Valuing People
Learning Disability Partnership Board in Surrey

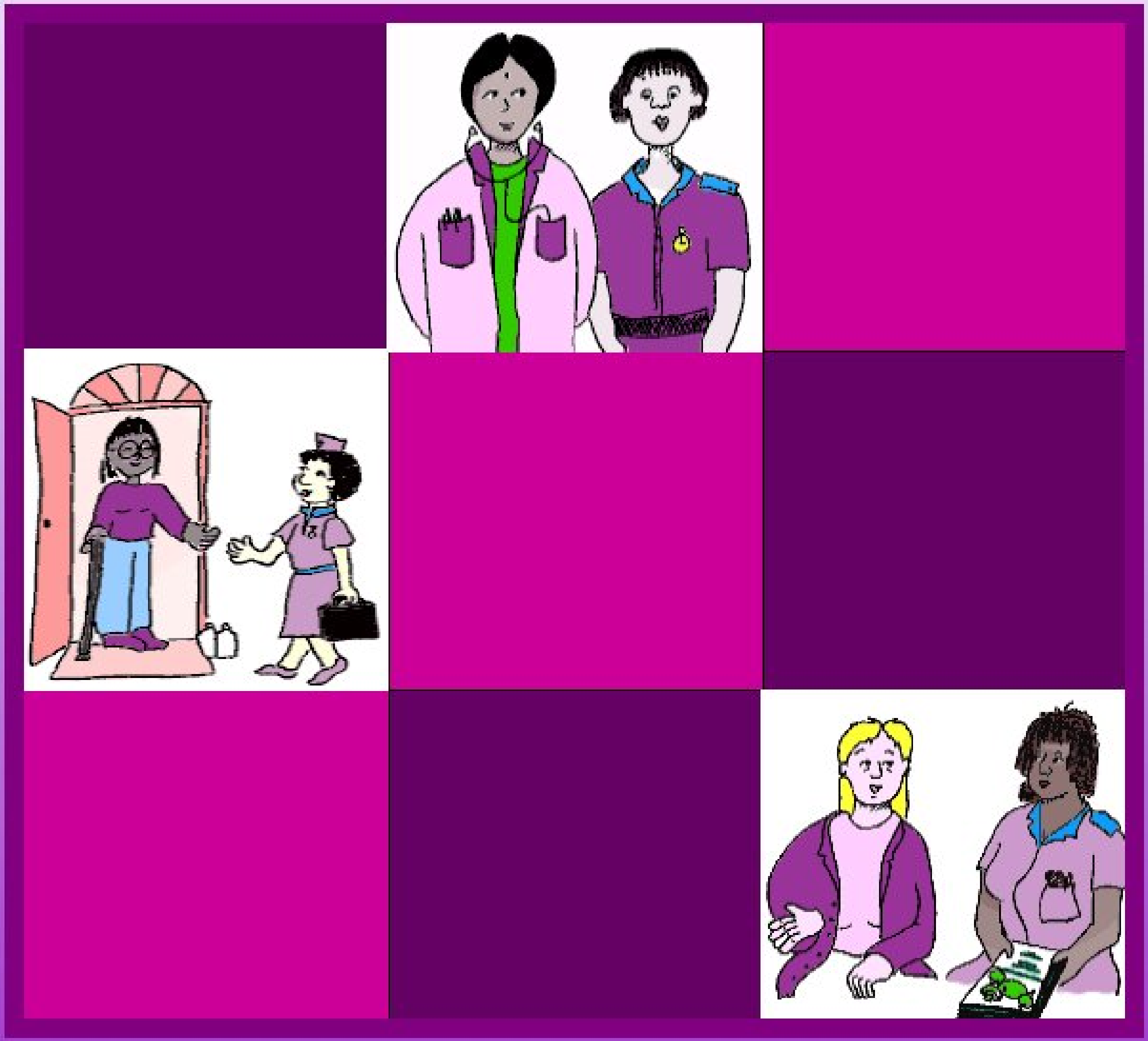
SURREY
COUNTY COUNCIL

NHS
Surrey

Surrey and Borders Partnership NHS
NHS Foundation Trust

Learning Disability in Surrey

Health Needs Assessment



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Contents

1. Background & Context

1.1 What is a 'Learning Disability'

The term 'learning disability' is often poorly understood. For example, there is often confusion between the meanings of the terms 'learning disability' and 'learning difficulty' (which is often used to refer to specific difficulties such as dyslexia).

For purposes of clarity, this Needs Assessment will adopt the definition of 'Learning Disability' provided within 'Valuing People', the White Paper on the health and social care of people with learning disabilities (Department of Health, 2001) (see Box 1A). Click the Link Box on the left to visit the Valuing People website.

As Box 1A illustrates, a Learning Disability is a life-long condition that has a wide-ranging impact on one's life and ability to live independently.

BOX 1A
Definition of a 'Learning Disability'

A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence).

A reduced ability to cope independently (impaired social functioning).

A disability that started before adulthood and has a lasting effect on development.

While the term 'Learning Disability' is prominently used within the UK, other countries an increasing number of international organisations and countries (e.g., USA, Canada, Australia) use the term 'intellectual disability' to describe the same or similar conditions. Indeed, this term has also recently been used in documents published within the UK (Department of Health, 2010).

1.2 Are all Learning Disabilities the Same?

While the definition of 'Leaning Disability' used above may seem simple and straightforward, there are many issues that serve to add complexity to assessment and diagnosis. Guidance regarding assessment was produced by the British Psychological Society (BPS, 2000). Evident in this guidance is the welcome trend away from assessments based exclusively on psychometric test results (which can result in over-simple classifications) to one that seeks to assess individual need.

Need will vary from one individual with a Learning Disability to another. For example, the level of disability can vary and is often categorised as mild, moderate or severe. It follows, therefore that people with a Learning Disability vary a great deal in the help they may need in meeting their basic needs. Some people may require help with washing and dressing for example, while many others will live quite independently with much less support. Of course, the level of need will depend not just on the severity of the Learning Disability, but any conditions or impairments that come with it. For example, many people with Learning Disabilities are also living with sensory impairments, mobility problems or mental health conditions.

Learning Disabilities also vary in relation to their cause. Rather than being a defined condition in itself, Learning Disability is a broad term that covers a pool of possible causes, symptoms, treatments, and outcomes. For example, a person can be born with a learning disability if he or she does not get enough oxygen during childbirth or is born too early. After birth**,** a learning disability can be caused by early childhood illnesses. A child can also be born with a learning disability if certain genes are passed on by a parent (inherited learning disability). The two most common causes of inherited learning disability are Fragile X syndrome and Down's syndrome.

Based on what is know about the causes of learning Disability, interventions aimed at prevention include the following: Early intervention for those at risk of mild learning disability (low birth-weight babies, children from disadvantaged families). Better obstetric care & control of neonatal infections (but this has also led to an increase in survival of small-for-dates deliveries, which are at risk of learning disability), Prevention of drug/alcohol abuse in pregnancy (foetal alcohol syndrome, teratogenic effects of substance misuse, HIV). Screening for heterozygotes/carriers in families with affected member and counselling by geneticists (ethical dilemmas as mostly no treatments available). Pre-natal diagnosis improving - but only ‘treatment' yet available is termination. Newborn screening for reversible disorders using Guthrie Test for phenylketonuria & other metabolic disorders, congenital hypothyroidism.

1.3 What about Autism?

Autism is a lifelong condition that can affect the way a person communicates and relates to other people. Specifically, the three main areas of difficulty associated with autism are with communication, social interaction and social imagination (ie: understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine).

Autism is not a learning disability in itself, but they are closely associated. For example, research shows that learning disability is present in four out of five cases of autism while the prevalence of autistic disorders among the adults accessing Learning Disability services is around 30% (with the prevalence rising to 58% among those in specialist day care and 64% of people with significant needs and resident in nursing homes (Morgan et al. 2002). In Surrey, of the 3341 people with Learning Disabilities known to social services in 2009/10, 371 (11%) were reported to also be diagnosed with autism.

There are a range of disorders which share the three essential features described above to a greater or lesser degree, and simply identifying those with classical autism does not address the extent of the problem. The family of ‘Autism Spectrum Disorders’ includes Asperger’s syndrome (currently distinguished from autism by absence of significant language delay, and general intellectual skills in the normal range), pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder. The National Autistic Society estimates a prevalence rate of people with autism spectrum disorders of 1 in 100 people. For an average list size of 2,000 people, each GP is likely to have up to 20 people on the autism spectrum on their list (NAS, 2010).

At present 41% of Surrey adults with Autistic Spectrum Disorders who require residential care are placed out of county. Surrey County Council has projected that between 2007 and 2016 there will be 229 people with Autistic Spectrum Disorders who will require new accommodation and a further 20 will require intermediate placements. New housing and support services have been developed for 13 young people with autism but these are localised to one geographical area.

Surrey County Council has estimated that the number of people with a diagnosis of Autistic Spectrum Disorders will increase from around 600 in 2003/04 to 1500 in 2015/16. This is due to increasing prevalence, better ascertainment and diagnosis and will depend on the definition of Autistic Spectrum Disorders used. The national POPPI website estimates that the numbers of adults of working age will increase by 1% per year but does not indicate how many of these individuals will also have Learning Disability. (Note: A full discussion on the current and future prevalence of Learning Disability follows in Chapter 3).

1.4 Key Legislation and Guidance

The issue of Learning Disability touches upon many aspects and domains of everyday life, including health, social care, housing, employment, finance and human rights. Therefore, to list every single piece of guidance and legislation relevant to people living with Learning Disabilities would be require and enormous amount of space in this document. Therefore, a very selective list follows of some documents that are absolutely central and specific to the issue.

Valuing People Now is a three year cross government strategy for people with learning disabilities. It says that all people with a learning disability are people first with the right to lead their lives like any other. The associated website is for people with learning disabilities, family carers and anyone who works with, or comes into contact with people with learning disabilities. *Visit the website at www.valuingpeoplenow.dh.gov.uk/*

The Mental Capacity Act (2005) provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It makes it clear who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity. It covers decisions about someone's property and affairs, healthcare treatment and where the person lives.
View details of the Act at www.publicguardian.gov.uk/mca/mca.htm

The Equality Act 2010 aims to protect disabled people and prevent disability discrimination. It provides legal rights for disabled people in the areas of employment, education, access to goods & services, buying and renting property and the functions of public bodies. The Equality Act also provides rights for people not to be directly discriminated against or harassed because they have an association with a disabled person. This can apply to a carer or parent of a disabled person. In addition, people must not be directly discriminated against or harassed because they are wrongly perceived to be disabled.

