Southwark Joint Strategic Needs Assessment

Adults with a learning disability

Version 5.0
All Southwark JSNA documents are available online. The Southwark JSNA covers: demographics, children & young people, adults (learning disabilities, disabilities, older people & carers), mental health, health behaviours (tobacco and smoking, healthy weight, alcohol), sexual health and disease groups (hypertension, diabetes, heart disease, cancer and respiratory conditions). The JSNA process is iterative and there is an on-going process for refresh.
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Summary

Introduction and background
This needs assessment summarises the health and social care needs of adults with learning disabilities in Southwark. It provides evidence to guide the development of services for people with learning disabilities and includes priorities for action.

The JSNA will:
- guide the PCT and the Council’s strategies and commissioning plans for people with learning disabilities
- provide a platform for the future work of the Southwark Health and Wellbeing Board and clinical commissioning groups

It will be made available on both Council and PCT websites (including an easy read version) and key data will be updated regularly.

People with learning disabilities are amongst the most vulnerable and marginalised people within Southwark. They are more likely to:
- be socially excluded,
- have poorer physical and mental health
- have difficulties in accessing health care
- be at risk from abuse
- be discriminated against
- need support to access housing, health, employment and independent living
- be at greater risk of ending up in prison

Although people with learning disabilities should be treated as equal citizens, they are often at the margins of our society. Very few have jobs, live in their own homes or have control over their lives. There is, however, a growing awareness of these issues backed up by recent national policy and a strong determination across the borough to make real improvements. This drive for improvement is steered by Southwark’s well established Learning Disabilities Partnership Board.

Population
There are about 5,740 people with learning disabilities in Southwark, of whom about 1,230 (21%) have moderate or severe learning disabilities. The number of people in the borough with learning disabilities is projected to increase by 22% to 7,000 by 2030. Recent data suggests that there are 599 people with learning disabilities known to social services and 623 people on primary care learning disabilities registers. The proportion of the population recorded on these GP registers (0.2%) is lower than average in Southwark.

The proportion of people with learning disabilities known to services who are aged 65 years and over is 7.5%, which compares with 10.2% in Southwark’s overall population. However more people with learning disabilities are living into older age groups, with a projected 40% increase in the borough by 2030. The ethnic group profile of people with learning disabilities known to services is broadly comparable to the profile of Southwark’s overall population.
Living with a learning disability
There are an estimated 495 people with moderate or severe learning disabilities aged 18-64 living with one or more parents in Southwark. This is expected to rise by 13% to 559 in 2020. Southwark’s carers commissioning strategy includes five key strategic objectives designed to support carers in the borough. There are currently clients who require re-housing and a key priority is to develop more supported living schemes with Southwark.

Dedicated funding to support people with learning disabilities gain employment is being reduced and the intention is that personal budgets can be used for this purpose instead. At present 15% of people with learning disabilities in Southwark are in employment.

People with learning disabilities are at greater risk of hate crime. This is often un-reported and there is now a greater and more co-ordinated focus on gathering information and challenging hate crime. A disproportionately large proportion of offenders are thought to have learning disabilities and there is a need to support people in the criminal justice system. Again a lack of local data impedes planning, but work is underway with a range of agencies including nearby prisons.

More people with LD are having children and there needs to be good quality support, resources and information available, including advocacy when required and support in care proceedings.

Young LGBT with LD need skilled and informed support on sexuality and self identification, and there needs to be a good balance between safeguarding / risk assessment and rights of LGBT with LD to be sexual beings. Good quality training and support for professionals, carers, parents and people with LD are key, as are non-ambiguous and clear information resources.

Health and wellbeing
People with learning disabilities have lower than average life expectancy but this is increasing over time. Risk factors related to obesity such as poor diet and lack of physical activity are more common among people with learning disability although some other risk factors (eg smoking) are a little less prevalent. Chronic conditions such as respiratory disease, epilepsy, sensory impairments and some mental health problems are more prevalent amongst people with learning disabilities.

It is important that access to health services is readily available and appropriate. A system of health checks is in place but only 34% of people on Southwark GP learning disabilities had such a check in 2010/11. The report also draws attention to the accurate identification of mental health problems amongst people with learning disabilities and the specialist services in place to support this.

People with additional needs
Just under 10% of adults with learning disabilities known to Southwark services also have a diagnosis of autism. This is normally diagnosed in childhood and underlines the importance of effective processes for the transition from children’s to adult services.

Recent work has indicated that nearly a third (31%) of people with learning disabilities known to services have additional needs as well as learning disabilities. These may include physical disabilities, dementia or other conditions. Co-ordination across agencies (including information sharing), person-centred care and support for carers are particularly important when people have complex needs.
Some people with learning disabilities are identified by services as having challenging behaviour. This can take a number of different forms and can stem from a variety of causes including the way in which people are supported by services. Southwark has reviewed its approach to challenging behaviour including the adoption of a more person-centred approach as a key part of its strategy.

**Priorities for action**
Most sections of this report contain specific recommendations or next steps. The final chapter briefly sets out some important themes for future action. These are as follows:

**Information**
There is no common register of people with LD across health and social care in Southwark, hospital activity figures under-report the number of people admitted and it can be difficult even to identify how many people are funded to live in residential care. Caseload information systems do not routinely provide some of the vital data for planning and for ensuring that services are equitably provided. Improving the coverage, quality and sharing of information will be critically important in developing evidence-based commissioning.

**Future planning**
Southwark will see a large increase in the number of people with LD at a time when public sector spending is being curtailed. The tension between growing need and restricted resources increases the need for clear priorities, realistic expectations and creative solutions while pursuing the personalisation agenda. Detailed modelling of future need (including activity levels and costs) can help to plan resources and make choices explicit.

**Awareness and rights**
Although wider population awareness and national policy may be improving, people with LD are still subjected to hate crime, lower access to some services and low employment levels. More people with LD are having children and there needs to be appropriate support and information. A recent national conference highlighted some gaps in meeting the sexual health needs of LGBT with LD. Further work needs to continue to ensure that equity is achieved and discrimination opposed. Better support, information and training for professionals, carers, families and people with LD (for example on hate crime, on offending, on parenting and on meeting LGBT needs and promoting and enabling people with LD to have a healthy sex life) will be needed to support effective targeted action.

**Accommodation**
Many people with LD still live outside the borough and in the type of residential care that may not be appropriate for their needs. Continued development of supported living means that real choice can be exercised and can also bring financial savings.

**Health inequalities**
In general, people with LD face worse health and higher mortality rates than the population as a whole yet only a small proportion are identified on GP registers. An equitable NHS would ensure that health improvement interventions, screening programmes and other services reflect these higher levels of need and provide additional support as appropriate. Again better recording and information on utilisation of services is important.

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1 Hidden Desires, 16th October 2012 organised by Stonewall and Oxleas NHS Trust.
[http://www.lgbtconsortium.org.uk/events/hidden_desires_improving_practice_people_learning_disability_who_are_lgb](http://www.lgbtconsortium.org.uk/events/hidden_desires_improving_practice_people_learning_disability_who_are_lgb)
1. Introduction

1.1 Introduction
This joint strategic needs assessment (JSNA) focuses on adults with a learning disability in Southwark. It forms part of a series of JSNAs that cover health and wellbeing in Southwark's population including a separate JSNA for children.

JSNAs provide evidence to guide the planning of local services. They are a key step in the commissioning process in that they help local partners to identify gaps in services, to set priorities for the future and to plan services that match the needs of the borough’s population. JSNA has been confirmed nationally as an important function of Health and Wellbeing Boards and set the scene for the development of Health and Wellbeing strategies in each borough. This process brings together NHS, local authority, clinical commissioners and other partners to agree local priorities and the action needed to meet local needs.

The document begins with background information about learning disabilities (LD) and the national and local planning context (chapter 2). The next chapter then looks in detail at the population of people with learning disabilities in Southwark and how this is changing over time. Chapter 4 focuses on the living circumstances of people with learning disabilities, covering issues such as housing, employment and the discrimination and crime that people can face. Information on the overall health and wellbeing of people with LD is set out in Chapter 5, including a range of physical and mental health issues which can be particularly important for people with LD.

Chapter 6 then looks at people with learning disabilities who may face additional challenges because of specific problems such as autism, profound and multiple needs and challenging behaviour. The final chapter then pulls some of the key themes together and sets out some priorities for action. These are based on local and national evidence and are intended to support the Partnership Board in developing plans for the future.

1.2 Acknowledgements
This JSNA was written by Keh Adelano, Paul Brotherton, Chris Dory, Karen Phillips, Jake Walsh and Gary Wood. The authors would like to thank the wide range of people who contributed to this JSNA process. In particular thanks are due to Jin Lim, Consultant in Public Health, for guidance and support throughout and to Kirsten Henriksen and Vicky Stobbart for additional material.
2. Background

This chapter sets the scene for the learning disabilities JSNA. It begins by looking at definitions of learning disabilities including those most commonly used in Southwark for planning local services. It then describes key elements of national policy – this guides commissioning in Southwark and helps describe what service users and their carers can expect. Finally, the chapter adopts a local focus by setting out the current arrangements for commissioning services for people with a learning disability in Southwark.

2.1 What are learning disabilities?

This report adopts the definition set out in the national strategy “Valuing People” which states that:

"Learning Disability includes the presence of:
- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development”

As the national strategy says, “this definition encompasses people with a broad range of disabilities and the presence of a low IQ (for example below 70) is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support”.

It is worth noting that by definition LD does not cover adults or young people in transition who have acquired brain damage or those with organic mental health problems such as dementia.

People with LD have a range of developmental needs as LD affects the way a person learns and copes with new things in any area of life. A learning disability can make it harder to learn, understand and communicate, and this may also mean the individual is more vulnerable to exploitation and abuse. There may also be other needs because of physical disabilities and/or sensory impairments.

Given this wide range of possible needs, people can be assessed with mild, moderate, severe and profound /complex disabilities. The distinction between these assessments is the level of help that people need with their daily living. In practice, people with LD may be identified in term of a diagnosis of severity, or in terms of their level of need (which is relative as it can depend on the family and social context). We have therefore used different classifications in this report depending on the circumstances.

