|-------|---------------------------|-------------------------------|
| 2008-09 | 22.83                         | 20.17 | 627.00                    | 2,217.00                      |
| 2009-10 | 40.66                         | 33.05 | 1,483.00                  | 3,153.00                      |
| 2010-11 | 48.64                         | 39.13 | 1,432.00                  | 3,231.00                      |
| 2011-12 | 52.73                         | 40.24 | 1,730.00                  | 3,482.00                      |

### **Health Action Plans**

Personalised Health Action Plans are offered to all adults with Learning Disabilities and through person-centred planning, 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**

A number of national screening programmes provide information leaflets promoted specifically to people with learning disabilities, although take up of screening remains 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 who 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 of these should be available as part of good practice.

- Easy guide to breast screening
- Easy guide to cervical screening
- Easy guide to bowel cancer screening
- Easy guide to Colonoscopy

The easy read guide: Good Health Care for All: What can I expect from the NHS?<sup>32</sup> 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 where required and necessary to improve the experience and can accompany people on hospital visits to ensure reasonable adjustment advice is provided.

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<sup>32</sup> Foundation for People with Learning Disabilities, Good Health Care for All: What can I expect from the NHS?

## **Hospital Admissions and Urgent Care**

Statistically, 50% of people with Learning Disabilities who are admitted to hospital are likely to be emergency hospital admissions compared to 31% of the general population (2008/9 figures)<sup>33</sup>. Although Kent performs significantly better than the England average for identifying people with learning disability in general hospital statistics, the number of emergency hospital admissions (66.7%) and the admission rate for non-psychiatric ambulatory care sensitive conditions (26%) for people with a learning disability is higher than the England average (50% and 23% respectively)<sup>4</sup>. This could be due to the robust reporting mechanisms adopted by East Kent Hospitals Foundation Trust. The Trust operates a flag system at the point of discharge which can help identify adults with learning disabilities who are frequent flyers (ie. are regularly admitted to hospital) and to alert the community nursing team of the need for greater support in the community or in primary care if needed. This system has resulted in a 5% reduction in readmission rates in 2012-13 although re-admission rates have increased in 2013/14 for Urological conditions, general surgery and ophthalmology. Most re-admissions are made 9-14 days after hospital discharge.<sup>34</sup>

However, high admissions for non-psychiatric ambulatory care sensitive conditions usually suggest that health care and support outside of the hospital environment is not being managed as effectively as possible so further investigation is needed into health provision and support in the community. The main reason for emergency admissions are epilepsy, gastrointestinal conditions and constipation. With better management of these conditions in the community, some hospital admissions (which can be unpleasant for patients and costly for services) can be avoided. Only 0.95 per 1,000 people with Learning Disabilities were admitted to hospital due to challenging behaviours throughout 2005-9.<sup>10</sup>

It is recommended that further exploration is needed into the health care pathway of adults with learning disabilities to ensure that their health conditions are managed effectively in the community and in primary care to avoid preventable hospital admissions. Public Health are undertaking a study on the diabetes management pathway for adults with learning disabilities in Kent and this may provide a suitable model that can be adopted for other health conditions.

## **Mortality**

Along with the general population, life expectancy is increasing for people with learning disabilities who are also living longer, however people with moderate to severe learning

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<sup>33</sup> Glover and Evison, Hospital Admissions That Should Not Happen, IHAL 2009

<sup>34</sup> Marsden, D, Learning Disabilities Research Paper, August 2013 (Appendix)