View details of the Act at www.equalities.gov.uk/equality_act_2010.aspx

Legislation relating to Carers includes the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004. These Acts promote cooperation between authorities and requires councils to inform carers of their right to an assessment which takes into account their outside interests (work, study, leisure).

View guidance on these Acts at…

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4118023

The Learning Disabilities Observatory is a new initiative aiming to provide better, easier to understand, information on the health and well being of people with learning disabilities. Gathering information from across England, it will help hospitals and other providers of health and social care, to understand better the needs of people with learning disabilities, and their families and carers.

Visit the Observatory website at http://www.improvinghealthandlives.org.uk/

1.5 Why do we need a Health Needs Assessment on Learning Disabilities?

People with Learning Disabilities have the same rights as any other citizen to be treated as individuals within their communities and society as a whole. They have the right to equal treatment and services that can help them maintain a good quality of life. And yet people with Learning Disabilities are amongst the most vulnerable and socially excluded in society. They experience more difficulties in life and have worse health outcomes than the general population.

For many people with Learning Disabilities access to the NHS can be poor and characterised by problems that undermine personalisation, dignity and safety. In recent years there has been significant change in the provision of healthcare for people with Learning Disabilities including the closing of old long stay hospitals, organisational reconfigurations and changes in commissioning.

The NHS must act within disability and human rights legislation and fully understand the requirements around making reasonable adjustments and best interest decision-making. All statutory services have a legal requirement to make themselves accessible to people with Learning Disabilities as with any other disability. The NHS Next Stage Review[i] states that the NHS will 'deliver high quality care for all users of services in all aspects'. For the NHS this will mean full inclusion of people with Learning Disabilities into mainstream services with specialist health services available when they are required.

References

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2. Scope & Methods

2.1 About the Local Area: Surrey

Surrey is one of the ‘home counties’ in the south east of England. It borders Greater London, Kent, East Sussex, West Sussex, Hampshire, Buckinghamshire and Berkshire. Divided into 11 boroughs and districts it is administered by one county council and 11 local councils. Surrey is a relatively affluent area of country, although like anywhere else, it does have its areas of economic deprivation.

The resident population of Surrey is approximately 1.1 million. Compared to England, Surrey has slightly more people in the 35 year and over age group and has fewer people in the 10-35 year age groups. While data regarding the number of individuals with a disability in Surrey are limited, estimates are that there are over 132,000 people aged 18 years and over with long-term limiting illness across the county (Surrey JSNA, 2009).

Currently, the majority of health services in Surrey are managed through NHS Surrey. As a Primary Care Trust, NHS Surrey commissions services such as those provided in hospitals and primary care, as well as providing Public Health input in the form of population-level health improvement initiatives (eg – addressing issues such as smoking and obesity) and health protection (eg – addressing the control of infectious diseases such as influenza). It should be noted that in 2010 the UK government announced a proposal to abolish all Primary Care Trusts and the reorganisation of health service commissioning.

Health services are directly provided within a range of ‘provider’ settings including Primary Care, Acute Hospital, Mental Health, Community Pharmacy and Dental settings. The main providers of Learning Disability Services are the Surrey & Borders Partnership NHS Foundation Trust along with the Social Services operated by Surrey County Council.

2.2 What is a 'Health Needs Assessment'?

A Healthcare Needs Assessment (HNA) is 'a systematic review of the health issues facing a population leading to agreed priorities and resource allocation that will improve health and reduce inequalities' (Health Development Agency, 2002). In short, a HNA looks at the health needs within a particular group of people, and at how those needs are being met by services in the local area. Invariably, a HNA will identify area in which needs are not being adequately met and make recommendations for change.

A HNA needs to be focused. That is, it should examine the needs of a specific *group of people* in a specific *area*. This HNA is focused on the needs of *people with Learning Disabilities* in the area of *Surrey*. This focus, however, does not mean that the situation in other areas is not relevant. It can be useful to place the local situation in context by comparing it to the national situation or the local situation in other, comparable areas of the country.

BOX 2A
What is a 'Health Needs Assessment'?

A HNA reviews the health needs of a specific group in a specific area.

It also looks at what services are in place to meet those needs.

On this basis suggestions for change and improvement can be made.

A wide range of information can be included in a HNA. For example, both primary data and secondary data may be used. While primary data is new information gathered specifically for the purposes of the HNA, secondary data is information already available that may have been gathered for another purpose (eg – local NHS data or a published research study).

Health needs and services develop and change over time, and new information is continuously becoming available. Therefore, a HNA should not be a one-off, static exercise. Rather, it should be a dynamic and developing project that is updated periodically. In particular, it is important to review the extent to which recommendations for change made in previous versions of a HNA have been acted upon and what effect they may have had.

2.3 The Survey: Methods and Limitations

As mentioned above, this Health Needs Assessment will draw upon a range of information sources. These will obviously include secondary sources such as research and other published information. However, as this information may not always meet the specific needs of a local assessment, a survey of people with Learning Disabilities and those that care for them was also undertaken.

Questionnaires were developed and covered a range of issues related to health and healthcare (see appendix for copies of questionnaires). These issues included 1) Demographics & Lifestyle, 2) Self reported health & mental health, 3) Experiences of health care services. The questionnaire drafts were reviewed and revised by service user groups, parents, carers and home managers. They were formatted with pictures and written in an easy read style.

The finalised questionnaires were distributed directly to individuals and via a variety of voluntary agencies, social care services and schools. Distribution was targeted in an attempt to include some of the 'excluded' groups that were identified in VPN (ref) – people with complex needs, BME and newly arrived communities and people with autistic spectrum disorders.

In certain groups, such as Children with Learning Disabilities and Support Workers, only very small numbers of responses were received. To produce a valid statistical analysis (using concepts such as means, standard deviations and any other parameter that relies upon a 'normal' distribution of values) statisticians generally agree that a sample of at least 30 is required (Brase, 2009). Therefore, for the purposes of this Health Needs Assessment, only data from groups represented by samples of greater than 30 respondents were analysed. These were Adults with Learning Disabilities (n=250) and Carers of Children with Learning Disabilities

BOX 2B
Survey Respondents

Respondent Group	Age (mean)	Sex (% male)
Adults with LD (n=250)	48	65%
Carers of Young People with LD (n=155)	13 *	59% *

*(age and sex of person cared for)

(n=155) (see Box 2B). Future survey work is required to gather data from younger people with Learning Disabilities and those who care for adults.

Aside from the lack of an adequate response from certain groups, one other major limitation of the survey was that no information was available on the number of participants who were invited to participate, and therefore on what the response rate may have been. A poor response rate in any survey increases the risk that a ‘self-selecting’ sample may not be representative of the population of interest, and indeed, makes the possibility that a ‘biased’ sample was utilised more likely. For example, one may argue that people included in the sample may be more likely to be those more engaged with health services, experiencing better health, less disabled or from a certain demographic group

The problem of a possible sampling bias is confounded by the fact that little information was available on the level of disability that participants were living with. While information was gathered on accommodation status (see Box 2C) this data cannot be used as a proxy for the level of disability or independence.

BOX 2C
Accommodation Status of Adults with AD Participating in the HNA Survey (n=250)

Accommodation	(%)
“Share with friends & staff”	50%
“Live with family”	20%
“Share with friends”	15%
“On my own”	11%
“Centre for people with LD”	2%
Other	2%

Given these problems, while the findings of the survey will be discussed within the HNA when relevant, they should be treated with caution. In particular, problems with health or health services may have been under reported because, aside from the possibility that a ‘self-selecting’ sample is more likely to be one experiencing better health or well-being, respondents may have felt reluctant to ‘complain’ or ‘criticise’. Therefore, while providing an interesting insight, the survey findings should not be used as the sole basis for conclusions or recommendations.

References

- NHS Surrey and Surrey County Council (2009) Joint Strategic Needs Assessment (JSNA) for Surrey. **[LINK]**
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- Brase (2009) Understandable Statistics. Boston:Houghton Mifflin

3. Prevalence of Learning Disability

3.1 The Nature of Prevalence Estimates

Estimating the prevalence of any health problem or symptom is problematic. Complexity arises from a number of sources, including that from the inevitable variation in definitions, inconsistencies in methods of diagnosis, sampling problems (eg- biased or non-representative samples) and under-reporting (especially when the condition in question is prone to misdiagnosis or stigma).

Attempts to estimate the prevalence of Learning Disability are prone to all these problems. As a result, there is a lack of comprehensive data available on the exact prevalence of learning disability, and further research is needed. Notably, in England, no comprehensive data is kept nationally on the numbers of people who have a learning disability and any figures are based on sources such as registers within social services and estimates in the general population.

Despite the barriers listed above, however, it is still important to attempt to estimate the prevalence of Learning Disability in our local area. Service planning and resource allocation do require some sense of the numbers of people affected and in need of support. Any estimates that are made, however, should be treated with caution and the possibility of inaccuracy (particularly of underestimation) should be kept in mind.

3.2 National Prevalence Estimates

One useful source of information on the prevalence of Learning Disability in England is the report by Emerson & Hatton (2008), which discusses data derived from a number of surveys. The authors' estimations were based upon extracted information from locally held Learning Disability 'registers' on the age and gender of 15,000 people known to services in 24 councils. They combined this with population data from the 2001 Census and made an adjustment for the large number of people who may not use the services surveyed.

Emerson & Hatton estimated that 985,000 people in England have a learning disability (2% of the general population). This figure includes 828,000 adults (aged 18 or more), and of these it was estimated that 177,000 (0.21%) were known users of learning disability services in England (equivalent to 0.47% of the adult population). This latter number is likely to largely represent those with a severe or profound level of Learning Disability.

More recently, data has been published based upon the use of care provided to adults by social services (NHSIC, 2010). This data indicated that 141,715 adult with a learning disability received care in 2009/10, thus giving a comparable (although lower) estimate to that provided by Emerson & Hatton. One explanation for why lower estimates are derived from surveys of service use is simply that not everyone eligible for services actually uses those services in any given period.

3.3 Local Prevalence Estimates

According to the “Valuing People Now: Annual Self-Assessment Report 2009-10”, there are 3341 adults with a Learning Disability in receipt of services from Surrey County Council. Of these, 1400 (42%) are female and 251 (8%) are of non-White British ethnic background. The overall figure represents approximately 0.4% of the Surrey adult population and is therefore comparable to Emerson & Hatton’s national estimates discussed above.