The categorisation of severity of LD, using guidelines set for GPs and also applied by Statement of Educational Needs classification for pupils with LD, includes four categories:

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2.2 National policy

Valuing People and the more recent Valuing People Now set out how children and adults with learning disabilities and their families should be enabled to live full and independent lives as part of their local communities. Valuing People has four key principles that lie at the heart of the Government proposals:

- **Rights**: People with learning disabilities have the right to a decent education, to vote, to marry and have a family, and to express their opinions. It is recognised that they may need help and support to exercise these rights.
- **Independence**: People with learning disabilities have differing needs. In meeting these needs, public services should offer support in a way that promotes their independence.
- **Choice**: People with learning disabilities should be able to make choices about where they live, what work they do and who should look after them. Given the right help and support, all people with learning disabilities including those with severe and profound disabilities should be able to make choices about their lives.
- **Inclusion**: This means enabling people with learning disabilities to make use of “mainstream” services and be fully active in their local community.

In particular, the strategy points to making significant improvements in giving people with LD much more choice and control over their lives through person centred planning, advocacy and direct payments. The strategy is all about “having a life” with better health, housing, employment, transport, leisure services and social activities.

In Valuing People, the Department of Health made a commitment to commission “a national survey of people with learning disabilities … in order to improve knowledge and provide a stronger baseline against which to evaluate the impact of Valuing People”. The results of this survey provide the most robust information available on the “typical” life experiences of people with learning disabilities in England.

Valuing People Now set out the following national priorities:

- **Personalisation** – so that people have a real choice and control over their lives and services;
- **What people do during the day (and evenings and weekends)** – helping people to be properly included in their communities, with a particular focus on paid work;
- **Better health** – ensuring that the NHS provides full and equal access to good quality healthcare;

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• Access to housing – housing that people want and need with a particular emphasis on home ownership and tenancies;
• Making sure that change happens and the policy is delivered – including making partnership boards more effective.

Published in 2006, *Our Health, Our Care, Our Say* set out the Government’s ideas for the future direction of wider health and social care community services. Recommendations of particular relevance to people with LD are:

• More people should be encouraged to use “Direct Payments” and “Individual Budgets” to choose the services that they want;
• Health Action Plans (HAP) should include a “Life Check”, social care key worker and information on long term medication, how to stay healthy and how to access relevant services;
• Transport arrangements are to be put in place to enable people to access the services that they need;
• Long term residential services where the NHS is the patient’s landlord are to undergo phased closure.

Following the publication of the Mencap report “Death by Indifference” on the deaths of six people with LD in social and health care settings, there has been one independent inquiry and one major investigation carried out jointly by the Local Government Ombudsman and the Parliamentary and Health Service Ombudsman.

Although they had different objectives, both investigations confirmed that in some cases there were significant breakdowns of communications between (and within) health care and social care agencies and teams. There was also a lack of preparedness to deal with the specific needs of clients with LD, as well as failure to communicate with, and involve, the relatives in the management of the clients’ conditions.

Recommendations included requirements that concerned bodies (PCTs, LAs and the regulators for health and social care) should review the state of provision of services to people with LD, should ensure that the monitoring framework is working effectively, and should make sure that PCTs consult with partner agencies and representatives of LD organisations to inform the JSNAs. The Parliamentary and Health Service Ombudsman also reiterated the recommendations of the “Six Lives” report in June 2010.

The Autism Act 2009 indirectly introduces a number of provisions that are also relevant to clients with LD. It stresses the importance of medical diagnosis as triggers for assessment (and re-assessment if necessary) of needs. It establishes the need for developing effective methods of diagnosis for the condition in relation to the provision of services and it requires that public services should be able to identify adults with autism regardless of the severity of the conditions, and provide appropriate services for each individual.

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5 Department of Health ‘Our Health, Our Care, Our Say: a new direction for community services’ DH 2006.
6 MENCAP. ‘Death by indifference – following up the Treat Me Right! Report’ MENCAP 2007
8 Parliamentary and Health Service Ombudsmen. ‘Six Lives – the provision of public services to people with learning disabilities’ Parliamentary and Health service Ombudsmen 2009.
**Personalisation**

Following the publication of the ministerial concordat *Putting People First: A shared vision and commitment to the transformation of adult social care*, local authorities have been increasingly moving away from traditional service-based responses to more person-centred arrangements that place the needs and aspirations of the individual at the heart of arranging support. This personalised approach places control over funds available for support with individuals or their loved ones in the form of personal budgets. This results in people having more control and choice about how they are supported and allows them greater freedom to achieve the kind of lifestyles they want.

The proportion of people with learning disabilities in Southwark receiving some form of self-directed support increased from 14.4% in 2009/2010 to 48.9% in 2010/11 ([Source: ASC- CAR, DH]). The borough has a target of 100% of people who are eligible for support being in receipt of some form of self-directed support by 2013/14.

Traditional service models and commissioning practices will change as more people take up personal budgets. Rather than tendering block contracts for residential, homecare or daycare, commissioners will undertake a more facilitative role by assisting individuals or small groups to organise support of their choice.

Similarly, service providers will need to adapt to this new approach. Successful providers will be those that are truly able to recognise and respond to the needs and wishes of individuals by providing support at times of their customer’s choosing at a price they can afford to pay from their personal budgets.

**2.3 Southwark’s Partnership Board**

Southwark’s Learning Disabilities Partnership Board has been existence since 2002 and is co-chaired with people with learning disabilities. It brings together a range of voluntary sector partners, education and employment support providers, health commissioners and specialist health and social care services for people with learning disabilities. The Board oversees local implementation of national policy relating to people with learning disabilities.

Southwark’s Partnership Board is themed around health, housing, employment and day opportunities. It has overseen the development of three key planning documents:

- Learning Disabilities Accommodation Strategy 2009 -2013: A Good Place to Live
- Learning Disabilities Health Framework Action Plan

These documents lay out Southwark’s forward plans and objectives designed to improve the lives of people with learning disabilities living in the borough.

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3. Population

This chapter looks at the size and characteristics of the population with learning disabilities in Southwark. It sets out the current estimates of prevalence and compares them with the numbers of people that are in contact with local services in the borough. The chapter then profiles the population according to key socio-economic characteristics and finishes by looking at how the population may change in future years. This includes two important elements for planning purposes; the numbers of young people who will in the near future become adults with learning disabilities and the growing number of older adults with learning disabilities.

3.1 Prevalence of learning disabilities in Southwark

There were an estimated 5,739 adults aged 18 and over with learning disabilities in Southwark in 2010. The exact number is not known, partly because there are varying definitions of learning disability and partly because local databases on adults with learning disabilities focus mainly on the more severely affected who are the most frequent users of local services.

The above estimate is based on prevalence rates calculated by the Institute for Health Research, Lancaster University. The authors take the prevalence base rates and adjust them to take account of ethnicity (for example the increased prevalence in South Asian communities) and of mortality (eg increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Figures are therefore based on national prevalence and may be an under-estimate in communities with a relatively large South Asian community such as Southwark. The prevalence estimates should therefore be used with caution.

Of the 5,739 adults with learning disabilities, 21% (1,226) are estimated to be people with moderate or severe learning disabilities (see Table 3.1)

Table 3.1: Breakdown of the estimated number of people with learning disability in Southwark, 2010.

<table>
<thead>
<tr>
<th>Number in Southwark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total adults (18+) with learning disability</td>
</tr>
<tr>
<td>Adults estimated to have a moderate or severe learning disability (18+)</td>
</tr>
<tr>
<td>Adults estimated to have Down’s Syndrome (18-64 years)</td>
</tr>
<tr>
<td>Adults with a learning disability, estimated to display challenging behaviour (18-64 years)</td>
</tr>
</tbody>
</table>

Source: PANSI and POPPI

It is projected that there will be a steady increase of 22% in Southwark’s learning disabilities population over the next 20 years to a total of 7,004 by 2030 (Figure 3.1). This reflects the projected general population increase in Southwark but also an expected increase in the

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10 Source: Projecting Adult Needs and Service Information System - PANSI - 2011
prevalence of learning disabilities. Projections suggest that by 2020 Southwark will have the third largest number of adults with learning disabilities in London (Figure 3.2).

Figure 3.1: Expected number of adults with learning disabilities in Southwark, 2010-2030

![Graph showing expected number of adults with learning disabilities in Southwark, 2010-2030](image)

Source: PANSI 2011

Figure 3.2: Estimated number of adults with learning disabilities by borough, 2010 and 2020

![Graph showing estimated number of adults with learning disabilities by borough, 2010 and 2020](image)

Source: PANSI 2011
**Down’s Syndrome**

An estimated 132 Southwark adults aged 18 to 64 years have Down’s Syndrome and this is expected to increase by 27 people over the next 20 years (source: PANSI 2011). While the population with Down’s Syndrome is small, Southwark has one of the largest number of adults in London in 2010 (joint 4th). By 2020 Southwark is projected to have the largest number of Down’s Syndrome adults in London.

**Challenging behaviour**

There are approximately 95 adults (18 to 64 years) with learning disabilities displaying challenging behaviour living in Southwark (source: PANSI 2011). This is expected to increase to 115 adults by 2030. Again, while the numbers are small, Southwark has the fourth largest number of adults with learning disabilities displaying challenging behaviour in London and by 2020 Southwark is projected to have the largest number in London.

### 3.2 People known to local services.

Although there are some 5,700 adults with learning disabilities in Southwark only a minority are in contact with specialist services for people with a learning disability. In 2010/11 a total of 599 adults were receiving services provided through Southwark Council and in March 2011 there were 623 adults recording as having learning disabilities on Southwark GP registers.

#### 3.2.1 Social Services caseload

People with learning disabilities receiving social care services are likely to be people to have a moderate or severe learning disability. During 2010/11 there were 599 adults with learning disabilities receiving services provided or commissioned through Southwark social care services. It is known that sixty per cent (359) of these clients were male and further information on the client profile is provided later in this chapter.

#### 3.2.2 Primary Care

Primary care practices have been expected to compile registers of their adult patients with a learning disability since 2006. The register should record all patients who have a learning disability, not just those with moderate or severe learning disabilities. However in practice the identification of patients to put on learning disabilities registers is done via automated scans of practice information systems that identify patients with an explicit diagnosis of a learning disability but do not include diagnoses which are consistently associated with learning disability (e.g. Down’s syndrome) or activities which imply a learning disability (eg learning disability health checks). Both the process and the small numbers identified suggest that registers have underestimated the number of people with learning disability actually registered with local practices.