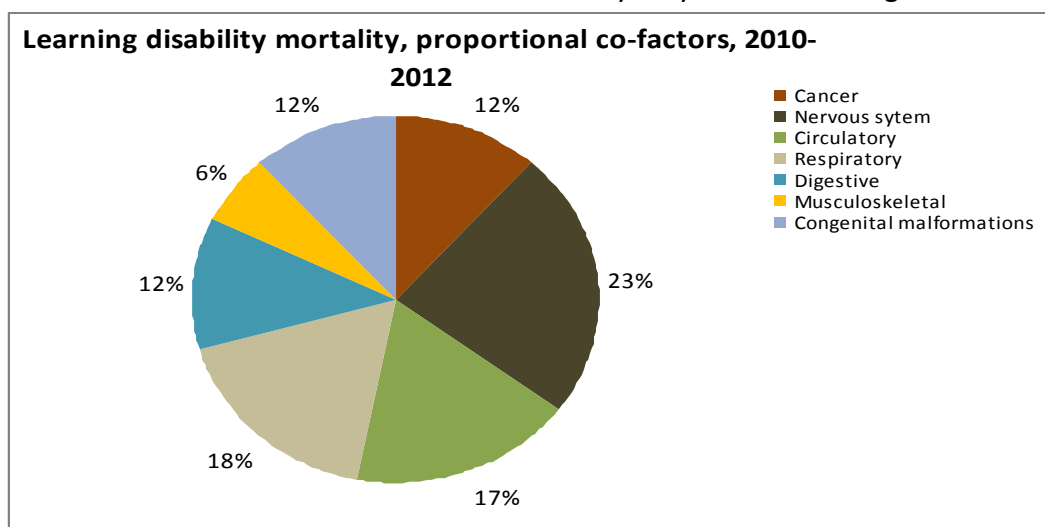
disabilities have mortality rates three times higher than the general population<sup>35</sup>. Recent research also suggests that people with mild learning disabilities are likely to live as long as the general population (age 70+) but mortality rates become statistically higher with the severity of learning disability and with the presence of other co-morbidities (eg. Cerebral palsy, epilepsy, diabetes).

The median life expectancy for people across all learning disabilities in Kent is slightly below the England average. Recording mortality rates should be treated with caution as very often learning disabilities are not recorded on death certificates if the disability is not the main cause of death.

Average Life Expectancy for People with Learning Disabilities (Source: IHAL Kent Health Profile 2013)<sup>4</sup>

|         | England (yrs) | South East (yrs) | Kent (yrs) |
|---------|---------------|------------------|------------|
| 2006-10 | 55            | 56               | 55         |
| 2008-11 | 56            | 56               | 55         |

Nationally, the main cause of mortality among people with learning disabilities are conditions related to the nervous system. Although this is fairly representative, the relevance of morbidities and co-morbidities may vary at local and regional levels.



Due to data limitations, no local mortality information is available.

The Confidential Inquiry makes 18 key recommendations to reduce the risk of people with learning disabilities dying prematurely. The recommendations set priority standards and good practice that are being implemented nationally and locally at all levels of the care

<sup>35</sup> A Step by Step Guide for GP Practices: Annual health checks for people with a learning disability; Royal College of General Practitioners (2010) in <https://myhealth.patient.co.uk/>

setting. Work to monitor the progress of each recommendation is ongoing (appendix) and is touched upon within the relevant sections of this assessment.

### **Inequalities**

Research has found little evidence between a causal effect of learning disability and socio-economic group. However, inequalities exist when accessing good health care and relatively higher mortality rates due to preventable diseases. In addition, Emerson and Baines make a direct link of exposure to bullying at school and overt discrimination in adulthood related to poor health outcomes of people with learning disabilities<sup>15</sup>.

Additional guidance is also available from organisations such as Mencap, who has launched its 'Getting it right' campaign to ensure that people with a learning disability get the level of health care they have a right to. 'Getting it right' calls on health professionals to commit to a charter that will help them work towards better health, wellbeing and quality of life for people with a learning disability (Mencap, 2010).

### **Respiratory Disease**

Respiratory disease is one of the leading causes of death for people with profound and multiple learning disabilities (46%-52%), with rates much higher than for the general population (15%-17%)<sup>15</sup>. People with asthma and learning disabilities were found to be twice more likely to be smokers than patients with learning disabilities who do not have asthma. More than half of women with learning disabilities and asthma are also obese. The Organisation, PAMIS, reports that people with PMLD are more susceptible to respiratory conditions, particularly pneumonia, although the symptoms are not often 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/respiratory\\_leaflet.pdf](http://www.pamis.org.uk/cms/files/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.<sup>15</sup>

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. There are currently no systems in place to record number of swallowing or dementia assessments that are undertaken but it is expected that health conditions will be measured and reported routinely from 2015.