Of course, as also discussed above, those individuals known to social services only represent a small proportion of the number of people with Learning Disability. However, it is also important to have some idea of the numbers of those people with Learning Disability who are not known to services as this group may have significant support needs. In a follow up of the National Child Development Study cohort to age 33, people with mild disability were significantly more likely than their peers to still be living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress (Maughan et al 1999).

Emerson & Hatton estimate that the individuals with a Learning Disability known to social services would represent only around 21% of all adults with a Learning Disability. Extrapolating this proportion to Surrey, one can very roughly estimate that, based on 3341 cases known to social services, there are around 15600 people living with any level of Learning Disability in the county. However, this figure should be treated with caution because, for the reasons discussed at the beginning of this chapter, it is likely to underestimate the true prevalence.

BOX 3A
Prevalence of Learning Disability

The actual prevalence of Learning Disability in Surrey is unclear.

Estimates are that there are well in excess of 3000 cases at the more severe level of disability, with possibly five times as many more cases of less severe Learning Disability.

There are currently 470 children on the Surrey disability register with Learning Disability as their primary diagnosis.

Systems for collecting and sharing data sharing need to be improved as a priority.

In relation to younger age groups, the national Child and Maternal Health Observatory (ChiMat) provides information and intelligence to improve decision-making for high quality, cost effective services. From this, the estimate for the number of children (aged from 5 to 19 years) in Surrey with Learning Disabilities is 3970 in total (with 617 being aged between 5 to 9 years, 1521 in the 0-14 group and 1832 aged 15 to 19 years.

Most population figures and models in the UK have been determined by service contact, often case registers. These can underestimate the true prevalence of LD and co-existing conditions. For children, delay in diagnosis can skew case finding so that prevalence appears higher in 15-19 year olds than younger children. Case ascertainment is more complete in older children as milder disability is more likely to be identified at a later age.

In relation to younger age groups, information is available through the children's disability register (jointly managed Surrey County Council and NHS Surrey). This register holds the names of children and young people with a disability (up to their 18th birthday). The criteria for registration have recently been widened and will now incorporate more children with Autistic Spectrum Conditions. The main purpose of the register is to assist with future planning. Registration is voluntary and does not automatically entitle children access to services but families do receive regular information on services, planning and transition.

There are currently 470 children on the Surrey County Council disability register with learning disabilities as their primary diagnosis. There are an additional 458 with learning disability as a secondary diagnosis. Of these 928 children 559 (60%) have moderate LD and 369 have severe LD. The gender breakdown reflects the predominance of LD in males (60%) (Table 6.3). If the CHIMAT estimates are correct there are around 3000 children with LD who are not known to services.

Healthcare service data can also provide insight into the prevalence of Learning Disability in an area, albeit again limited by reporting limitations and the inherent bias towards more severe levels of disability. In General Practice, for example, systems exist for the recording of people with a Learning Disability (via specific read codes).

In Surrey, at the end of March 2010, there were 3217 people with Learning Disability identified within General Practice registers, which is comparable to the 3341 cases known to social services. However, as there is currently no comprehensive system for cross referencing General Practice and Social Services databases, the extent to which these two groups of individuals overlap is uncertain. Additionally, there is currently no system for attaining a countywide breakdown of General Practice data by gender, ethnicity or age.

Taking more specialist health services, in April 2009, an audit conducted within Surrey and Borders Mental Health Foundation NHS Trust revealed that there were 1048 open cases across all professionals within the Community Teams for People with Learning Disabilities (CTPLD) (excluding psychiatrists). Of these, 5% were under 21 years old and 17% over 60 years old, with just over half (54%) of the CTPLD service users being male. In relation to diagnosis, 23% had genetic conditions and nearly 12% had autism as their primary cause of Learning Disability.

3.4 Future Prevalence Estimates

The report by Emerson & Hatton goes on to address the prevalence of Learning Disability in the future. They argue that at least three factors are likely to lead to an increase in the age-specific prevalence rates for adults with learning disabilities in England over the next two decades. These are: (1) the increase in proportion of younger English adults who belong to South Asian minority ethnic communities; (2) increased survival rates among young people with severe and complex disabilities; (3) reduced mortality among older adults with learning disabilities.

Taking all these factors into account, Emerson and Hatton estimate that the total number of adults with a learning disability (defined as people aged 20 and over) will increase by 8% in 2011 to 868,000, and by 14% in 2021 to 908,000 (from the 2001 figure of 800,000). Significantly, all the growth projection show much higher percentage increases in the number of adults aged over 60. Taking the rough estimate of the total Learning Disability prevalence for Surrey calculated in the previous section (n=15600), this would rate of increase would translate into a total local prevalence of 16330 by 2021.

In a subsequent report, Emerson & Hatton (2008b) went on to examine the impact of this prevalence increase in service use and resources. The authors predicted a sustained growth in the need for social care services for adults with learning disabilities over the period 2009-2026. Average estimated annual increases varied from 1.04% (lower estimate of eligibility, services only provided to new entrants with critical or substantial needs) to 7.94% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs).

3.5 Conclusion & Recommendations

The true prevalence of Learning Disability in Surrey is far from certain. However, examining data across various sources seems to indicate that the number of cases of severe or profound disability may be well in excess of 3000, with the possibility of around 16000 cases of Learning Disability in total. This figure is likely to rise significantly over the next 10 years.

It is clear that reporting and data systems relating to Learning Disability need to be improved. In particular, the lack of data relating to mild and moderate levels of Learning Disability needs to be addressed, as does the compatibility of systems across health and social services.

References

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4. Health Needs

4.1 Defining Health

People with learning disabilities are more likely than other people to have certain health problems. Before we can effectively plan and evaluate health services for people with a Learning Disability, it is important to be able to establish exactly what health issues and needs exist within that particular group.

In thinking about health needs we need to take a broad view of what we mean by the term ‘health’. Indeed, thinking in more holistic terms about health is not a new idea. As long ago as 1948, the World Health Organisation defined health to be “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

Therefore, while this Health Needs Assessment will consider the impact of Learning Disability on more ‘traditional’ concepts of health such as epilepsy and life expectancy, it will also examine issues such as sensory impairment, mobility problems, mental health and self-rated health.

A recent and comprehensive report on the health and well-being of people withy Learning Disabilities was recently published by Eric Emerson and Susannah Baines (2010).

4.2 Life Expectancy and Mortality

People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. For example, Hollins et al (1998) examined 2000 people with learning disabilities registered as service users in two London districts and followed them up for 8 years. They found that people with

Learning Disabilities have an increased risk of early death, with the risk of dying before the age of 50 being 58 times higher than in England and Wales generally. Early death was significantly associated with cerebral palsy, incontinence, problems with mobility, and residence in hospital.

All cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down's syndrome (Tyrer & McGrother, 2009).

BOX 4A
Life Expectancy and Mortality

People with Learning Disabilities have a much shorter life expectancy than the general population.

This is particularly the case for people with more severe levels of disability.

A leading cause of death among people with Learning Disability is respiratory disease.

Life expectancy is increasing among people with Learning Disabilities however. In particular for people with Down's syndrome there is evidence to suggest that for people with mild learning disabilities it may be approaching that of the general population (Puri et al.1995).

In relation to the cause of death, Hollins et al. reported that respiratory disease was the most commonly cited, being the leading cause of death in 52% of the study population. This is compared with only 15% of males and 17% of females in the whole population. Respiratory diseases are discussed in more detail below.

No comprehensive data is currently available for the Surrey area in relation to mortality and life expectancy. Data has been collected on deaths of people with Down's Syndrome and dementia in the Mid / East parts of Surrey by SABP. There have been 49 reported deaths of people with Down's Syndrome in the area since January 2001. The mean age of death was 58.9 years (range 39 – 80). Of these 28 had diagnosed dementia and a further 9 had suspected dementia. In addition, A project looking at people who died whilst living in residential services in East and Mid-Surrey from 2003 to 2007 found that respiratory disease, cardiovascular disease and cancer were the three main causes of death. These causes mirror national trends. The project is being expanded to include community deaths over the next few years.

4.3 Physical Health

There is clear evidence that people with Learning Disabilities have poorer health than the rest of the population and are more likely, at any one time, to be living with an illness or health problem. Specific health problems are discussed individually below, with the focus being on those conditions or issues likely to be more prevalent among people with a Learning Disability. It is of course important to remember that many people will have more than one of these conditions and / or be living with other conditions not listed.

It is also important to bear in mind that illness does not occur independently of social context. In particular, poverty and social support also contribute to the health and social inequalities experienced by certain groups in society. This includes people with learning disabilities, who are more likely to be exposed to poverty, poor housing conditions, unemployment and social exclusion (Emerson & Baines, 2010).

BOX 4B
Some Key Physical Health Issues among People with Learning Disabilities

- Respiratory (Breathing) Problems
- Epilepsy
- Diabetes
- Sensory Impairments (Seeing & Hearing)
- Oral Health (Teeth and Gums)
- Mobility Problems (Walking & Moving)

The association between exposure to such adversities and health status is at least as strong among people with learning disabilities as it is among the general population. For example, it has been estimated that increased exposure to poverty may account for 20–50% of the increased risk for poorer health and mental health among British children and adolescents with learning disabilities (Emerson & Hatton, 2007).

4.3.1 Respiratory Problems

As mentioned in the previous section, respiratory disease is possibly the leading cause of death for people with Learning Disabilities. In relation to asthma, Gale et al (2009) found a prevalence of 12% among adults with a Learning Disability.

The survey conducted as part of this HNA in Surrey (although not directly comparable to Gale et al's survey for various reasons) found a prevalence of 'breathing problems' among adults with Learning Disabilities of 10%. While there was no statistically significant association between respiratory problems and either age or sex, there was a significantly higher rate of breathing problems among respondents that lived on their own (53%) than among other respondents (7%) ($Chi^2 = 20.86$, $p<0.001$).

4.3.2 Epilepsy

Epilepsy, particularly if uncontrolled, can have serious negative consequences on both quality of life and life span. Seizures can be the cause of fractures and soft tissue injuries and there is an increased risk of sudden death. The prevalence rate of epilepsy amongst people with Learning Disabilities has been reported to be between 20% -50%, and at least twenty times higher than for the general population, with seizures commonly multiple and resistant to drug treatment (Branford, 1998).

The prevalence of reported epilepsy within the survey conducted as part of this HNA in Surrey was 17% (42 respondents), with only four respondents reporting that they currently experience seizures. There was no association between reports of epilepsy and either age, sex or accommodation status.