There has been a steady increase in the number of adults recorded on the Southwark learning disabilities registers since 2006/07 (Figure 3.3). In 2010/11 there were 610 adults identified on these registers, which would give a learning disabilities prevalence of 0.2% in Southwark. This compares with a national average recorded prevalence of learning disabilities on QOF registers of 0.3% and a range across London PCTs of between 0.2% and 0.5%.
Figure 3.3: Trend in the number of patients on Southwark’s primary care learning disabilities registers, 2006/07 to 2010/11.

Nearly two thirds (62%) of the adults on the primary care learning disabilities registers were male (Table 3.2). The table also provides a breakdown by age and suggests that the highest recorded prevalence (0.4%) is found in the 45-54 and 55-65 year age groups. This may have implications for services in terms of health issues and elderly carers/loss of carers.

Table 3.2: Number and proportion of people with LD on Southwark GP registers by age and sex, 2010/2011.

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of people on GP Registers*</th>
<th>Number recorded on LD registers**</th>
<th>Percentage with LD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>All</td>
</tr>
<tr>
<td>15/18-24</td>
<td>19,029</td>
<td>21,209</td>
<td>40,238</td>
</tr>
<tr>
<td>25-34</td>
<td>37,764</td>
<td>38,013</td>
<td>75,777</td>
</tr>
<tr>
<td>35-44</td>
<td>34,916</td>
<td>27,096</td>
<td>62,012</td>
</tr>
<tr>
<td>45-54</td>
<td>24,021</td>
<td>19,024</td>
<td>43,045</td>
</tr>
<tr>
<td>55-64</td>
<td>11,914</td>
<td>10,503</td>
<td>22,417</td>
</tr>
<tr>
<td>65+</td>
<td>12,277</td>
<td>15,338</td>
<td>27,615</td>
</tr>
<tr>
<td>Total</td>
<td>139,921</td>
<td>131,183</td>
<td>271,104</td>
</tr>
</tbody>
</table>

* Source: Exeter, December 2010

** Source: Contract Focus, March 2011, data for 46/47 practices.

Figure 3.4 shows the prevalence of learning disabilities by practice as recorded on QOF. There is great variation in the prevalence between Southwark practices, ranging from 0.07% to 0.6%.
It has been suggested that the overall number of people with learning disabilities recorded as part of QOF registers corresponds to the number of people with profound and multiple disabilities in the population as a whole\textsuperscript{12}. This suggests that people with moderate and mild learning disabilities are not being included. Sir Jonathan Michael also suggests that some people at the milder end of the learning disability spectrum may be uncomfortable being branded as having a disability.

The numbers of people on the general practice registers are different from those seen in social services for several reasons. Social services only have on their system those people that are assessed for their services and these tend to be people with moderate or severe learning disabilities. The two systems also serve slightly different populations: social services are responsible for the resident population (some of which have been placed in accommodation outside of the borough and may not be known to local GPs), while Southwark general practices look after all those registered with the practices some of whom may live outside the borough. These may include some patients that other local authorities are responsible for.

An exercise to improve the number of adults with learning disabilities identified and recorded on the GP registers is currently underway in Southwark. All adults with learning disabilities who received a service from Southwark social services in 20010/11 and live within the borough are being checked to see if they are on a Southwark GP learning disability register. In total in 2010/11 there were 599 adults who received a service from social services. Seven of these are known to have died, 23 had an unknown address and 156 live outside of the borough. One difficulty in carrying out this exercise is that there is no unique patient identifier (such as NHS number) used across both social services and health systems.

3.3 Population Profile

Age
The age profile of adults with learning disabilities is not very dissimilar to the age profile of the general Southwark population (Table 3.3). Adults with learning disabilities are slightly younger, with a smaller proportion being in the older age groups than the general Southwark population. This is especially true for adults with moderate or severe learning disabilities, where only 5.6% are estimated to be 65 years or older compared to 10.9% of the general population. The majority of adults in Southwark with learning disabilities (69%) are young adults aged 18 to 44 years.

Table 3.3: Age profile of Southwark overall adult population and of adults with learning disabilities

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Southwark general population</th>
<th>All learning disabilities</th>
<th>Moderate or severe learning disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2009</td>
<td>2010</td>
<td>2010</td>
</tr>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
</tr>
<tr>
<td>18-24</td>
<td>32,700</td>
<td>14.2</td>
<td>950</td>
</tr>
<tr>
<td>25-34</td>
<td>68,400</td>
<td>29.7</td>
<td>1,768</td>
</tr>
<tr>
<td>35-44</td>
<td>50,900</td>
<td>22.1</td>
<td>1,246</td>
</tr>
<tr>
<td>45-54</td>
<td>33,900</td>
<td>14.7</td>
<td>815</td>
</tr>
<tr>
<td>55-64</td>
<td>19,400</td>
<td>8.4</td>
<td>447</td>
</tr>
<tr>
<td>65-74</td>
<td>12,800</td>
<td>5.6</td>
<td>273</td>
</tr>
<tr>
<td>75-84</td>
<td>8,600</td>
<td>3.7</td>
<td>167</td>
</tr>
<tr>
<td>85+</td>
<td>3,700</td>
<td>1.6</td>
<td>72</td>
</tr>
<tr>
<td>total 18+</td>
<td>230,400</td>
<td>100</td>
<td>5,739</td>
</tr>
</tbody>
</table>

Source: ONS 2009 mid-year estimates and PANSI

Table 3.4 shows the age breakdown of those adults with learning disabilities who are known to local services. There is a greater proportion in the 45 to 64 age groups among those known to both social services and primary care than was suggested in Table 3.3 above.
Table 3.4: Age profile of adults with learning disabilities known to Southwark services

<table>
<thead>
<tr>
<th>Age</th>
<th>Known to social services</th>
<th>Known to primary care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>18-24</td>
<td>101</td>
<td>16.9%</td>
</tr>
<tr>
<td>25-34</td>
<td>112</td>
<td>18.7%</td>
</tr>
<tr>
<td>35-44</td>
<td>111</td>
<td>18.5%</td>
</tr>
<tr>
<td>45-54</td>
<td>134</td>
<td>22.4%</td>
</tr>
<tr>
<td>55-64</td>
<td>92</td>
<td>15.4%</td>
</tr>
<tr>
<td>65-74</td>
<td>32</td>
<td>5.3%</td>
</tr>
<tr>
<td>75+</td>
<td>17</td>
<td>2.8%</td>
</tr>
<tr>
<td>Total</td>
<td>599</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Sources: Social Services – Care First 2010/11 Contract Focus, March 2011, data for 46/47 practices.

The number of adults with learning disabilities in Southwark is projected to increase in all age groups over the next 20 years. The biggest percentage increase will be seen in the 55 to 64 year age group (a 60% rise between 2010 and 2030). However in terms of actual numbers of people the greatest increase is expected in the 35 to 44 year old age group, with an additional 355 adults by 2030 (Table 3.5a). Changes in the relative age profile of people with LD over the next 20 years are also illustrated in Figure 3.5.

Figure 3.5: Projected age profile of Southwark adults with learning disabilities, 2010 and 2030

![Age Profile Chart](chart.png)

Source: PANSI

Looking specifically at adults with moderate or severe learning disabilities, the greatest relative increase is also projected to be seen in the 55 to 64 year age group (a 59% rise over
20 years). In terms of actual numbers of people the greatest increase is expected to be in 25 to 34 year olds (with 99 more people) closely followed by the 35 to 44 year old age group. (Table 3.5b).

Table 3.5: Projected number of people with learning disabilities in Southwark by age group (a) all people with learning disabilities and (b) people with moderate and severe learning disabilities, 2010 to 2030.

(a) All

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>950</td>
<td>16.6</td>
<td>944</td>
<td>15.3</td>
<td>889</td>
<td>13.7</td>
<td>902</td>
<td>13.4</td>
<td>977</td>
<td>13.9</td>
</tr>
<tr>
<td>25-34</td>
<td>1,768</td>
<td>30.8</td>
<td>1,952</td>
<td>31.6</td>
<td>2,027</td>
<td>31.3</td>
<td>1,977</td>
<td>29.3</td>
<td>1,927</td>
<td>27.5</td>
</tr>
<tr>
<td>35-44</td>
<td>1,246</td>
<td>21.7</td>
<td>1,326</td>
<td>21.4</td>
<td>1,433</td>
<td>22.1</td>
<td>1,549</td>
<td>23.0</td>
<td>1,601</td>
<td>22.9</td>
</tr>
<tr>
<td>45-54</td>
<td>815</td>
<td>14.2</td>
<td>923</td>
<td>14.9</td>
<td>955</td>
<td>14.7</td>
<td>992</td>
<td>14.7</td>
<td>1,061</td>
<td>15.1</td>
</tr>
<tr>
<td>55-64</td>
<td>447</td>
<td>7.8</td>
<td>512</td>
<td>8.3</td>
<td>622</td>
<td>9.6</td>
<td>699</td>
<td>10.4</td>
<td>717</td>
<td>10.2</td>
</tr>
<tr>
<td>65-74</td>
<td>273</td>
<td>4.8</td>
<td>275</td>
<td>4.4</td>
<td>302</td>
<td>4.7</td>
<td>341</td>
<td>5.1</td>
<td>417</td>
<td>6.0</td>
</tr>
<tr>
<td>75-84</td>
<td>167</td>
<td>2.9</td>
<td>170</td>
<td>2.7</td>
<td>165</td>
<td>2.5</td>
<td>176</td>
<td>2.6</td>
<td>195</td>
<td>2.8</td>
</tr>
<tr>
<td>85+</td>
<td>72</td>
<td>1.3</td>
<td>80</td>
<td>1.3</td>
<td>89</td>
<td>1.4</td>
<td>99</td>
<td>1.5</td>
<td>108</td>
<td>1.5</td>
</tr>
<tr>
<td>Total 18+</td>
<td>5,739</td>
<td>100</td>
<td>6,183</td>
<td>100</td>
<td>6,482</td>
<td>100</td>
<td>6,736</td>
<td>100</td>
<td>7,004</td>
<td>100</td>
</tr>
</tbody>
</table>