## **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 UK<sup>36</sup>.

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 syndrome in institutional settings although these rates are not statistically significant<sup>37</sup>. 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 deficiency<sup>37</sup>. Other conditions at risk of endocrine disorders are Turner's syndrome, Klinefelter's syndrome, Noonan and William syndromes. People with Prader-Willi syndrome may be at risk of hypothalamic-pituitary dysfunction and DiGeorge's syndrome with a parathyroid insufficiency<sup>2</sup>. 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 on health checks for people with learning disabilities demonstrated the value of health checks in revealing previously undiagnosed endocrine problems.

## **Cardiovascular Disease**

Chronic Heart Disease (CHD) 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 in 1992.<sup>17</sup> Further research is needed to ascertain and address more recent prevalence on obesity for people with learning disabilities. Increased support in better weight management, a more healthy diet and increased physical activity may assist in

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<sup>36</sup> <http://www.webmd.boots.com/diabetes/guide/endocrine-disorders?page=2> accessed 19/5/14

<sup>37</sup> Emerson, E et al *Health Inequalities & People with Learning Disabilities in the UK: 2011, Ihal*, p.9

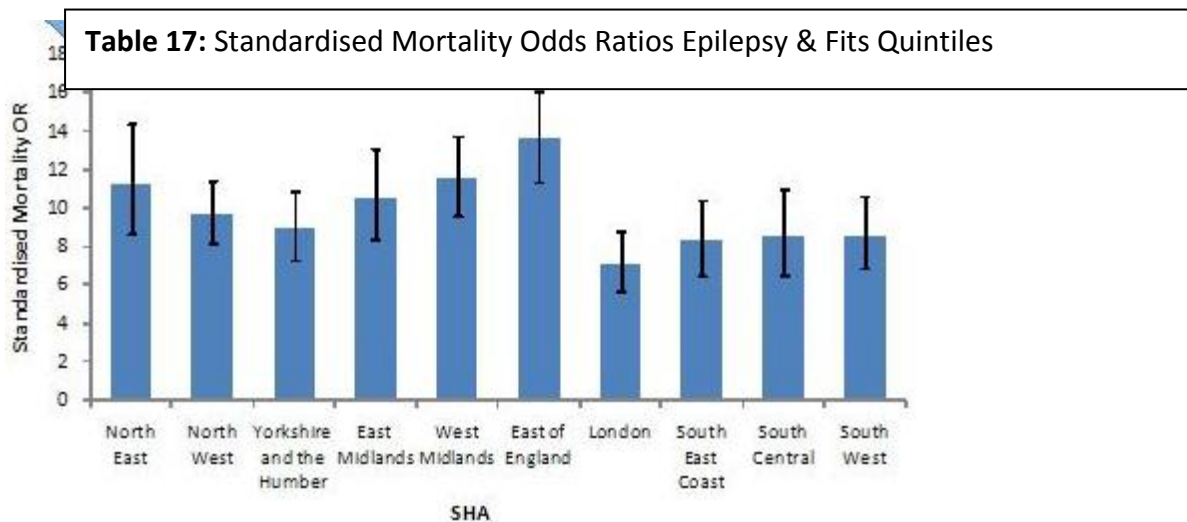
<sup>37</sup> Emerson, E et al *Health Inequalities & People with Learning Disabilities in the UK: 2011, Ihal*, p.9

reduced mortality rates in CHD. Some specific conditions, such as Down’s Syndrome are more affected by congenital heart disease and obesity.<sup>3</sup>

### **Epilepsy**

Mortality rates due to epilepsy are 13% for people with learning disabilities against a national average of 0.4%<sup>38</sup> for the general population. 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. It is estimated that 13% of preventable deaths are caused by epilepsy<sup>36</sup> 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<sup>30</sup>.

The QOF method of reporting does not enable us to clearly identify those on the Epilepsy register who have learning disabilities, but it is estimated that there are approximately 428 adults with learning disabilities and epilepsy in Kent. Mortality rates due to epilepsy are relatively low in the South East compared to other regions in the country.