The relationship between epilepsy and learning disability is complex as both are symptoms of an underlying brain disorder or possible brain damage and although the two are not a given together approximately 1/5 of people with epilepsy also have a learning disability (National Society for Epilepsy 2008). Whilst some 2/3 of people with epilepsy achieve long term remission from seizures (Sander *et al* 2007) people with learning disabilities and epilepsy tend to have more frequent, severe and long lasting seizures and they are included in the group most likely to be especially resistant to treatment (National Society for Epilepsy 2008) (Emery, 2009).

4.3.3 Diabetes

Diabetes may be a particularly relevant condition to people with a Learning Disability for a number of reasons. First, they may be more likely to have problems with their weight (see later section on obesity). Second, communication difficulties may lead to delayed diagnosis with consequent complications. Finally, people with a Learning Disability may have difficulty in understanding or carrying out the often fairly complex ways of managing diabetes, including dietary control and use of insulin injections.

Although there is no UK data on the prevalence of diabetes among people with Learning Disabilities, increased rates of diabetes among adults with learning disabilities have been reported in a population-based study undertaken in the Netherlands (Straetmans et al, 2007).

4.3.4 Sensory Impairments

Problems with hearing or seeing can obviously impact greatly on a person's quality of life, and can exacerbate many other issues faced by people with Learning Disabilities such as those relating to communication or independence. In a review, Carvill (2001) estimates that people with learning disabilities are up to 200 times more likely to have a vision impairment compared to the general population. Carvill also highlights that approximately 40% of people with learning disabilities are reported to have a hearing impairment, with people with Down's syndrome at particularly high risk of developing vision and hearing loss.

The data collected as part of this HNA in Surrey indicated that 48% of adults with Learning Disabilities reported some degree of visual impairment. Of these, 18 participants (7% of total sample) reported being blind, while another 15 (6% of total sample) reported being partially sighted. In relation to hearing, 61 (24%) respondents described problems with their hearing, and among these, 5 (2%) reported that they were deaf.

It is, of course, important to remember that any survey based study sample will be more likely to include those without any significant sensory impairment, especially in relation to vision. Therefore, the figures presented above are likely to underestimate the true prevalence of impairments among people with Learning Disabilities.

4.3.6 Oral Health

Oral health is an important contributing factor to overall health and wellbeing. Good oral health is important for communication, good nutrition and positive self esteem and can lead to a reduction or elimination of pain/discomfort in the mouth.

Oral health *and standards of oral hygiene are* often poorer in people with Learning Disabilities. Research suggests that one in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums (Barr et al. 1999). Adults living with their own families have more untreated decay and poorer oral hygiene. Adults living in residential services have more missing teeth (Tiller et al. 2001).

There is increasing evidence of links between poor oral health and general systemic disease. A weak association between periodontal disease and cardiovascular disease and strokes has been described (Beck 1996) and more recently a stronger association of poor oral hygiene modifying the course of respiratory disease (Sjogren 2009). It is estimated that 1/10 deaths from respiratory disease are attributable to poor oral hygiene.

The barriers to oral health that people with Learning Disabilities experience will vary with age and the degree of support required by the individual. In many cases, fear and anxiety are the barriers to dental care in the general population and people with Learning Disabilities have similar concerns. This can be compounded by difficulties in communication and irregular dental attendance. Anxiety, distressed behaviour and difficulty coping and cooperating with treatment increases the need for behaviour management techniques such as conscious sedation and general anaesthesia. Access and provision of these sedation services often requires a referral to a specialist as they are not provided by general dental practitioners.

The oral health survey data collected as part of this HNA in Surrey was self assessed by the patients / carers. The data indicated that 22% of the respondents with Learning Disabilities had problems with their oral health. The majority of these problems were with ill fitting or absent dentures (24%). However there were a significant proportion with gum disease (13%) and missing/no teeth (16%). However as described earlier this data should be viewed with caution.

4.3.7 Mobility Problems

A population-based studies have suggested that people with Learning Disabilities are 14 times more likely to have musculo-skeletal impairments (van Schrojenstein et al. 2000). Of course, mobility problems have consequences beyond those posed to an individual getting around independently. For example, among adults with Learning Disabilities, being non-mobile has been associated with a sevenfold increase in death and being partially mobile has been associated with a twofold increase of death when compared with being fully mobile (Tyrer & McGrother, 2009).

From the data collected as part of this HNA in Surrey, of the 250 adults that responded to the questionnaire, 25% reported that they required assistance with walking. The majority of these (88%) required a wheelchair, walking frame or stick. The rest required a sighted guide due to visual impairment. Whether a respondent required help with walking was unrelated to their age or sex.

4.3.8 Thyroid Disorders

There is a high prevalence of thyroid disorders; hypothyroidism commoner than hyperthyroidism, both congenital and acquired, more frequent in females than males and increasing with age. A "high index of suspicion" is required as the diagnosis of thyroid disorders in people with Down syndrome is difficult. Presentation may be atypical or may be associated with other medical conditions (premature puberty, diabetes mellitus, dementia). A number of immunological and genetic aspects still require further investigation. Management of thyroid disorders is similar to that in the general population but a greater emphasise on screening is required (Prasher, 1999).

4.4 Mental Health and Behaviour

Conditions defined as 'psychiatric' such as depression or schizophrenia are quite distinct from Learning Disabilities. However, the two can occur together, and the prevalence of psychiatric disorders is significantly higher among young people with Learning Disabilities compared to general population rates. Cooper (1997b), in a population based study, estimated prevalence rates for specific mental problems (see Box 4C).

BOX 4C
Prevalence of Mental Health Problems among People with Learning Disabilities

Schizophrenia	3%
Bipolar affective disorder	1.5%
Depression	4%
Generalised anxiety disorder	6%
Specific phobia	6%
Agoraphobia	1.5%
Obsessive–compulsive disorder	2.5%

These estimates should be treated with caution as the exact nature and prevalence of mental health problems with learning disability (especially among adults) is still unclear. As Smiley (2005) points out, most of the research in this area has been carried out on biased samples using inadequate methods of identification, and consequently few results are generalisable. Recent developments include the publication of diagnostic criteria specifically for use in this population (DC– LD) and the development of tools for the identification and diagnosis of mental health problems with reasonable reliability and validity (PAS–ADD).

Challenging behaviour is of course difficult to objectively define. It can refer to any behaviour that puts a person (and others around them) at risk of injury or significant distress. It may, in some cases, include aggression, destructive acts and self-injury. This type of behaviour has been estimated to be exhibited by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49 (Cooper at al, 2009). In Surrey, of the 3341 people with Learning Disabilities known to social services in 2009/10, 470 (14%) were reported to exhibit ‘behaviour that challenges services’.

Challenging behaviour can of course result from the experience of mental health problems. However, this is not always the case and such behaviour can also represent an attempt to communicate distress, fear, pain (resulting from some underlying health problem) or simply an understandable frustration with one’s circumstances. Whatever the cause, this type of behaviour can inevitably interfere with home life and family members, and can affect the person’s ability to be able to interact with health or social services.

4.5 Dementia

Among those over 65 years old, over in 5 (22%) people with Learning Disabilities exhibit symptoms of dementia as compared with 6% among the general population (Cooper 1997). Those with Down’s syndrome may be especially at risk and tend to develop dementia at a much younger age (Holland et al 1998). Unsurprisingly, people with Learning Disabilities are particularly vulnerable to the effects of Dementia and it can be associated with a range of potentially challenging behaviours and health problems.

Surrey and Borders NHS Trust (SABP) has developed a register of individuals with Down’s Syndrome who are screened regularly for signs of dementia in order to better plan and adapt their care. Ongoing assessment in affected individuals provides an accurate and timely assessment of disease progression compared to baseline.

Figures from April 2008 show that across Surrey there were 416 adults identified with Down’s syndrome. In total 345 individuals aged over 30 with Downs are known to the screening programme. Of these 88 (25.5%) were suspected or diagnosed with dementia.

The results of screening for those aged 30 and over is presented in Box 4D by age band. The prevalence of suspected or diagnosed dementia increases with age with the highest proportion of actual or suspected cases in the 60-69 year age band (63.1%).

However a large proportion of those screened (14.9%) were displaying signs or symptoms of dementia under the age of 50. The largest number screened was 100 in Mid Surrey (29% of the total) but the highest proportion of positive cases (37%, 20/85) was seen in East Surrey.

BOX 4D
People with Down's Syndrome Screened for Dementia

Age Group	Number Screened	Number with suspected dementia
30-39	75	3 (4%)
40-49	110	12 (11%)
50-59	102	37 (36%)
60-69	57	36 (63%)
70-79	1	-
TOTAL	345	88 (26%)

In addition to these numbers there were 84 individuals who are awaiting baseline assessments (27 Mid Surrey, 45 East Surrey, 12 SW Surrey, 0 NW Surrey).

National data estimates from the 'Projecting Adult Needs and Service Information' (PANSI) database suggest that there should be 44 individuals aged over 45 with Down's syndrome and dementia. This significant underestimate of national data compared to Surrey actual data highlights the difficulties of applying national prevalence rates to a county with the legacy and complexities of Surrey.

From the survey for this HNA in Surrey, 22% of adults reported that they had problems with their memory (both long & short term) but in many cases this was attributed by the individual to the underlying Learning Disability. It was not possible to ascertain if the individuals reporting problems with memory had Down's syndrome from the information in the questionnaires.

4.6 Self-Rated Health

The method of asking participants to report on their own health may be criticised for the degree of subjectivity involved. Indeed, the extent to which symptom or illness reports are truly an index of physical outcome rather than a psychological outcome is open to debate. Complaining about these physical correlates has been suggested to be a good marker of depression rather than physical ill-health (somatising) (Stansfeld et al, 1993).

However, there are clear advantages to assessing physical health outcomes via self-ratings. One such advantage its relatively simplicity (in comparison to physiological assessment for example). This approach also has the advantage of representing a clear end point and arguably has high 'face validity'. That is to say, the level of symptoms or illnesses experienced by an individual will almost certainly be of direct and immediate importance to them. Thus, self-reported health may be argued to be closer in conceptual terms to the quality of life of the individual.

In relation to people with Learning Disabilities, research has found that one in seven adults rate their general health as not good (Emerson & Hatton, 2008). From the data collected as part of the HNA for Surrey it was evident that there was significant variance in how adults with Learning Disabilities rated their health (see Box 4E).

BOX 4E
Adult's with LD: Self-Rated Health

Really Bad	0%
Bad	2%
OK	24%
Good	45%
Really Good	22%
Not Stated	7%

It is notable that these ratings were unrelated to participants' sex, or the presence of most other health related outcomes (such as epilepsy, sensory impairments or psychological well-being).