(b) Moderate or severe LD

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>216</td>
<td>17.6</td>
<td>216</td>
<td>16.1</td>
<td>204</td>
<td>14.3</td>
<td>209</td>
<td>13.9</td>
<td>228</td>
<td>14.5</td>
</tr>
<tr>
<td>25-34</td>
<td>346</td>
<td>28.2</td>
<td>399</td>
<td>29.8</td>
<td>432</td>
<td>30.3</td>
<td>439</td>
<td>29.3</td>
<td>445</td>
<td>28.3</td>
</tr>
<tr>
<td>35-44</td>
<td>313</td>
<td>25.5</td>
<td>333</td>
<td>24.9</td>
<td>360</td>
<td>25.3</td>
<td>389</td>
<td>25.9</td>
<td>403</td>
<td>25.6</td>
</tr>
<tr>
<td>45-54</td>
<td>185</td>
<td>15.1</td>
<td>209</td>
<td>15.6</td>
<td>216</td>
<td>15.2</td>
<td>226</td>
<td>15.1</td>
<td>243</td>
<td>15.4</td>
</tr>
<tr>
<td>55-64</td>
<td>98</td>
<td>8.0</td>
<td>113</td>
<td>8.4</td>
<td>137</td>
<td>9.6</td>
<td>152</td>
<td>10.1</td>
<td>156</td>
<td>9.9</td>
</tr>
<tr>
<td>65-74</td>
<td>44</td>
<td>3.6</td>
<td>45</td>
<td>3.4</td>
<td>49</td>
<td>3.4</td>
<td>56</td>
<td>3.7</td>
<td>68</td>
<td>4.3</td>
</tr>
<tr>
<td>75-84</td>
<td>18</td>
<td>1.5</td>
<td>18</td>
<td>1.3</td>
<td>17</td>
<td>1.2</td>
<td>18</td>
<td>1.2</td>
<td>20</td>
<td>1.3</td>
</tr>
<tr>
<td>85+</td>
<td>7</td>
<td>0.6</td>
<td>8</td>
<td>0.6</td>
<td>8</td>
<td>0.6</td>
<td>9</td>
<td>0.6</td>
<td>10</td>
<td>0.6</td>
</tr>
<tr>
<td>Total 18+</td>
<td>1,226</td>
<td>100</td>
<td>1,339</td>
<td>100</td>
<td>1,424</td>
<td>100</td>
<td>1,500</td>
<td>100</td>
<td>1,574</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: PANSI 2011
Ethnicity
Evidence suggests that there is a higher prevalence of learning disabilities in some South Asian populations compared to other ethnic groups\textsuperscript{13}. Southwark has a larger Asian population than the national average (8.4\% compared to 6.1\% in England\textsuperscript{14}). This may mean that the figures above are an underestimate of the numbers in Southwark as they use the national ethnic profile.

A comparison of the ethnic breakdown of adults receiving services provided by Southwark social services with that of the borough’s general population is shown in Figure 3.6. Just over a third of the population is estimated to be from a minority ethnic group and a similar proportion is seen in the ethnicity of people with a learning disability receiving a service. There are some differences for specific ethnic groups, for example the Black/Black British population is slightly overrepresented amongst people using social services while only 4\% of people with learning disabilities receiving services from Southwark council were of Asian ethnicity (compared to 8\% in the general population). The data may be a true representation of the picture in Southwark but further work is needed to ensure that there are no cultural and language barriers to accessing services.

Figure 3.6. Ethnic breakdown of Southwark population and of people with learning disabilities receiving a service from Southwark social services

![Ethnic Breakdown Graphs](image)

Sources: ONS estimated resident population by ethnic group mid-2009; Southwark Social Services 2010/11

Where do adults with learning disabilities live?
Figure 3.7 shows the prevalence of adults with learning disabilities who receive social services per 10,000 population living in different parts of Southwark. This excludes the 157 people who were currently living outside of the borough. A higher prevalence of LD is seen across the middle of the borough with lower prevalence towards the north of the borough. The data presented here may partly reflect the location of some of the residential and supported care homes but after taking this into account can be used to help ensure that services are equally accessible to clients across the borough.

\textsuperscript{14} ONS Estimated resident population by ethnic group and sex, mid-2009, (experimental statistics)
Figure 3.7: Ward of residence of people with LD receiving a service from Southwark Social Services in 2010-11.
Deprivation
Southwark is very diverse in terms of deprivation and affluence but in general it is a relatively deprived borough compared to the country as a whole. The Index of Multiple Deprivation (IMD) 2010 ranked Southwark as the 41st most deprived out of 326 local authorities in the country.

Evidence suggests that the prevalence of severe and profound learning disability is fairly uniformly distributed across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are thought to be higher in deprived and urban areas.

Figure 3.8 shows the deprivation bands in national quintiles (fifths) of the general Southwark population compared to those people with learning disabilities who received a service from Southwark social services in 2010/11. The pattern is similar between the two groups, with both being more deprived than the national average. However the data on people with LD are probably skewed as adults receiving services tend to be people with more severe learning disabilities (which as stated above is not linked to deprivation) and is not therefore representative of people with LD as a whole. Other factors may be that many service users may be living in residential or supported care homes (where location is decided by the council and not related to the individual’s status), people in more affluent areas might be less likely to access services, and patterns of access to services may differ across ethnic groups.

Figure 3.8: Deprivation levels of people with LD known to social services and of the Southwark general population (based on IMD 2010 score of place of residence)

Sources: Care First 2010/11; IMD 2010; ONS LSOA population estimates mid-2009
3.4 The changing population

An aging population
The number of people with learning disabilities surviving into old age is starting to increase, mainly due to reduced mortality among older adults with learning disabilities. Projections suggest that Southwark’s population aged 65 years and over with learning disabilities will grow from 512 in 2010 to 720 in 2030 (Figure 3.9). Over the next five years there is projected to be a very small increase in the number of people with learning disabilities in this age group, but after 2015 steeper increases are projected, particularly in the 65-74 year age group. Many people in these older age groups may no longer have family carers and service provision may therefore need to be adapted accordingly.

Figure 3.9: Estimated number of older people with learning disabilities in Southwark by age group, 2010 to 2030

A similar pattern is found for the numbers of older people with moderate and severe learning disabilities (Figure 3.10). These people are more likely to be in receipt of services but again may no longer have family carers.
Transition is the term used to describe the move from children’s services to adult services. It can be a challenging time for the young people and their families. However, transition provides a great opportunity to develop a person centred plan. As more children with severe and complex needs survive into adulthood, transition arrangements need to be adaptable to ensure that entry into adult services is as smooth as possible and that independence is maximised.

There is a history of joined up working in Southwark, underpinned by the Transition Protocol 2007 and the multi-agency Transition Steering Group and workplan. However, there is no overall lead for co-ordinating the transition process for individuals and ensuring that young people and their families are supported between the ages of 14-25 in a seamless manner. While the transition steering group and protocol reflect some joint governance of transition, the governance is weak at the interface with customers, who experience delays, gaps, and inconsistent messages when dealing with two departments at a critical stage of their lives.

The absence of seamless assessment and care management, support planning and brokerage at an individual level raises the question as to whether resources are being used in the most effective way, with young people being given the right support at the right time to ensure that they can take control of their lives and what the future holds.

There are currently two groups that manage the process in Southwark: the Transition Steering Group (TSG) and the Transition Panel. The TSG’s role and remit is to develop and implement a work-plan for transition in Southwark, providing oversight and governance for the transitions process. The Transitions Panel meets every other month and decides which adult service, if any, will conduct an assessment. Cases are then brought back to the panel for regular updates.

Source: POPPI
Southwark is currently in the process of establishing a Transition Team in Southwark to support young people who have disabilities or special educational needs aged 14-25. The purpose of the transition team will be to re-shape the current offer to young people in Southwark and introduce whole life planning. The future offer for young people going through transition will see a shift in the balance of care from costly residential placements and buildings based day services to a more personalised, community service. The overall objective for the Transition Team is to move young people from a model of dependency on paid for services to one where there is self-direction over all aspects of life.

The Transition Team will ensure effective multi-agency engagement, which is a key way to ensure a smooth transition for young people with disabilities. The Transition Team will involve young people and their families from the start of the development of comprehensive transition plan.

The figures below show the number of child and young people in Southwark who have been referred to the Transition Panel in the last three years. The majority of these were for children with learning disabilities:

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>53, 6 of which only required signposting.</td>
</tr>
<tr>
<td>2009</td>
<td>41, 2 of which only required signposting.</td>
</tr>
<tr>
<td>2010</td>
<td>46, 4 of which only required signposting</td>
</tr>
</tbody>
</table>

Southwark has an Information Guide on Transition for Young People and Families that it aimed at empowering both young people and their parents throughout the transition process. This gives information about what can be expected from the transition process and it is hoped that through the guides young people are enabled to participate more effectively in the process. The guide has three parts to it, one for the young people, one for the parents/carers and one for the professionals. Feedback on the guide has been very positive.

3.5 What else needs to be done?
Key actions relating to this section of the report include:

- Health Action Plans should be carried out for all people turning 18, as these help in the transition process.
- Complete the matching process of comparing people with learning disabilities known to social services to those recorded on general practice learning disabilities register.
- Practices should be encouraged to ensure all patients with learning disabilities are included on their learning disabilities registers.
Chapter 4. Living with a learning disability

This chapter looks at some of the key day to day issues affecting people with a learning disability. It begins with a section on the important role of carers and some of the challenges that they can face. It then examines the living circumstances of people with learning disabilities and daily activities including employment. The chapter then looks at discrimination against people with learning disabilities including that expressed as hate crime and at some of the issues encountered by people with LD who find themselves involved in the criminal justice system. Finally it considers some of the issues faced by parents who have a learning disability.

4.1 Carers

4.1.1 Background
A carer is someone of any age who spends a significant amount of unpaid time providing care and support for a relative, partner, friend or neighbour. The key national drivers for the transformation of carers' services are detailed below. These have informed Southwark's strategic approach and will ensure that carers' services remain financially sustainable and of excellent quality in the future:

- ‘Carers at the Heart of 21st Century Families and Communities’ is the National Carers Strategy (2008), which followed a large scale consultation exercise. The strategy sets a national context for carers' services and reinforces the themes of 'recognition' and respite, whilst placing a greater emphasis on effective emergency planning and on supporting carers to address economic disadvantage and poor health. This strategy is reflected in Southwark's local commissioning plans.