Source: IHAL, 2010

Kent’s Epilepsy strategy acknowledges the specific need that adults with learning disabilities may encounter if they also suffer from epilepsy:

<sup>38</sup> Glover and Ayub, How People with Learning Disabilities Die, IHAL, 2010

*“Cognitive difficulties in individuals with learning disabilities are due to the underlying brain damage which gives rise to the epilepsy. If the seizures are under optimal control, then further cognitive difficulties are unlikely. Seizures, however, if poorly controlled and particularly if undetected may result in additional impairments of cognitive function.*

*It is of the utmost importance that people with learning disability who also have epilepsy have ready access to all forms of treatment for their seizures. Freedom from seizures with minimum side effects can contribute greatly to their quality of life”<sup>39</sup>.*

The strategy, therefore strongly suggests that Epilepsy Nurses and other key professionals are up-skilled to be aware of and recognise the needs of those with learning disabilities and ensure that services are equitable and accessible, providing consideration to the additional communication skills that may be needed. Further recommendations that raise awareness and equity at key stages of the service pathway could also be introduced to maximise opportunities for reasonable adjustments, where required.

There is also an increased risk of osteoporosis in people who also have epilepsy due to the side effects of some anti-epileptic medication and in people who also have cerebral palsy due to reduced bone mineral density.

### **Dementia**

Adults with a learning disability are almost four times more likely to develop dementia at the age of 65+ than the general population of that age; but as people with a learning disability can now expect an increased life expectancy, the prevalence of dementia also increases. People with Downs Syndrome, too, are at a high risk of developing dementia 30-40 years younger than the rest of the population.<sup>15</sup> 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 (appendix). The Directed Enhanced Services (DES) requires GPs to screen people with Downs Syndrome and other people with Learning Disabilities over the age of 50.

### **Cancer**

Cancer rates amongst people with learning disability are lower than the general population although gastrointestinal cancer is likely to be twice as high in people with learning disability than the general population<sup>15</sup>. 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.<sup>40</sup> Support in

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<sup>39</sup> East Kent NHS, Epilepsy Strategy, 2013

<sup>40</sup> [http://www.medicinenet.com/stomach\\_cancer/page2.htm#risk\\_factors](http://www.medicinenet.com/stomach_cancer/page2.htm#risk_factors)

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

### **Diabetes**

There is limited evidence of a correlation between diabetes and people with learning disabilities and little mentioned in the most current Diabetes Needs Assessment and 2010 Learning Disabilities needs assessment. However, research studies are emerging to show a positive correlation between overweight, obesity and incidence of hyperinsulinaemia (condition of excess insulin circulating in the blood) and other risk factors<sup>41</sup>. It has already been established that adults with learning disabilities are more likely to have a poor diet and low levels of exercise and to be overweight than the general population. These factors increase the likelihood of the onset of Type II diabetes but as diabetes registers do not systematically identify patients with learning disabilities, the prevalence, effective management and recognition of reasonable adjustments needed remains unclear and at risk of being ignored. Further studies are being undertaken by the Public Health team to establish identification and need of adults with learning disabilities at risk of diabetes in Kent. This should include ensuring there is access to the Reasonable Adjustment resources that are available to assist people with learning disabilities to understand diabetes, include diabetes support in Health Action Plans and improve access to eye care services for people with diabetes and learning disabilities<sup>42</sup>. It is anticipated that the diabetes project work may provide a suitable model that can be adopted for other health conditions which will include the identification and implementation of reasonable adjustments throughout the care pathway.

### **Falls and mobility**

Higher rates of falling among people with learning disabilities have been noted in Denmark, Australia and Canada and the US. There does not appear to be similar data in the UK to determine the rates of falls among people with Learning Disabilities but this can and should be collected and measured through multi-disciplinary falls assessments<sup>15</sup>. Around 15% of people with learning disabilities have difficulty in walking and 10% unable to walk, so it is essential that assisted equipment is made available to reduce the risk of falls and that the Kent postural stability falls programme adequately records and delivers in a way that reduces the prevalence of falls in people with learning disabilities.