However, there was a statistically significant relationship with the participants' age, with older participants giving less positive ratings of their health ($r=-0.21$, $p<0.01$). There was also an association with mobility, with those participants requiring help with walking giving less positive ratings of their health ($t=-2.74$, $p<0.01$).

4.7 Healthy Living & Illness Prevention

Increasingly, the health of our population is influenced by our own behaviour. These include behaviour that worsens our health (eg – poor weight management, smoking) or a lack of behaviour that can improve our health (eg – low levels of physical activity).

In relation to weight management, people with learning disabilities are much more likely to be either underweight or obese than the general population. Poor weight management is, in turn, likely to increase the risk of certain conditions, such as diabetes or heart cardiovascular disease. The most recent data on weight management comes from an analysis of the General Practice Research Database (GPRD) (NHSIC, 2010). The records of 500,000 people with Learning Disabilities were compared to an equal number of individuals without such disability. The data revealed that patients with Learning Disabilities were more likely to be obese (22% vs. 15%), and less likely to be a healthy weight (23% vs. 31%) than those in the unexposed cohort. In relation to who is at most risk, other research suggests that women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity (Emerson & Baines, 2010). An increased risk of obesity will naturally be exacerbated by low levels of physical activity and/or poor diet, which have both been reported among people with Learning Disabilities (Messent et al, 1998; Robertson et al. 2000).

No data on weight management among adults with Learning Disabilities was available from the survey conducted for this HNA in Surrey. The data did indicate that 45% of respondents reported that they engaged in some level of physical exercise, although the nature or frequency of that exercise was unknown. The only factor related to whether or not respondents engaged in physical exercise was visual impairment (53% of those with no visual impairment reported physical exercise compared with only 37% of those with visual impairment) ($Chi^2 = 5.71$, $p<0.05$). A lack of physical exercise was unrelated to age, sex, accommodation status, problems with walking or any other physical condition.

The survey conducted with Parent Carers of Children revealed that 16% described their child as overweight or obese. Just over half of those (56%) who described their child as overweight/obese wanted help in getting their child to lose weight

In contrast to weight management, it seems that problems related to alcohol and smoking are not so prevalent among people with Learning Disabilities. Data from the GPRD in 2010 revealed this group were more than twice as likely to be teetotal than the general population (33% vs. 14%) and less than half as likely to be categorised as drinkers (25% vs. 63%). They were also less likely to have ever smoked (25% vs 40%).

From the data collected for this HNA in Surrey it was evident that 36% of adults with Learning Disabilities reported that they drank alcohol and less than 10% smoked.

In relation to sexual health, a population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases (van Schrojenstein et al. 2000).

4.8 Conclusion & Recommendations

People with Learning Disabilities experience poorer health than the rest of the population. Health inequalities exist across a range of areas, including both physical and mental health outcomes. While some of these inequalities are a result of the physiological issues inherent in the underlying causes of Learning Disabilities (eg – genetic factors), health problems will also be exacerbated by other, more controllable factors. In particular, the accessibility and quality of healthcare services will be a major influence, and these will be examined in the next section.

On a local level, there is inadequate data on the health status of people with learning Disabilities. While the survey data collected as part of this HNA in Surrey may provide some insight into levels of morbidity, it is insufficient and likely to underestimate true prevalence. Multiple sources of information, including those from General Practice, need to be collated and used to more reliably describe the health problems of people with Learning Disabilities in our local area.

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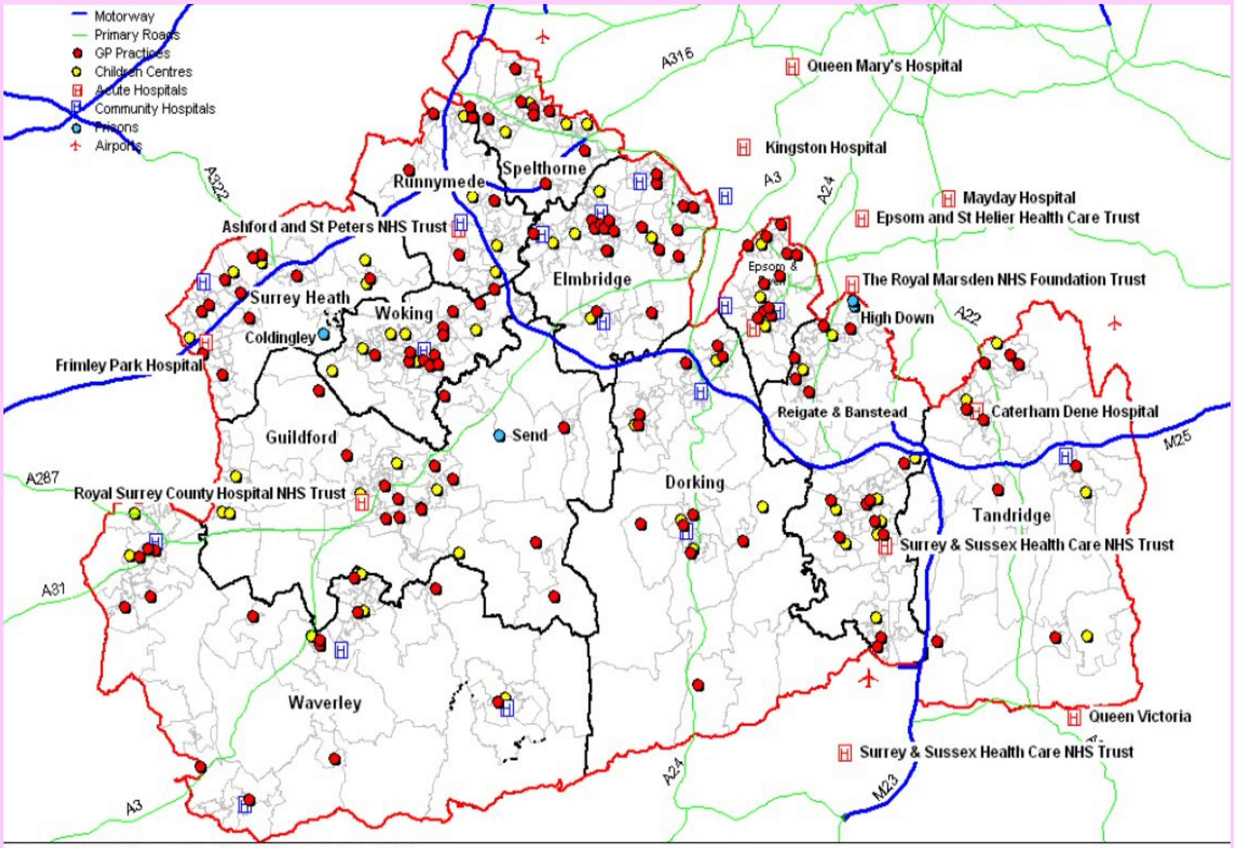
5. Health Services

5.1 Healthcare Services in Surrey

There is a wide range of healthcare services and organisations in Surrey. Aside from NHS Surrey (the local Primary Care Trust) and Surrey County Council, there are several Acute Hospital Trusts, a large network of primary care services (eg – General Practices, Dentists etc) and the mental health services provided by Surrey and Borders Partnership NHS Trust (see Box 5A).

BOX 5A
Map of Healthcare Services in Surrey



Source: ONS Geography, Health Boundaries, 2008

In relation to Learning Disability, all of these types of healthcare services have a role to play. In addition, health is also influenced by the work of other agencies that focus upon issues such as housing, education and employment. Therefore, a major challenge that should be acknowledged from the outset is that of effective collaboration. Appropriate liaison, information sharing and joint-working in relation to service provision are essential if services are to be provided effectively and efficiently.

In working towards this, a number of cross-organisational agencies have been established that aim to bring together commissioners, service providers and service users. These include the Surrey Learning Disabilities Partnership Board. The Partnership Board was set up in October 2001 as a first step towards implementing Valuing People, the Government White Paper on learning disabilities. It is based on recognising people's rights as citizens, community inclusion, choice in daily live and opportunities to be independent.

5.2 General Practice

In Surrey, 2009/10 figures show that there are 139 General Practices in Surrey. These Practices are the first point of call in relation to many health issues and services. Aside from providing health care services directly, General Practice acts as the gateway to many other services such as those provided by hospitals or mental health professionals. As such, the quality and accessability of General Practice services are crucial, particularly for groups who may experience vulnerability to ill-health such as people with Learning Disabilities. What is more, given recent Government proposals to switch a large proportion of commissioning responsibility to General Practice, the influence of these settings over the quality of healthcare is sure to increase even further.

It is important to note that a range of healthcare professiocals work within General Practice settings. Aside from doctors (GPs) a patient may receive care from nursing staff, physiotherapists and other professionals. Also very influential when it comes to the quality and accessability of General Practice services are the Practice Managers and administrative staff (such as receptionists). When it comes to an issue such as Learning Disabilities, all staff in General Practice settings need to be aware of best practice and operating in a way that accomodates any needs that may arise.

Based on Learning Disability prevalence estimates (see Chapter 3) an average GP practice with a list size of 2029 per wte per partner may be expected to have approximately 8 people with severe Learning Disabilities and 41 with mild to moderate Learning Disabilities on their list. On average an individual who has been discharged from a long stay hospital requires 4 times as much workload from GPs as people without LD. Their prescribing costs are on average 6 times greater (Chambers 1998).

BOX 5B
Satisfaction with General Practice
(Adults with LD)

Rating	%
Really Good	22%
Good	44%
OK	25%
Bad	1%
Really Bad	1%
Not Stated	7%

The survey carried out for this HNA in Surrey provided data on how satisfied adults with Learning Disabilities were with their General Practice services. Respondents rated their satisfaction from 1 (‘really bad’) to 5 (‘really good’) (see Box 5B). The results indcated that two thirds of the respondents felt that the services they received were either ‘Good’ or ‘Really Good’ with a very small minority (2%) giving ‘bad’ or ‘really bad’ ratings.

While these results are very positive, it was also notable that 17 respondents declined to answer this question, raising the possibility that a 100% response rate may have revealed more negative ratings. In addition, it can be difficult to interpet the response of ‘OK’, and it least in some cases, this response may indicate a moderate level of dissatisfaction (together with a reluctance to go as far as giving a ‘bad’ rating’). It is notable, for example, that some of the free text responses that were associated with ‘OK’ ratings included “It’s often a bit rushed” and “Difficulty seeing doctor, feels there is little consultation time to discuss health issues”.