- The Carers (Equal Opportunities) Act 2004 made it a duty of local authorities to ensure that all carers know they are entitled to an assessment of their needs. Councils must consider a carer's outside interests (work, study or leisure) when carrying out an assessment. Improved partnership between councils and the NHS is required with the aim of delivering increasingly coherent support from the carer's perspective.

- The development of personal budgets for carers with an assessed eligible need, under the statutory guidance outlined in the Fair Access to Care criteria, is a key driver for integrated service provision around the need of the carer. Carers who have been assessed as being eligible have been provided access to respite, leisure opportunities and support to take up or continue employment and training. These opportunities will continue but will be procured by the individual themselves using a personal budget.

- Commissioning for Carers guide (DH, 2008) acts as a blueprint for better commissioning for carers. With “Improving outcomes, independence and choice for both carers and those they care for” the key objectives have been adopted in Southwark’s carers strategy.

- Personalisation: The transformational approach to the future of care and support was set out in the Government’s White Paper, ‘Our Health, Our Care, Our Say’ (DH 2006). The paper outlines a scenario where service users are supported to take greater control and exercise more choice over the services they receive. This
A personalised approach is being developed across all adult client groups including carers in Southwark. It recognises the different stages of a ‘customers journey’ through the social care system, focusing on the need to obtain a balance between advice, prevention and the provision of individual budgets for those requiring support. There will be an option of receipt of payment through some form of personalised budget for carers who are assessed as being eligible for services following a formal ‘Carers Assessment’ under The Carers (Recognition & Services) Act 1995 and complying with local Fair Access to Care (FACs) criteria, (for example respite care).

- The Preventative Agenda: The Council aims to support carers to continue their valued work preventing vulnerable people from needing acute care and care in institutional settings. There is a need to ensure that there is the correct balance between investments in universal and targeted prevention. This emphasis will be reflected in well-planned prevention in commissioning priorities. This work programme is set out in the Southwark Health and Social care joint Prevention Strategy 2010-13.

- Value for Money: Southwark’s commissioning strategy for carers will be implemented during a time of unprecedented pressure on public finances and available resources. There will need to be an approximate 25% reduction in current spend on carers’ services between 2011 and 2014.

4.1.2 The position in Southwark
There has been limited analysis of the exact number of carers in Southwark due in part to a difficulty in ascertaining hidden demand, where carers are unknown to care services. 2001 census data suggested that in Southwark:

- 18,515 people described themselves as a carer
- 40% were from black or minority ethnic communities
- 14,778 (81%) were of working age
- 442 Children (0 – 15 years) provided unpaid care for a family member

Source: 2001 census, ONS

The census revealed that the proportion of carers who say that they are caring for more than fifty hours per week in Southwark was 22.3% compared to 19.5% for London and 20.5% for England and Wales. This suggests that the needs of those being cared for are greater in Southwark than comparative areas. Furthermore, 14% of carers in Southwark reported that their health was poor compared to 10% of non-carers, which illustrates the importance of services being flexible to these specific requirements and of integration between health and social care services. 60% of Southwark carers were aged between 35 and 64, emphasising the importance of supporting these carers to be active in employment and in their local community.

However at a decade old, this data does not provide a sound evidence base for needs assessment in the borough and the results of the 2011 census will provide a much needed update. Meanwhile the 2009 national survey of vulnerable and elderly homecare customers\(^\text{15}\) showed that Southwark was second lowest in London for the proportion of cared for people in receipt of unpaid care from someone living in their home. Southwark was the fifth lowest of the London boroughs for the proportion of people receiving unpaid care and practical help from friends, neighbours or family members.

The number of carers is set to grow in coming years - projections of the overall growth in the number of carers in Southwark are shown in Table 4.1 below.

Table 4.1: Projected number of carers in Southwark 2008 to 2020

<table>
<thead>
<tr>
<th>Year</th>
<th>2008</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Carers</td>
<td>20,800</td>
<td>21,600</td>
<td>23,700</td>
<td>25,500</td>
</tr>
</tbody>
</table>

Source: GLA Round Population Projections 2007

More specific estimates of the number of people with learning disabilities living with carers are shown in Table 4.2. This also suggests that numbers are rising, with a 13% increase projected from 2010 to 2020. The increase is proportionately higher in the older age groups.

Table 4.2. Projected number of people aged 18-64 with moderate or severe LD living with parent(s) in Southwark, 2010 to 2020.

<table>
<thead>
<tr>
<th>Age group</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24 years</td>
<td>140</td>
<td>140</td>
<td>132</td>
</tr>
<tr>
<td>25-34 years</td>
<td>179</td>
<td>206</td>
<td>222</td>
</tr>
<tr>
<td>35-44 years</td>
<td>122</td>
<td>131</td>
<td>141</td>
</tr>
<tr>
<td>45-54 years</td>
<td>43</td>
<td>48</td>
<td>50</td>
</tr>
<tr>
<td>55-64 years</td>
<td>9</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>495</td>
<td>536</td>
<td>559</td>
</tr>
</tbody>
</table>

Source: PANSI

The current portfolio of services is not a viable way of meeting increased demand, particularly given that available resources are reducing. A core over-arching aim of the Carers Commissioning Strategy is to make the case for a changed model that allows all carers to realise improved outcomes, whilst ensuring economic sustainability and achieving value for money.

Southwark’s vision is to support carers to continue their caring role, supporting their independence and capacity to make positive choices in relation to their life beyond caring. Southwark’s strategy refers to people who care for adults, including child carers of adults. Southwark will support carers to take advantage of opportunities enjoyed by other citizens such as leisure time, employment and good health, allowing them to tailor their support using personal budgets. In discussion with carers and other partners Southwark have developed five strategic objectives that will enable joint working with carers to support them in their role. These are:

1. Improved identification and recognition of carers - As statutory agencies, we must recognise that carers are partners in care and as such we should work together to create the services they want

2. Access to information and effective assessment of carers' needs - All carers should have access to good quality advice and information in order to make informed choices and plan for the future in a responsive fashion. Carers must be able to quickly access assessments of their need, which focus on supporting them to
achieve the outcomes they want. Timely assessment will ensure that those requiring help and support are able to obtain it at their convenience

3. Personalisation and greater flexibility, choice and control for carers - Adult social care services are undergoing a major transformation in the way services are delivered. Services will be personalised where possible, with individuals supported to take control of the resources used to commission their care and support. The personalisation of services underpins our strategic approach to delivering improved care with personal budgets the key driver of this change

4. A healthy life of their own outside of caring - We will support carers to undertake a range of activities to help them achieve further independence. In health we will continue to develop quality and accessible services that support carers to maintain good mental health. We want carers to be able to develop their own interests and utilise their abilities

5. Making the best use of resources - This strategy will be delivered in the context of limitations on public sector resources. The most likely financial scenario will mean that budgets will shrink by 25% of the amount we currently spend on carer services over the next three years. In order to achieve sustainable, quality provision in Southwark we must develop a provider market that delivers value for money. Where we provide services directly, we must ensure they are of optimal cost-effectiveness.

It is a key objective to ensure that those with the greatest need and those with the most complex needs are most intensively supported to take control of their packages of support. Whilst it is an aim to develop a provider market that caters for a broad array of preference, it is also particularly important to recognise the specific issues facing carers with complex needs. This group may include child carers and Southwark will work closely to ensure they receive the services and support they need. Ultimately, the aim is to foster a new relationship between the carer and health, social care and other agencies. This will put people in control over how resources are used and make sure that organisations fit around carers to best facilitate their choices.

Southwark Council and NHS Southwark invested £1.6million across universal and specialist (e.g. BME) carer services in 2010/11. Adult services invested an additional £1.16m into residential respite care. NHS Southwark contributes approximately £160,000 annually. This figure does not include home-based respite care, funded as part of individual care packages for cared for people or services funded through the Aiming High initiative. This investment has been allocated to 33 different support services including home-based respite; advocacy; therapy services and play schemes.

The new model: self-directed support and specialisation
The current dispersed portfolio of provision does not provide carers with a single point of information and advice. Support and respite is not always allocated to those with assessed needs in the most effective manner. This position is undesirable and financially unsustainable and a different way of supporting carers must be adopted in order to deliver strategic objectives.

The new model of delivery will focus on supporting carers to exercise choice and control over the support they receive. Where possible this will be done with the use of a personal budget for those with an assessed eligible need. The following elements characterise the new system:
1. Southwark have commissioned a carers ‘Hub’, which will act as a single central point of information, advice and promotion of primary and secondary preventative support to all adult carers. It will function as a bridge for carers to access universal services (law centres; housing officers; Citizens Advice Bureau; Job Centre Plus; health services etc.). The Hub may also host the provision of services for carers, including specialist direct provision (e.g. young carers’ services) as well as those which can be purchased with a personal budget. ‘Spokes’ will be considered as a way of providing specialist services in the community and in targeting hard to reach groups.

2. Southwark will use personal budgets to put eligible carers in control of the services they want. The Council will secure provision for carers with the most complex needs and develop the mechanisms for the use of personal budgets for all other carers.

3. Southwark will undertake a comprehensive programme of work to develop the market for carers’ services in Southwark so people are able to exercise genuine choice over the support they need.

4.1.3 What else needs to be done?

The five objectives outlined above are tied into the core areas of the Southwark Business Plan 2010-13 that relate to carers services. The key specific actions that are required to meet these objectives are set out below. Although these relate to carers as a whole, they are all relevant to carers of people with learning disabilities and assessment of individual requirements is a central plank of implementing the strategy.