The multi-disciplinary falls team in Kent are now including the needs of people with Learning Disabilities in their programme and the outcome of this work should continue to be measured.

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<sup>41</sup> Draheim, CC, Williams, DP & McCubbin, JA (2002) Physical Activity, dietary intake and insulin resistance syndrome in non-diabetic adults with mental retardation, *Am J Ment Retard*, 105, 361-375 in Burton, S et al (2011) *Weight Management for Adults with a Learning Disability Living in the community*, Birmingham, The British Dietetic Association

<sup>42</sup> Turner S & Emerson E, *Making Reasonable Adjustments to diabetes services for people with learning disabilities*, Iha, 2013

### **Reasonable Adjustments**

Reasonable adjustments form part of the Disability Discrimination Act 2005 and Equality Act 2010 requiring public bodies to make reasonable adjustments to their premises policies and services to ensure that all people with learning disabilities are treated equitably. A number of *Evidence into Practice* Reports published by Improving Health and Lives (IHAL) provide guidance for commissioners and providers on Reasonable Adjustments in a range of health and care settings which should be considered best practice and embedded into policy and practice. Easy Read versions are also available. Reasonable Adjustment guidance covers broadening access to information, making adjustments to meet the individual needs of people with learning disabilities and comprehensive understanding of the **capacity to consent** under the Mental Capacity Act 2005. Clear recommendations are set out in *Evidence into Practice* for Health Trusts and other Public sector bodies. Although many of the recommendations are implemented across individual agencies, there would be added value in working collaboratively across organisations to improve the quality to the user's experience, sharing resources and good practice and enable reasonable adjustments to be delivered and monitored in a systematic way. There would be particular advantages in developing a Kent-based resource bank of 'best practice' materials that can be shared and accessed at a Kent-wide level. Public Health would be well placed to lead a multi-agency working group responsible for the good standard of delivery of reasonable adjustments. An example of a Reasonable Adjustment checklist is given at the end of this document.

### **Recommendations:**

- Explore national best-practice initiatives to support improved access to health care, specifically working with Community of Practice and other relevant stakeholders.
- Increase numbers of people with learning disabilities receiving a health check.
- Maximise opportunities to use Health Action Plans as part of health and health promotion care planning and delivery
- Ensure Easy Read health guides are available and accessible.
- Explore health care pathways to reduce emergency hospital admissions
- Reduce risk of respiratory conditions by promoting PAMIS awareness raising publicity
- Promote healthy eating and exercise programmes to support effective weight management
- Public Health to share outcomes and conclusions of diabetes management work programme with partners.
- Epilepsy nurses to be up-skilled to recognize identified needs of people with learning disabilities and epilepsy
- Develop a comprehensive multi-agency strategy for delivering Reasonable Adjustments across Public Sector in Kent.
- Promote Getting it Right campaign
- Work collaboratively to deliver action plan on the key 18 recommendations set out by the Confidential Inquiry.

## **Key Partners**

Kent Public Health Department  
Kent Community Health NHS Trust  
Kent County Council Families and Social Care Accommodation Solutions Team  
Kent County Council Families and Social Care Learning Disabilities Teams  
Kent County Council Supporting People  
Kent Good Health Group  
Kent Learning Disability Partnership Group

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## **Appendices**



Definition of Learning  
Disabilities FINAL.doc

### **Appendix 1 – FSC Definition of Learning Disabilities**



Opticians  
Familiarisation Progra

### **Appendix 2 - Opticians Familiarisation programme**



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**Appendix 3 - Dementia pathway**



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**Appendix 4 - Learning disability research paper August 2013**



LDMH report 5th Dec  
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**Appendix 5 - Palmer, B Update on the Sensory Strategy Learning Disability Sub-Group paper to KCC LDMH Integrated Divisional Management Team – 5 December 2013**



CONFIDENTIAL  
INQUIRY 18 reccs.do

**Appendix 6 - Confidential Inquiry Recommendations (summary)**



Reasonable  
Adjustments Checklis

**Appendix 7 - Reasonable Adjustments Checklist**



Abuse focus group  
Wales Easyread\_Rep

**Appendix 8 - Tackling Abuse Research project**