Ratings of satisfaction with General Practice were unrelated to demographic or other health related factors. The only exception was that the data suggested a statistically significant association between rating General Practice positively (ie- ‘Good’ or ‘Really Good’) and giving positive ratings of one’s own health (again ‘Good’ or ‘Really Good’). Specfcially, among those respondents rating their own health positively, 79% also rated their General Practice positively. However, among those respondents not giving a positive rating for their health, only 51% rated their General Practice positively ((Chi^2 = 17.70, $p<0.001$). This association may simply reflect a general tendency among a proportion of individuals towards positive satisfaction ratings. However, it is also possible that those individuals feeling less well are having their needs less well met within General Practice. Without further investigation, of course, such interpretations must be treated as speculative.

In order to enhance the extent to which people with Learning Disabilities are appropriately cared for in General Practice, and more generally across the health service, Surrey has appointed Dr. Jill Rasmussen as a GP with Special Interest. Dr. Rasmussen operates as a clinical champion, sitting on a range of committees and working groups relating to Learning Disability (as well as mental health) and delivering on projects aimed at enhacing care. Her work has recently included an audit of the Learning Disability Directed Enhanced Services agreemement (see below).

5.3 Annual Health Checks

One relatively recent development concerning General Practice has been that of Enhanced Services. These aim to plug a gap in essential services or deliver higher than specified standards, with the aim of helping reduce demand on hospitals and other providers of secondary care. Directed Enhanced Services (DES) must be provided within all areas, while Local Enhanced Services (LES) are locally developed and are designed to meet the specific health priorities that have emerged in a particular geographical area. A Directed Enhanced Service (DES) for Learning Disabilities was introduced in 2008 which focused on increasing the delivery of Annual Health Checks.

The DES gives general practices the opportunity to be financially rewarded for ensuring that people within their practice identified as having a learning disability are offered an annual health check. The DES makes provision to help GPs improve the accuracy of information about people with learning disabilities on their patient register. A requirement of the DES is that General Practice staff attend appropriate training in relation to Learning Disability and Annual Health Checks.

The Annual Health Check covers a wide range of issues relating to the patient's physical and mental health. Included in a health check will be the provision of relevant health promotion advice, a chronic illness and system enquiry, a physical examination, a consideration of whether the patient suffers from epilepsy, a consideration of the patient's behaviour and mental health, a specific syndrome check; checks on the appropriateness of any prescribed medicines and a review of coordination arrangements with secondary care.

The DES targets the provision of health checks towards adults with a learning disability who have the most complex needs and therefore are most likely to benefit from an annual review of their health needs. People with learning disabilities known to Social Services are likely to be people with moderate/ severe learning disabilities or people with mild learning disabilities and additional complex needs and it is these people that should be identified by each local authority and this information shared with Primary Care Trusts to enable health checks to be offered (PCC, 2009).

People who have a mild learning disability should still be identified as part of the learning disability QOF register. Whilst these individuals are not directly covered in relation to the Annual Health Checks aspects of the DES, Practices should consider that these individuals may still require regular reviews of their health needs, and indeed, have the right (under Disability Discrimination legislation) to expect that reasonable adjustments or enhancements should be made to healthcare services in order that their needs be met.

An audit of how the Learning Disabilities DES has been operating in Surrey was carried out by Dr. Jill Rasmussen across 2009/10. At the time of the audit, 60 out of the 139 General Practices in Surrey (43%) had signed up to the DES. Of these, 51 (37% of all practices) had completed the required DES training. A total of 601 annual health checks had been undertaken by practices and paid for by the PCT.

A total of 59 practices (42%) of the 139 General Practices in Surrey responded to the audit questionnaire. Of these, 29 were practices that had signed up to the DES, with the other 30 not having signed up at the time of responding. The audit revealed that, 468 health checks had been carried out by the 29 DES practices responding to the audit. While these 29 practices represent less than half of the 60 practices signed up to the DES, it seems that they do represent most activity, completing among them over three-quarters of the 601 annual health checks known to the PCT.

No significant differences emerged between the DES and non-DES practices in relation to overall practice size or the number of patients on the Learning Disability Register. There was also no significant difference in staffing levels (either in relation to the numbers of doctors, nurses or other staff). Most practices signed up to the DES (75%) reported using a template for the annual health checks. They also reported an average Annual Health Check duration of 55 minutes.

A number of issues were raised by Practice teams in relation to their engagement with the DES. These included complications in identifying which patients were eligible for an Annual Health Check under the DES, issues relating to previous enhanced service agreements relating to Learning Disabilities and the issue of ‘out of county’ patients.

More recent data has come from the Department of Health quarterly audit of Annual Health Checks across the 152 English PCTs. This reveals that, as of the end of September 2010 only 18% of those estimated to be eligible for health checks had received one, This figure is low by comparison to other areas, putting Surrey in the lowest 15% of PCTs.

Aside from the general Annual Health Checks, people with Learning Disabilities should of course be invited to attend more specific screening appointments (such as those relating to cancer). Unfortunately, however, there is no specific data to demonstrate that people with Learning Disabilities are sent screening invitations in a targeted manner that is appropriate to their disability- e.g. easy read invitation. There is also no evidence that invitations and take up of cancer screening among people with Learning Disabilities are systematically monitored by General Practices.

5.4 Health Action Plans

Annual Health Checks are greatly enhanced by Health Action Plans. Health Action Plans were originally introduced in the 2001 white Paper, *Valuing People,* followed shortly by practical guidance in *Action for Health* (2002). They are individual health plans written for (and by) people with learning disabilities. The purpose is to identify health actions that will make a positive difference to the health and well being of the individual. Properly completed and maintained Health Action Plans have been demonstrated to help people with Learning Disabilities become more involved in self care as well as enabling carers and support workers to better meet their health needs.

Just like the Annual Health Checks, the Health Action Plan should cover a wide range of physical and mental health issues, and as such, make reference to the equally wide range of services that may provide care (including family carers). should include Information should be included on appropriate management interventions (e.g. long term medication), monitoring existing health needs (e.g. annual health check), health promotion activities (e.g. nutrition, oral health) and disease prevention (e.g. screening, immunisation).

BOX 5C
Health Action Plans should be...

- Based on a patient's own perspective & views, not just those of health professionals.

- Wide ranging, including physical and mental health

- Current and regularly updated

- Acted upon – not just filed away.

Health Action Planning should also be a 'Person-Centred' process. That is, it should be based on the patient's own perspectives on their health needs and what may be put in place to maintain or improve health. However, a Health Action Plan will of course benefit from the input of others, especially when a person's level of disability is high. Carers, healthcare staff and support workers are just some of those that may be involved. As such, training on how to complete and compile a Health Action Plan has been made available across Surrey for carers and support workers. In addition, web-based resources and guidance have been developed specific to Health Action Planning at

www.surreyhealthaction.org including a tool to help healthcare staff create Easy Read health check appointment letters.

Data was collected as part of the survey conducted for this HNA in Surrey. Of the 250 adult respondents with Learning Disabilities, 56% reported that they had a Health Action Plan, with 38% reporting no Health Action Plan and 6% not responding. Of the 80 parents who responded to the survey, 15% of their children had a Health Action Plan. The majority (92%) of those whose child had a Health Action Plan found it useful and 50% of the plans were up to date. Two thirds of the parent carers whose children had plans had received training. 16 parents whose children did not have a plan stated that they would like training in health action planning.

Among the adults, a number of factors were found to be significantly associated with the likelihood that a person reported having a Health Action Plan. First, in relation to other types of disability, those requiring help with walking and those with visual impairments were more likely to have Health Action Plans than those without such problems ($\text{Chi}^2 = 14.17$, $p<0.001$; $\text{Chi}^2 = 10.14$, $p<0.005$).

In relation to accommodation, those who lived alone were significantly less likely to have a Health Action Plan than those living with others ($\text{Chi}^2 = 10.14$, $p<0.005$). Finally, in relation to age, those with Health Action Plans were (on average) significantly older than those without plans ($t=6.98$, $df=220$, $p>0.001$). No other factors, including sex, self-rated health or the existence of other health problems seemed to be associated with individuals having Health Action Plans.

5.5 Hospital Services

For people with Learning Disabilities going into hospital is likely to be complicated, and potentially stressful, for a wide range of reasons. First, they are likely to find it more difficult to communicate any fears or distress regarding their condition or the impending treatment. For example, they may be less able to explain any pain or discomfort they may be in. Second, people with Learning Disabilities may have difficulty in adjusting to the hospital environment and routines, which will be exacerbated if hospital staff do not know or understand their mental, physical and personal care needs. Third, it follows from the previous two points that a person with a Learning Disability may well have had poor experiences of healthcare in the past, which will naturally make them defensive against treatment or efforts by staff to help them.

A local audit of admissions to hospital from residential and care homes was carried out covering the period April 2006 to March 2009. The address of the home was mapped to the summary care records and where an NHS number was present this was matched to inpatient admissions data. During this time period records were found for 392 patients with 902 admission episodes indicating that some individuals had more than one admission. There were on average 25 admissions per month and the majority of the admissions recorded were for women (55%). The majority of admissions were for gastrointestinal disease, injury and signs/symptoms that could not be classified in any of the other categories.

It is likely that the figures quoted above represent an underestimation of the true number of people with Learning Disability admitted to hospital from residential and care homes. A range of factors, including inconsistent recording of NHS numbers and failures to record Learning Disability status, would inevitably have contributed to this underestimation.

Guidance on improving how people with a Learning Disability are supported when in hospital has been published (‘Working Together’ - HFT, 2009). Aimed at hospitals, families and paid support staff, the guidance was based on the principle of good preparation, effective communication and the importance of listening more to the families and support staff. In line with this, an emphais is placed on the use of tools for clearly recording key information about the individual with Learning Disability, their health and preferences prior to a hospital admission.I

In Surrey, resources were identified to recruit three full time nurses to work with the five acute hospitals and with Surrey and Borders Partnership NHS Foundation Trust to close the gap between primary, community and acute hospital care for people with Learning Disabilities. When recruitment into the three posts was completed int he Summer of

2010 it was the first time a group of NHS Hospital Trusts has teamed up to provide the new Learning Disability Liaison Service across a whole county.

The role of the Liaison Nurses can be wide ranging. When someone with Learning Disabilities goes to hospital they will assess their needs and work with ward staff to determine what reasonable adjustments can be made, such as allowing extra time for their appointments or offering additional staffing during a hospital stay. The primary aim is to ensure that a programme of care is in place, as well as to offer reassurance and assisst in the communication of needs.