Objective 1: Better identification and recognition of carers
- To recognise and respect of the role of the carer as a genuine partner in the delivery of high quality care for the vulnerable person
- To understand the importance of the carer’s role in helping vulnerable people identify how their care can be best delivered to meet their needs and desired outcomes
- Identifying harder to reach carers and those who do not traditionally access services
- Supporting the commissioning of services that enable carers to participate in their communities and feel less socially isolated
- To develop a Hub as a carer-led organisation and for it to represent the needs of carers in wider strategic planning

Objective 2: Improved access to information and assessments
- Improved access to Carers Assessments needs under Department of Health statutory criteria
- Assurance that tailored support and training for carers enables them to deliver their specific caring role
- To ensure that resources are directed towards the greatest need and most effective outcome possible
- Improved access to information in a range of formats in a method and locations that are accessible and known to all carers
- Strong services to support carers starting in their caring role and at times of emergency or crisis

Objective 3: Personalisation and greater flexibility, choice and control for carers
- Carers are put in control over the services that they use and can exercise meaningful choice
- Personal budgets are the key mechanism for commissioning services for those receiving support via a statutory carer assessment.
• That there is an effective market for carers services for carers to choose from
• Carers are comprehensively supported to procure the services they want, including 'non-traditional' modes of support
• Carers supported to plan for emergencies and contingencies
• Strong support for carers to plan, monitor and evaluate services

Objective 4: A healthy life outside caring
• Support carers to manage their health, using personal budgets where desirable
• Improve access to primary care and universally available talking therapies as part of achieving good mental health
• Intensively encourage the development of carers peer support linked to the new Hub

Objective 5: Optimal use of available resources
• Funding and supporting carers to commission services that achieve the outcomes they want
• Commissioning in the context of reduced budget.
• Supporting the development of a market for services and use of personal budgets to procure 'non-traditional' carers' services
• Promote effective preventative services.

The strategic objectives above have been completed in dialogue with carers and partners, set the framework within which our commissioning priorities. These outline how Southwark plans to deliver the new model of care of sustainability; the devolution of choice and control and improved outcomes.

4.2 Accommodation

4.2.1 Background
The council has a statutory duty to adhere to and implement the government’s strategy Valuing People. The guidance states that people with learning disabilities are able to live in a full range of housing options if they are given the right support. A key goal has been to reduce the number of service users living in residential service by 5% between 2009 and 2011.

Supported living schemes and its funding arrangements have a more modernised model of functioning in line with personalisation. New service users accessing the supported living schemes will automatically be assessed and transferred onto individual service funds following an outcome based assessments and thorough support plan. The core aims and objectives of supported living accommodation schemes is to enable individuals to live as independently as possible, minimising their need for support and preparing them for moving on into independent living in the community.

It is through personal budgets that the service user will pay for their own service and the provider assist service users to manage their budget to purchase other assessed outcome focused services.

Supported Living Accommodation and support service for adults with learning disabilities comply with the principles of the following local and national plans:
• Fair Access to Care
• The NHS Plan
• Valuing People
• Valuing People Now – White paper
• Learning Disabilities Accommodation Project Commissioning Strategy
• Southwark Learning Disability Services Joint Commissioning Strategy
• Single Conversation Housing Strategy
• Personalisation Agenda
• Social Care Business Plan
• The National Assistance Act
• Safeguarding adults – the service will have a strong emphasis on the safeguarding of vulnerable adults
• The Southwark Charter of rights - supporting and encouraging people to maintain and/or regain their independence.
• Our care, our health, our say White Paper

All these policy initiatives aim to maximise choice for adults with learning disabilities by offering a range of care and support options aimed at enabling people to live independently in their own homes and prevent homelessness and the use of institutionalised services.

The Supported Living Accommodation Schemes contribute to the following corporate priorities:
• Promote and encourage independent living and prevent homelessness for people with learning disabilities.
• Increase Service User’s ability to maintain their tenancy and meet occupancy obligations.
• Establish links to appropriate community based services to work with other local services and agencies in delivering an effective and holistic package of support to the client group to allow for a full and active live in the community.
• To work with carers and service user families to ensure appropriate support and engagement with the service to maximise independence and outcomes for service users.
• To ensure service users have more choice and develop more control over their own lives
• To promote personalised service provision through person-centred planning approaches and support service users to develop person centred plans.
• The support services will help address individual needs as identified in community care assessments.
• To have in place approaches to support service users against victimisation and discrimination in the community.
• To enable service users to move on to other accommodation suitable to their needs.
• To enable service users to make their own decisions and support them through this process.
• Everyone achieving their potential – maximising the opportunities for people to participate in education, training and employment.
• Adult social care charter of rights - supporting and encouraging people to maintain and/or regain their independence.

The service will also contribute to the Care Quality Commission 2010/11 outcomes of improving health and wellbeing and maintaining personal dignity and respect by supporting people to maintain their independence.
4.2.2 The position in Southwark

Southwark has a high number of people living in residential care. As more ordinary living options are made available with personalised support it is anticipated that the numbers of people living in residential care in Southwark will substantially reduce.

The strategy will continue to increase the demand from people with learning disabilities for ordinary housing. This is creating pressure on the Southwark’s social housing sector which is compounded by the overall shortage of social housing in Southwark and the pressure from other groups needing housing.

The supported living schemes will be offered to vulnerable adults with support needs, in order for them to maintain themselves in their own accommodation. Southwark will be able to offer its service users accommodation with more choice, personalised support, security and control than that provided in residential care homes. The service may also assist people in the transition from moving from temporary accommodation to alternative accommodation suitable to their needs.

Having these schemes in borough will help to reduce out-of-borough spend on residential care and develop appropriate services in the borough that people want and are more cost effective.

There is a lack of wheelchair accessible and mobility standard housing for people with learning disabilities; however this service will provide two placements for wheelchair users. The Supported Living Accommodation and Support Service will undertake culturally specific work where appropriate and has provisions in place to work with a diverse mix of service users that reflect the demographics of Southwark.

The service will support women and men from all cultural backgrounds, enhance their quality of life and aim to:

- Promote and encourage independent living and prevent homelessness for people with learning disabilities.
- To equip service users with the skills to and preparing them for move on into independent living in the community.
- Help to reduce social isolation and exclusion and integrate individuals back into the community

Resources

Steps are being taken, as part of the Accommodation Strategy, to reduce out-of-borough spend on residential care and develop appropriate services in the borough. This will require investment in the short-term to provide assessment, support for change and development of local services that people want and are more cost effective. The first step will be to review the people living out of the borough, to identify those people that want, or need, to come back to supported living in Southwark. Plans also need to be put in place to prevent young people in transition from being placed out of borough if their needs can be met locally in supported living.

This Supported Accommodation and Support service will ensure considerable savings for the department as the housing element part of this service will be funded through housing benefits payments. Supported living service will deliver significant savings for the department - it is estimated that the new supported living model could release savings for the health and social care budget; when compared to the cost of residential care. Service users are also left with more disposable income under the supported living model.
4.2.3 What else needs to be done?
A supply and demand exercise looking at the housing requirements of over 600 service users with learning disabilities identified 62 service users requiring immediate changes to their current housing; with a specific need to live in a supported living establishment. This supported living (and more independent forms of accommodation) accords with Southwark’s Learning Disabilities Joint Commissioning Strategy that seeks to reduce the number of people living in congregated institutional settings. This entails shifting away from using residential care homes and developing more supported living, where people with learning disabilities have assured tenancies and personalised care and support arrangements.

Plans also need to be put in place to prevent young people in transition from being placed out of borough away from their social networks, and often in high costing placements due to the gap in supported living services within the borough.

There is an evidenced need to increase the range of housing options and opportunities for service users with learning disabilities. A key step in achieving this is to invest in the development of more short term local supported living services within the borough. These services provide excellent outcomes for service users to gain valuable skills that will enable them to live independently in a range of housing tenures.

4.3 Employment

4.3.1 Background
Valuing People Now is a values and rights based paper and one of the key themes is the right to employment for all people with a learning disability. This was followed up later in 2009 with Valuing Employment Now, a second White Paper which challenged authorities to address the inequality of employment opportunities for people with moderate and severe learning disabilities.

The Government estimated that the paid employment level for people with learning disabilities nationally is around 10%. This contrasts with 48% for people with disabilities as a whole. The government also aspired to more people working for 16 hours or more as this is the point where people are financially better off.

Employment is seen as a beneficial activity for people with learning disabilities as it provides income and therefore increases independence, it establishes a role in the community, gives access to wider social networks and increases self respect.

4.3.2 The position in Southwark
Southwark has been very successful in attaining and retaining work for people with a learning disability. In the financial year 2009/10, 142 people known to social services were in employment which represented 15% of people known to Southwark services. This made Southwark the 2nd highest performing authority in London on this indicator.

Many of the people supported into employment have low or moderate needs. Some of the people supported are on the autistic spectrum and others have additional physical disabilities. The Table below is a summary of the statistics on employment as provided in Southwark Council’s learning disabilities partnership board annual report.
Table 4.3: Summary of employment status of people with LD known to Southwark services

<table>
<thead>
<tr>
<th>Category</th>
<th>2009/10</th>
<th>2010/11</th>
<th>2011/12 (projected)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working as a paid employee or self-employed</td>
<td>66</td>
<td>97</td>
<td>95</td>
</tr>
<tr>
<td>(Less than 16 hours per week)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working as a paid employee or self-employed</td>
<td>43</td>
<td>37</td>
<td>35</td>
</tr>
<tr>
<td>(16 hours or more per week)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>109</td>
<td>134</td>
<td>130</td>
</tr>
<tr>
<td>Working as a paid employee or self-employed</td>
<td>10</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>and in unpaid voluntary work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In unpaid voluntary work only</td>
<td>61</td>
<td>74</td>
<td>90</td>
</tr>
</tbody>
</table>

Source: Southwark Council

The success in employment is as a result of investment in employment projects by both Southwark’s Health & Social Care (H&SC) and Southwark’s Economic Development Unit (EDU). Three services are funded: Toucan Employment, Bede Plus and Work Train Southwark. Work Train Southwark is a collaboration between Bede Plus, The Camden Society, Southwark Works and Toucan Employment.

However, both funding sources are under threat for 2011/12 and 2012/13. EDU used the Working Neighbourhoods Fund (WNF) to fund the employment services but this has been significantly cut as part of the comprehensive spending review.

The financial support by H&SC is also changing and moving away from block contracts. Increasing numbers of clients will be receiving a personal budget and the block funding of employment services may cease and be replaced by clients purchasing the employment support they receive directly from the support provider. This will be subject to customer choice and they may choose not to prioritise employment support with their budget.

There are therefore risks to the future funding of employment support in Southwark although the Council will continue to work with the providers in an attempt to ensure the services are sustainable.

There will be major changes to incapacity benefit over the next three years that include a work capability assessment. This may result in people being moved onto Job Seekers Allowance or Income Support and an expectation to be seeking work. If a claimant is assessed as having limited capacity for work he or she will be put onto Employment and Support Allowance and the Department for Employment and Learning will provide support to enable and prepare the person for work.