Box 5D: Hospital Passport

Please return my passport to me when I am discharged

My Hospital Passport

My name is:
I like to be known as:
Type of home I live in:
E.g. supported living, family home
Hours of staff support I get each day:
Who to contact for more information about me:
Adverse drug reactions or allergies

If I go to hospital this book needs to go with me. This is essential reading for all hospital staff working with me. It gives important information about me. This book should be kept at the end of my bed, with my notes, and used when you talk to me.

Things you must know about me
Things that are important to me
My likes and dislikes

Filled in by:
please sign here
Date:

The work of the Liaison Nurse team has been supplemented by the development of the Hospital Passport resource (see Box 5D). The aim of the passport is to capture key information about the needs of a person with a Learning Disability as part of the pre assessment for planned admissions. They form an invaluable source of Information if prepared as part of a Health Action Plan taken to hospital by the carers to support with an acute admission. If used correctly (and in conjunction with other resources such as the Hospital Communication Book) the information contained in the passport can support acute hospital staff in understanding the person's specific needs and support in the provision of reasonable adjustment.

The development of the Hospital passport was a collaborative process. For example, it included a service user panel both to assist with the design and give valuable feedback regarding accessibility for people with Learning Disabilities. In addition it has been approved by the 5 acute trusts within which it will be used across Surrey. The

Passports are now being promoted across a range of settings and organisations, as well as on-line at **www.surreyhealthaction.org** which includes information not only on the passports, but on other tools such as the Hospital Communication Book and Hospital Questionnaires.

As a new resource, it will be important to obtain qualitative and quantitative feedback from service users, their carers, paid support staff, nurses and other clinicians at the end of each hospital stay. This data will be collected and reviewed to identify any changes needed and improvements that can be made.

Key challenges in the implementation of the Hospital Passport project will include the effective identification of people who need the passport prior to admission, obtaining appropriate information from people with a Learning Disability (as well as carers or support staff), using the admission protocols to support with communication gathering and implementation of the passport, using the passport information to ensure best practice and to support acute staff in understanding individual needs and identifying where to get additional support when required from specialist services.

5.6 Specialist Learning Disabilities Services

Following the recommendations in Valuing People Now, NHS Surrey is in the process of transferring the commissioning and funding of social care for adults with Learning Disabilities to the Local Authority. The aim of the change is to ensure that the correct functions lie with the authority with lead responsibility and so that the PCT can focus on meeting the health needs of people with Learning Disability.

In Surrey the social care of approximately 856 individuals will be transferred. Of these, 778 individuals are currently in residential care, 25 in nursing care and 53 at home. Resources transferred under these arrangements for social care purposes can form part of an individual budget. It is government policy that this transfer should continue beyond the deaths of individuals previously living in hospitals in order to meet the needs of new generations entering services. From 2011 the funding for these services will be given directly to Surrey County Council.

The majority of adults with Learning Disabilities have their health needs met by mainstream health services. There is a significant minority of people with Learning Disability who need to access specialist care. These may be individuals with severe challenging behaviour, severe mental health problems, profound and multiple learning disabilities or complex health needs.

There are eight Community Teams for People with Learning Disabilities (CTPLDs) in Surrey (2 x E.Surrey, 3 x mid Surrey, 2 x SW. Surrey, 1x NW. Surrey). Their aims are to improve the coordination of service delivery, provide better continuity of care and consider the specific needs of individuals and their families. The teams provide assessment, support, advice and therapeutic interventions in partnership with users, carers and a range of statutory and voluntary organisations. Interventions may be with individual clients or by providing advice and support. In addition to interventions the teams provide training to a variety of agencies.

At April 2009, there were 1048 open cases to the teams, excluding psychiatrist's caseloads. Of these, 53.9% of the CTPLD sample were male, 236 (22.5%) people had genetic conditions, and 121 (11.5%) had autism as their primary cause of Learning Disability with 53.4% of unknown aetiology.

The CTPLD structure and function is currently under review as they have historically had differing numbers and availability of healthcare professionals as well as different referral criteria. For example teams in the East and Mid Surrey have managed adults and children, while the team in the North West is not multidisciplinary. Teams in the east and south west of Surrey provide specialist support for challenging behaviour that impacts on an individual's quality of life. In the west of the county the Specialist Community Assessment and Treatment Service (SCATS) provides an additional domiciliary assessment and treatment and outreach service.

The challenges facing CTPLDs in providing a needs led integrated service in the community are role ambiguity, failing to provide a coordinated response and organisational accountability. In future CTPLDs will have a designated link into children's teams.

In relation to Residential (Social Care Change Programme) & Campus projects, there has been considerable progress on the transfer of residential care homes from Surrey & Borders NHS Partnership Foundation Trust (SABP) to the independent sector. A total of 26 homes across Croydon and East Surrey having transferred by 31 March 2011, leaving 6 'transfer' care homes to resolve.

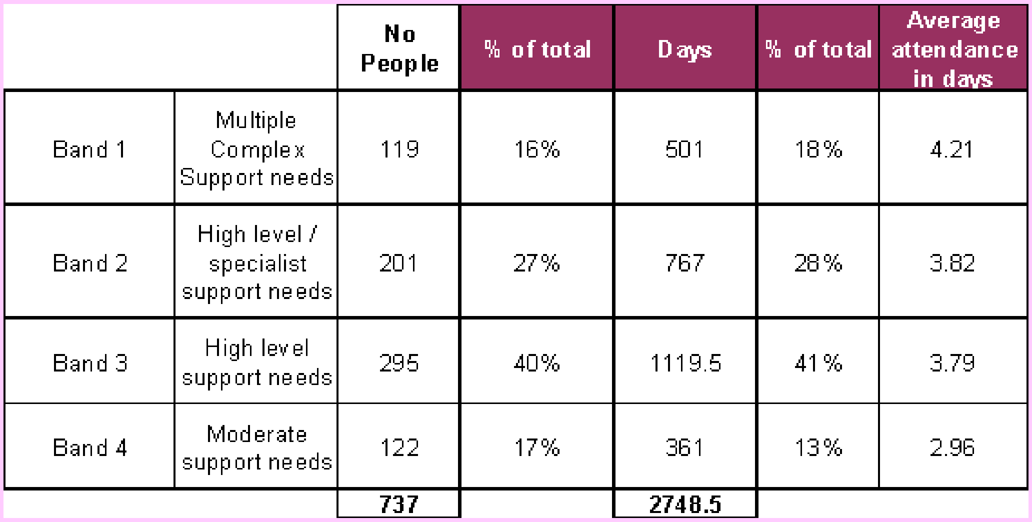
The care & support provided in the 'development' homes are being re-provided in new services on a phased approach. To date, 10 for development homes have closed with new services being identified for the individuals based on their individual assessed needs. There are 13 development homes left to be resolved and it is expected that these will be re-provided for by the end of June 2011.

For the campus reprovision, Surrey & Borders has reconfigured some of the homes as the occupancy levels have reduced across the campus. The Capital for accommodation has been released and new accommodation is being procured. It is expected that residents will start to move into the new accommodation from June 2011.

Surrey County Council In-House Day Services are currently accessed by 737 adults ranging in age from 20 to 93 years old (see Box 5E). The modal age group for individuals accessing day services is 41-45 years of age (average age 44). Of the individuals accessing services 16% (119 individuals) have complex or multiple needs and this group receive 18% of the services provided. The majority of those accessing day services (67%) require daily support (69% of service) and only a small proportion (17%) have lower levels of need. Aside from those accessing in-house day services, a large number (circa 2000) people with Learning Disabilities attend activities from residential care providers, domiciliary care agencies and private or voluntary day service providers.

Surrey & Borders Partnership NHS Trust also provides day services: *Gallwey* site provides day services and work experience for people with Learning Disabilities and complex needs. *Ellen Terry* day services also serves people with Learning Disabilities and challenging behaviour. The *Geoffrey Harris Unit* and the *Geesemere* day service also provide sedentary and physical daytime activities for people with multiple and complex needs.

Box 5E: County Council Day Service Use



		No People	% of total	Days	% of total	Average attendance in days
Band 1	Multiple Complex Support needs	119	16%	501	18%	4.21
Band 2	High level / specialist support needs	201	27%	767	28%	3.82
Band 3	High level support needs	295	40%	1119.5	41%	3.79
Band 4	Moderate support needs	122	17%	361	13%	2.96
		737		**2748.5**		

5.7 Dental Services

As already discussed, there is evidence to show that people with a Learning Disability experience poorer general and oral health and have many unmet needs in this area.

In Surrey there are 198 dental practices offering a range of treatment options both privately and on the NHS. Data collected for this HNA in Surrey from parent carers of children with Learning Disabilities addressed the issue of dental services. Specifically, parents were asked about their rating of their child's annual dental check up. Although the majority rated the experience as good (44%) or really good (34%), some reported a poor experience (7%).

People with Learning Disability will often require additional care, however, and this can be met within Special Care Dentistry which is concerned with the improvement of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors.

Provision of Special Care Dental services is available through the Salaried Dental Services, Hospital services and a few general dental practitioners who are willing and able to provide the care for this client group. Within Surrey there are currently two Salaried (Special Care) dental services offering specialist dental care for people with a range of dental special needs. This includes those who have a Learning Disability which prevents them from accessing mainstream dental care. In 2010 Selina Master was named Surrey Community Health Valuing people Champion for Oral health and has established a Special Care Dentistry working party.

The *Surrey and Sussex Salaried Dental Service based at* East Surrey Hospital (ESH), run a clinic once a week that only provides care for patients with profound disabilities. People with a mild Learning Disability are also seen in the general clinic at ESH, at Dorking, Caterham Dene Hospitals and Merstham clinic. Referrals to the service are usually made by a general dental practitioner (GDP) but can also be made by a General Medical Practitioner if an individual is not already registered with a GDP. Patients are triaged by the senior dental nurse and allocated to the appropriate clinic or for a domiciliary visit. Data on triage is currently unavailable. Figures from the Special Care Dental department from April 2008 to March 2009 show that there were 39 general anaesthetic (GA) sessions in which there were 104 GA cases. In addition there were 12 assessment clinics in which 207 patients were assessed.

Surrey Community Health (SCH) Special Care Dental Service is available from clinics based at 19 locations across the county. They also provide dental treatment under general anaesthetic at Frimley Park, Epsom General, St Peter's and Ashford Hospitals. Although many patients have a learning disability, separate data is not recorded.

In addition, Surrey Community Health Dental services provide NHS Access at 3 Dental Access centres for people who find it difficult to register with an NHS dentist. These are located in Epsom, Woking and Guildford, and details can be found at *www.surreyhealthaction.org*. Some patients with a learning disability may be referred to the special care dental service as a result of a visit to an Access Centre.