These changes may result in customers who are eligible to receive support from the council being more encouraged to spend some of their personal budget on employment support to both attain and retain work. Personal Budgets have no impact on entitlement to benefits and they are to be used to meet the social outcomes agreed with the customer. They can be used in very inventive ways to enable people to lead full lives. An example may be to fund a job coach, travel training or even driving lessons.
4.3.3 What else needs to be done?
All clients that have an assessment and are eligible for services will be encouraged to consider employment as a realistic option and to look at how they can use their personal budgets to fund the support they require. Clients that do not meet FACS criteria will be encouraged to access mainstream services such as Remploy and Job Centre Plus.

There are three main priorities for the future:

1. For FACS eligible clients, ensure employment is fully explored in people’s person centred plan to enable clients to purchase employment related support
2. For non FACS eligible clients, ensure signposting to Remploy and Job Centre Plus mainstreaming their need.
3. Work with supported employment providers to develop appropriate charging structures for people

4.4 Hate crime

4.4.1 Background
A hate crime is targeted victimisation which can include a range of offences such as:
- Physical assault
- Harassment
- Threats
- Criminal damage to property or a place of residence
- Arson
- Bullying
- Verbal abuse and other offensive behaviour.

The Crown Prosecution Service (CPS) and Association of Police Officers (ACPO) have agreed five monitored strands of hate crime:
- Disability
- Race
- Religion or Belief
- Sexual Orientation
- Transgender Identity

Hate crimes can be part of a sustained campaign against a particular individual or group, or can occur as random attacks, and they may lead to serious injury or death. However, research shows that the majority of recorded racist incidents, for example, involve either damage to property or verbal harassment.

Following the Crime and Disorder Act 1998, the police have to record whether incidents are ‘racially or religiously aggravated’. The Racial and Religious Hatred Act, which came into effect in 2007, makes it a criminal offence to use threatening words or behaviour with the intention of stirring up hatred against any group of people because of their religious beliefs, or their lack of religious beliefs.

Nationally, the typical hate crime offender is a young white male. Most homophobic offenders are aged 16 to 20 years-old and most race hate offenders aged under 30
As well as resulting in physical injury, hate crime can affect people’s mental health and quality of life, and increase their fear of crime. It can lead to anger, insecurity, stress and depression, and can leave people afraid to leave the house.

Hate crime - key overall facts and figures:
- In the four years ending March 2010, more than 53,600 defendants were prosecuted for hate crimes through the Crown Prosecution Service (CPS)
- The conviction rate rose from 77% in 2006-07 to 82% in 2009-10
- Guilty pleas increased from 64% to 70%
- The majority of defendants across the hate crime strands were men
- Data on victim demographics are less complete and remain under development. However, where gender is known, men formed the largest proportion of victims across all strands, at 68% of the total.
- The most commonly prosecuted offences were those against the person and public order offences (43% and 40% of the total respectively)
- 75% of hate crime defendants were identified as belonging to the White British category, and 79% were categorised as White
- 50% of defendants were aged between 25-59 and 30% between 18-24
(Source: Crown Prosecution Service)

A cross party national plan to reduce hate crime was developed in 2009. This is currently being redeveloped and should be reissued later in 2011. The Association of Chief Police Officers (ACPO) are releasing new guidance and recommendations for the police and local authorities with the aim of increase reporting and eventually reduce hate crime incidents.

The CPS has recognised the needs of people with learning disabilities and in June 2010 developed an easy read leaflet about disability hate crime. This is available at:


4.4.2 The position in Southwark
Southwark has an active Hate Crime Working Group which monitors hate crime and promotes awareness of hate crime against all groups. The working group is attended by the voluntary sector, council staff and Speaking Up (the self advocacy group for people with learning disabilities in the borough). Speaking Up is especially keen on ensuring that people with learning disabilities report hate crimes when they are victims and are supported appropriately when they do.

In 2008/09 there were 199 reported crimes in Southwark against people with a mental impairment of which 70 (35.2%) incidents were against people with a learning disability. In 2009/10 there were 261 crimes against people with a mental impairment of which 80 (30.7%) incidents were against people with a learning disability The number of incidents of all hate crime in Southwark has risen year on year but as a percentage the number of victims with a learning disability has reduced.

In Southwark there is anecdotal evidence that people with learning disabilities are often the victims of hate crime. Many people prefer not to travel on public transport when school
children are also travelling as they have experienced name calling and bullying. Many of these incidents remain unrecorded.

In response to this, and in conjunction with Transport for London, there is access to a bus for 6 hours where people with learning disabilities are accompanied by police officers and police community support officers. This gives the opportunity to travel-train people, to work through scenarios, and users get the opportunity to discuss safety issues and the support that they need. The group also enact role plays of incidents that may occur when travelling on a bus.

The Hate Crime Working Group held an event in June 2011 to launch the theme of reporting hate crime when it happens and also reducing hate crime through awareness. It is recognised both locally and across London that improving recording is an ideal but will not be easy. The Hate Crime Working Group will look to lead on this area, but it will also require the police to be fully engaged for this to be successful.

Positive publicity will be needed to encourage the reporting of hate crime and for incidents to be recorded. Southwark will initially work towards encouraging people to report by using existing services and look at how best to increase the methods/opportunities available.

The Hate Crime Working Group will be forming recommendations to take the work forwards this will include developing a new hate crime strategy. The event in June will feed into the recommendations and will be key in developing the local hate crime agenda with all communities. Southwark violent crime strategy 2010-2015 also includes an action plan which contains a review of what is recorded as low level hate crime incidents to provide greater strategic direction on the prevention of these crimes.

4.4.3 What else needs to be done?
Southwark’s Hate Crime Working Group will develop a strategy during 2011 with recommendations for future work to increase reporting and reduce offending. People with learning disabilities are represented on this group by the co-chair of the LDPB who is also a member of the self advocacy group Speaking Up.

The Hate Crime Strategy will be co-agreed by Southwark’s Learning Disability Partnership Board and Speaking Up in regard to disability hate crime. The strategy will look to engage all community groups and look to enable individuals and groups to provide intelligence on incidents in the borough.

The following Strategic aims relate to all community groups

Reenergise the hate crime agenda:
- Develop a shared understanding of what a ‘hate crime’ is and communicate this with individuals, community groups and organisations
- Provide regular hate crime updates to the developing mailing list
- Review where and how hate crime work takes places in schools/ youth environments and make recommendations for future work
- Review the effects that restorative justice has had in schools and youth groups
- Plan a follow up hate crime event for 2012

Promote the support services available:
- Develop hate crime communication messages
- To create and promote an up to date directory of services/ support available
- Develop resources to promote the support available
• Utilise existing communications tools to cascade information
• Utilise new and existing technology (blogs, e-bulletins, social networking sites, podcasts etc) to provide information

Encourage communities to work together to tackle the issue:
• Develop hate crime awareness training
• Build a community network of support and signposting organisations (Single Points of Contact) to effectively support and refer to the appropriate support
• Develop a shared understanding of who, where and how hate crimes affect communities
• Promote stories where positive action has been taken to tackle hate crime
• Include information within the ASB community newsletter
• Develop tools for enabling communities to feed into an ever developing map of hate crime problem locations and issues

Encourage people to approach services for support and report:
• Work towards ensuring resources and information is as accessible as possible
• Review the various ways, tools and resources that people can use to record/report a hate crime
• Develop new and existing tools for recording and reporting hate crime
• To develop a picture of a Southwark hate crime ‘hot spot area’ to enable work to be developed and targeted at a particular location and evaluated to benchmark best practise
• To develop a hate crime minimum standards
• Work to build community confidence in recording and reporting hate crimes

4.5 Offending and criminal justice

4.5.1 Background
The exact number of people with a learning disability coming into contact with the police is not known, as there is no national requirement for the police, or any other criminal justice agency, to keep these statistics. This lack of information is an issue when it comes to estimating the scale of the problem and the planning of services.

However, research by the Prison Reform Trust, in ‘No One Knows’16, identified that 20 to 30% of offenders have learning difficulties or learning disabilities that interfere with their ability to cope within the criminal justice system. It is recognised therefore, that there is a significant number of people arrested and taken into police custody who have learning disabilities.

It is also identified in the Bradley Report 200917, that:

“the current prison population represents a huge diversity of individuals with a range of very complex needs, including a high number who are suffering from mental health problems or learning disabilities. The first step to the effective management of offenders is the existence of good early identification and assessment of problem.”

Valuing People Now states that some people with mild learning disabilities are in prison and that often their specific needs are not recognised or met because their learning disability is not visible. In addition a significant number of people with learning disabilities are placed in secure “forensic” establishments. The Sainsbury Group\(^\text{18}\) describe forensic services as:

> “the care of mentally disordered offenders - people who have been in contact with the criminal justice system and who have been transferred to secure hospitals. There are two main levels of security in forensic services hospitals to which both offenders charged with an offence and prisoners can be transferred: high secure and medium secure”

Valuing People Now 2009 highlighted that person-centred planning and health action planning are particularly important for people who are in prison or subject to community sentences, as they are the first step towards appropriate education and rehabilitative programmes. There are huge potential benefits for people with learning disabilities at risk of offending in having a Person Centred Plan and Health Action Plan, and there are many overlaps with offence related interventions. Prisoners may have a sentence plan, and people on probation will have a plan to fulfil their order. A person centred plan could support and improve the quality of these plans.

Any contact with the criminal justice system for people with learning disabilities should trigger appropriate adult support. The custody officer (usually a police sergeant) who is responsible for all detained people has a responsibility to identify vulnerable people. Those considered vulnerable are anyone who appears (to the custody officer) to be under the age of 17, people with mental health difficulties, people with a learning disability and those who have trouble communicating and understanding things. The custody officer then has a duty to request the attendance of a responsible adult, who is known as an Appropriate Adult.

The role of the Appropriate Adult is to support and advise a vulnerable person in police custody and to facilitate communication between them and the police. An Appropriate Adult can be a family member, friend or a volunteer or social/health care professional.

The Bradley Report states that studies into the use of Appropriate Adults have concluded that provision of the Appropriate Adult is very inconsistent. Firstly, the needs of a defendant have to be identified but are often missed. Even when a need for an Appropriate Adult is identified it is suggested there is a shortage of individuals who can perform the role effectively.