All patients are graded by case mix (medical status, oral risk factors, ability to communicate, ability to cooperate, access and legal barriers) and the communication category does include Learning Disability as one of the possible causes of communication restriction. Exact details however are not recorded

In 2010, a Valuing People Learning Disability feasibility pilot project was carried out in Surrey. A primary aim was to examine links between the GP Annual Health Checks and an annual Oral Health Check. Unfortunately, it was found that General Dental practitioners were reluctant to participate within the study. Reasons included funding issues as well as a perception of a lack of appropriate skills when dealing and treating people with a Learning Disability.

Data suggests that there may be a lack of consistency in the Acceptance and Discharge policies between the two Special Care dental services for people with Learning Disability. Survey data suggests that very few patients are referred by General Medical Practitioners (GP’s) and that attendance rates are low. This may be due to a number of contributing factors e.g. lack of escort/carer, dental phobia or failure of onward referral from GPs. It was also noted that patients who had been referred did not have an existing Oral Health Action plan indicating a lack of dental awareness.

The report recommended that Surrey needs to develop an action plan to include a clear and easy to understand referral system and treatment pathway that is standardised and adopted across the whole county. Feedback from valuing people groups suggested that oral health promotion should be increased amongst carers and support workers.

In 2011 it is hoped that salaried Special Care Dental Services in Surrey will work together to agree equitable access and provision of care across the county using nationally recommended integrated care pathways for people with a Learning Disability. Agreed quality outcomes will be required, as will a comparable and accurate means of data collection.

Additionally, and in collaboration with the Valuing People Health Care group, CTPLD’s, the clear Communication People Ltd, and other stake holders, will continue to finalise and implement the Oral Health Action planning tool. Following training for Salaried special care dental staff, this will hopefully be rolled out in due course to General Dental

Practitioners. Ideally these would also be shared with General Medical practitioners and health care facilitators to become part of an integral Health Action Plan.

Following the training and accreditation of Oral Health Promoters in Active Support, in relation to the maintenance of good oral hygiene (planned for May 2011) it is hoped that an Oral Health training package will be developed and instigated for carers and Health care facilitators who support people with Learning Disabilities. An easy-read guide to looking after your teeth and gums has been produced for *www.surreyhealthaction.org* to accompany information on accessing dental care.

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5.8 Transition Services

The transition from adolescence to adulthood is a critical time. If planning and services to support transition are not in place there is a high risk of social exclusion. The Surrey Transition Service is for all young people including those with physical disabilities. Young people will stay with the Transition Team for around 2 to 4 years depending on their individual circumstances before moving on to the Adult Team in their local area.

The Transition Planning Team estimates that during any 5 year period approximately 595 young people with a registered disability will leave full time education. Of these children approximately 477 (80%) will have some degree of learning disability. This averages at approximately 95 young people a year.

Therefore at any one time the Transition Team may have a caseload of 300-400 cases. The majority of young people will continue their education for 3 years at a local or residential collage. Of the 477 only approximately 12 will be referred to and access Surrey County Council day services.

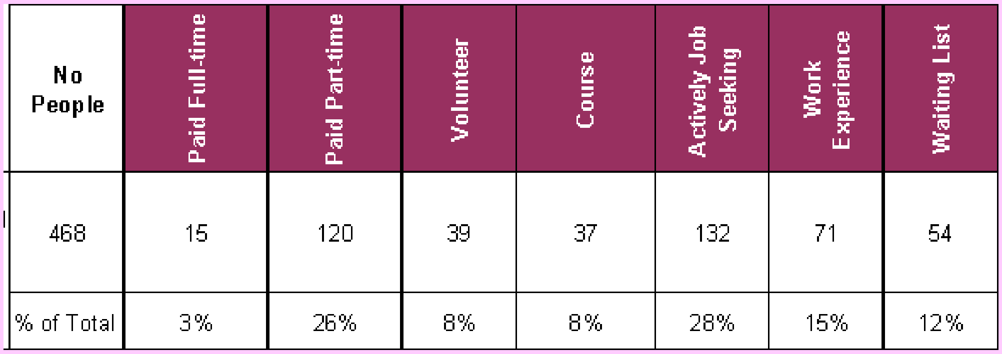
As of the summer 2010, 154 young people were currently receiving packages of care. The team provide a range of services including helping to smooth the transition from a Children’s Social Worker to Adult Services, working with parents/carers to discuss future services options (eg- a place on Housing Register etc), Carers Assessments where necessary and linking with key partners (Schools/Connexions/Health etc) to ensure they are aware of the role and function of social care support.

Government policy, as set out in *Valuing People* is that by 2012 young people with Learning Disabilities aged 14 – 19 yrs should have person centred reviews of their needs. In Surrey, a Person Centred Transition Review Pack has been developed that is now being used to aid this process. Notable for the purposes of this Health Needs Assessment is that all transition plans and year 9 reviews contain a section on health needs (akin to the Health Action Plan discussed above).

Getting the right educational support in the right setting is key to helping children with Learning Disability reach their potential and be part of society. Social exclusion can occur for many children with Learning Disability at the point of access to nursery school. Surrey County Council has 23 special schools and 50 specialist centres (some of which specialise in Learning Disability). Children with moderate Learning Disability attend specialist resource centres which are integrated with primary schools. Each of these has a roll of between 10 and 12 children. In general all Surrey County Council maintained special schools have a named Community Paediatrician.

A crucial issue for young people transitioning to adulthood is their entry into the workplace. EmployAbility, the Surrey County Council supported employment service, supports over 450 people between the ages of 19 and 25 with varying support needs to find and maintain work and volunteering opportunities (see Box 5F).

Box 5F: Employability Service Use



No People	Paid Full-time	Paid Part-time	Volunteer	Course	Actively Job Seeking	Work Experience	Waiting List
468	15	120	39	37	132	71	54
% of Total	3%	26%	8%	8%	28%	15%	12%

In addition, Connexions Surrey, now part of Surrey County Council, provides advice and support on education and employment to all young people from 13-19 years old (up to 25 years old for young people with learning difficulties and disabilities) through Connexions Personal Advisers. Connexions Surrey also provides targeted support for vulnerable young people who are at risk of becoming or who are already not in employment, education or training (NEET), for example projects to support teenage parents into employment, education or training. Figures from December 2009 state that the total number of 16-18 year old people known to be NEET in Surrey was 1062. Of these 486 (46%) are NEET due to learning disabilities or learning difficulties.

5.9 Health Services in Prison

There are many difficulties in the provision of health services t for people with Learning Disabilities in the criminal justice system, and specifically, within prisons. At the root of many problems is the issue of appropriate identification and assessment.

The Health Needs Assessments for the 4 HM Prisons in Surrey and 1 Young Offenders Institute were completed in 2009-10. The HNAs identified that services in Surrey prisons need to improve and that there needs to be improvements in identifying prisoners with Learning Disabilities. In response to the HNA, NHS Surrey has redistributed funding to a Learning Disabilities Nurse specialist post, which will assist in implementing screening questions for Learning Disability at reception, training health and prison staff in how engage prisoners with LD, support access to healthcare services, develop health action plan and deliver annual health checks.

Funding has also been allocated to support the development of "easy read" material relevant fro people in prison. Post will be advertised during 2010. NHS Surrey is also conducting a review of the community forensic pathway and court diversion scheme to assess whether Surrey is "Bradley" compliant.

5.10 Conclusions & Reccomendations

There are a wide range of services available to people with learning Disabilities in Surrey. While in some areas great progress has been made (eg: Acute Liaison Nursing Service) there are other areas in which there is still room for improvement. For example, referral systems and treatment pathways in relation to dental care are in need of development that are standardised and adopted across the whole county.

Fundamental to many problems, and indeed solutions, may be planning. Most notably, the accessability of Annual Health Checks and Health Action Plans needs to be greatly improved. More widespread engagement in these initiatives is urgently required within General Practice and beyond.

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7. Specific Recommendations

1. An annual review of this Learning Disability Health Needs Assessment should be conducted, including the insertion of new data, updates on progress against recommendations, and the creation of new recommendations if appropriate. This should be the responsibility of the Public Health Department.

2. All agencies, including County Council, NHS Surrey and General Practices, should maximise access to common data they hold to avoid duplication of effort and speed up the development of care plans and risk assessments

3. A survey to collect Learning Disability data held within General Practice should be conducted in order to inform future commissioning (coordinated by Public Health at NHS Surrey). Specifically data should be made available on:
   - the age, ethnic background, diagnosis (including autism), level of disability and parental / caring responsibilities of people with Learning Disabilities
   - annual health checks and screening uptake (eg – cancer, retinal, etc)
   - carers age and ethnic background

4. The proportion of people with Learning Disability with an up to date Annual Health Check should be significantly increased. Again this should be driven by incentives within contracts (eg – LES) with General Practice.

5. Health Action Planning should be made more widespread in relation to both the numbers of people with an up to date plan, and the numbers of staff (across all health and social care organisations) receiving training in their use.

6. The Learning Disability Liaison Service in Acute Hospitals should be maintained and expanded. This should include raising greater awareness of the service, as well as important tools such as the Hospital Passport. This should be the responsibility of the Acute Liaison Nursing Team supported by the local NHS Trusts and Surrey County Council.

7. The Care Pathway for people with Learning Disabilities and Epilepsy needs to be examined and improved. Agreed assessment procedures should be maintained along with awareness training for health professionals. Consideration should be given to the appointment of a Coordinator specific to Epilepsy care pathways for people with Learning Disabilities. Possible funding routes include CQUIN agreements with either the Acute Hospital Trusts or SABP.

8. Data collection should be carried out, and plans for improvements implemented, in relation to the 'reasonable adjustments' being made by professionals such as dentists, physiotherapists and optometrists for the care of people with Learning Disabilities. These should be taken forward by NHS Surrey via its liaison with Local Professional Committees.

9. The data collected on people with Learning Disabilities in Prisons should be improved, with a particular focus on screening at the point of reception. Prison health services should provide regular (eg – annual) reports on the numbers of

people with Learning Disabilities in their care, broken down into age, sex, ethnic background and level of disability. Reasonable adjustments to health services offered within prison for people with Learning Disabilities should be made and evidenced.

10. Regular service user consultation should take place on the availability and adequacy of health services for people with Learning Disabilities. These consultations should be conducted by the Public Health Department in conjunction with the Surrey Learning Disability Partnership Board. Information from these consultations should be fed into updates of this Health Needs Assessment and the Big Service Health Check.

Appendix One

Tiered model of services for people with Learning Disability