4.5.2 The position in Southwark
Currently there is no recording or specific data collated about people with learning disabilities in contact with the criminal justice system. There will be a detailed record on individual files but this is not used then to inform future service developments/needs.

The Appropriate Adult role is key is supporting people with learning disabilities to have a fair and equitable experience of the criminal justice system. Without this type of support people with learning disabilities are suggestible and may give false statements to please the interviewer.

All the social workers in the Southwark Community Learning Disabilities Team service (CLDT) can potentially act as appropriate adults. Social workers have had specific training in the past but none has been undertaken recently. The CLDT do not ask other organisations (eg advocacy) to act as appropriate adults on their behalf but the police will often ask other

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organisations. There is no protocol for recording of this at the moment. Although the CLDT record acting as an Appropriate Adult on an individual’s file, this information is not collated centrally.

There are no prisons based in Southwark, but there are some in neighbouring boroughs (eg HMP Brixton in Lambeth and HMP Wandsworth in Wandsworth). There are currently strategies or systems co-ordinated via the South London and Maudsley NHS Trust that operate consistently and effectively to identify people with mental health problems who have a learning disability in the police and criminal justice system, and to ensure they receive appropriate, skilled support.

These arrangements include:

- Involvement in Police Liaison Committees (MIETS)
- Multi-Agency Public Protection Arrangements (MAPPA)
- Court Liaison partnerships on behalf of Southwark
- Adult Mental Health and forensic services (community and inpatient)
- A project is planned to start on identifying people with a learning disability in local prisons on arrival at reception.
- A larger three-year Trustees funded service across the Criminal Justice Service began in April 2011. The project will use the Learning Disabilities Screening Questionnaire (LSDQ), a screening tool developed to help those who work with adults who are suspected of having a learning disability to have a quick and easy indication of whether they do.
- HMP Brixton is also being supported to undertake a training programme on Mental Health & Learning Disability

People also have access to the High Support Team, a forensic community mental health team (CMHT) via South London and Maudsley NHS Trust. This provides support, rehabilitation and advice for people aged 18-65 who have severe and ongoing mental health problems and learning disabilities. Twenty four hour care is available for people who live in the London Borough of Southwark (and those funded by Southwark placed outside the borough) who are placed in high security and low support accommodation.

A forensic community team provides care for people with offending histories who, with appropriate care and treatment, pose a low risk to the public. A team of health and social care professionals includes nurses, occupational therapists, psychologists, social workers, support workers, and consultant psychiatrists work with the police, public protection unit and the local Multi-Agency Public Protection Arrangement (MAPPA) team to manage people in the community. The team visits and assesses people either in their homes or outpatient clinics with the aim of moving people on to greater independence in their communities.

A number of adults with learning disabilities are also placed in residential forensic settings. These people receive support via CLDT and all have access to person centred approaches to help ensure their care and support delivers the best outcomes for their needs. In addition their placements are reviewed every 12 months, so we can identify and plan as early as possible with the individual their potential moves to less secure community based settings. Once in these settings, people have access to a range of community based services, education and support to help them improve their lives and reduce the risk of re-offending.

A project has also started which aims to offer those people with forensic needs placed out of borough the opportunity to return to Southwark. The project aims to develop supported living accommodation with appropriate support delivered in a person centred way, which will help people re-integrate into communities and improve their quality of life. Although in the early
stages it is planned that within a year a viable project will be up and running with further schemes to follow.

4.5.3 What else needs to be done?
Although a lot of the current focus is on people with higher levels of need in the criminal justice system (eg mental health issues) people with lower levels of need also need to be supported. Southwark’s LDPB should request representation from criminal justice services on the Partnership Board.
Valuing People Now states that “Person Centred Planning and Health Action Planning are particularly important for people who are in Prison or subject to community sentences” (p42). The Learning Disability Partnership Board should monitor that these are provided.

A mapping exercise should be carried out to review how services in Southwark are identifying and meeting the needs of people with learning disabilities who have offended or are at risk of offending. This will identify any gaps and support the development of a plan for meeting the needs of people with learning disabilities who have or are at risk of offending.

Key areas of focus should be:

- Identifying people who have or are at risk of offending
- Support available for people who have or are at risk of offending and current gaps
- Review how people with learning disabilities in Southwark are being identified by the criminal justice services, and a multi-agency improvement plan put in place
- Community Learning Disability Teams reviewing the skills available and required within their teams to meet the needs of offenders with a learning disability
- A review of the Appropriate Adults support provided, including training needs.
- Arrangements for multi-agency working including with Children’s services
- A review of local services with aim of reducing the number of forensic out of borough placements and support diversion from the criminal justice services, as described in Tough Times and the Mansell Report.
- Progression of the project designed to bring people living in forensic settings out of borough back to supported living projects in Southwark.
- Training in LD for staff members in criminal justice services and a plan to meet any identified gaps
- The availability of accessible information for people with learning disabilities involved in the criminal justice system

Other key actions should include:

- The Valuing People Now Delivery Plan states that “The DH, through its Offender Health initiatives on commissioning will work with PCTs to improve coverage by Learning Disability Specialist Nurses in all care settings in the Criminal Justice System (2009-2010)”. Local work should review of the role of LD Specialist Nurses to ensure this section of the LD population is being supported.
- The possibility of developing a local mentoring scheme for people with learning disabilities in conflict with the criminal justice system (as recommended by The Bradley Report) should be explored.
- A joint review with the Police Service of the Appropriate Adults scheme should be carried out with a view to improving and expanding the availability of Appropriate Adults by involving the voluntary sector and improving the training for the role.
- Better information management needs to be in place to record people’s contact with the criminal justice system to inform future planning. Data recording including age, gender, ethnicity, type of contact and the use of an Appropriate Adult, whether from the CLDT or alternative organisation would also help future planning.
4.6 Parents with a learning disability

4.6.1 Background
More people with learning disabilities are having children. A study on child protection applications to family courts found that 15% of them involved a mother and/or father with learning disabilities\textsuperscript{19}. People with learning disabilities report that they are often treated as “the problem” rather than being seen as people who need support. They say that the services that support parents in general do not know how to support parents with learning difficulties. This means that when problems arise they are more at risk of having their children taken away.

Many people believe that the legal system does not help. Judges and lawyers often have little training or experience of people with learning difficulties. The time limit put on care proceedings can, at times discriminate against parents with learning difficulties who tend to struggle to keep up with the pace of events.

It is therefore important to help people with learning disabilities to be good parents. The National Gathering of parents with learning disabilities\textsuperscript{20} noted the importance of:

- Accessible information about how to look after your baby
- Coming together with other parents
- Getting support before things go wrong
- Being assessed in your own home – not a separate assessment centre.
- Assessment and support by people who understand learning disabilities
- Advocacy when you need it
- The courts being more accessible
- Support for dads with a learning disability.

Research has found that there are certain things that make it possible for people with learning disabilities to be good parents:

- Believing that people can be good parents rather than starting off with the belief that they cannot
- Good advocacy support
- Specialist services for parents with learning disabilities
- Being willing to learn from parents themselves\textsuperscript{21}

An overview of all the research on parents with learning disabilities\textsuperscript{22} found that the main things that stop people looking after their children properly were:

- Not enough support
- The only support out there being designed for non-disabled parents
- Lots of different people involved and not talking to each other or agreeing what should happen
- Few role models
- Little support from family and friends

\textsuperscript{20} Change – Report of the national gathering of parents with learning disabilities’ Change 2005
\textsuperscript{22} McGaw S. ‘What works for parents with learning disabilities’ Barnados 2000.
4.6.2 The position in Southwark
In May 2007 the Southwark Safeguarding Children Board launched a ‘Joint Service Protocol to meet the needs of children and unborn children whose parents have disabilities’. The joint protocol was developed to meet the requirements (set out in *Every Child Matters and the Children Act 2004*) that all services should work more closely together to promote the health and well-being of children and young people, families and carers. The protocol is a practice guide for practitioners who may have concerns about the well-being or safety of children whose parents or carers have disabilities, specifically where these difficulties are impacting on their ability to meet the needs of their children.

The majority of people with LD known to services do not have children, but there are currently 23 people who have had one or more children in Southwark (5% of the learning disability social work caseload). It is acknowledged through research that parents with learning disabilities are much more likely to have their children removed; national statistics highlight that 50% of those adults with learning disabilities who are parents are not caring for their own child or children\(^{23}\). In Southwark, the percentage is higher than the national average, with 80% of parents not caring for their own child.

4.6.3 What else needs to be done?
Key priorities locally are to:
- Review and re-write the Joint Service Protocol to ensure that it takes into account legislative changes and policy changes.
- Continue to have interface meetings between adult disability services and children’s services to:
  - promote the increased understanding of the impact of an adult’s disability on children’s lives.
  - ensure that the provision of universal and specialist services are co-ordinated for families who have dependent children of parents, carers or pregnant women with learning disabilities.
  - ensure effective co-operation and collaborative decision-making between services.

4.7 LBGT with learning disabilities

4.7.1 Background
A review of literature highlighted some key issues for LGBT persons with LD. They include:
- The importance of skilled and informed support for young LGBT with LD recognising the complexities of self identification and sexuality, recognising that educational activities for young people with LD may not adequately address sexuality and that caregivers would benefit from concrete approaches to support choice, power and control for people with LD.\(^{24}\)
- More work needs to take place to meet the sexual health needs of young LGBT adults with LD, including their right to be sexual in private in their homes. Without this privacy, this group is having sex in places where they do not feel comfortable (in

\(^{23}\) Tarleton B, Ward L and Howarth J. ‘Finding the right support’ Baring Foundation 2006

\(^{24}\) Thompson S, A Subversive political praxis: supporting choice, power and control for people with learning difficulties. *Disability & Society*, 01 October 2003, vol./is. 18/6(719-736)
public places) and are least likely to practice safer sex, where they would be least likely to use condoms and experience abuse.  

- There is greater risks of HIV transmission for men with learning disabilities who have sex with men.
- Women with LD are 1.5 to 10 times more likely to experience sexual violence as women without LD. Furthermore, it is estimated that a high proportion of perpetrators in these crimes are well known, trusted by, and often service providers for women with LD.
- Balanced information and support on sexual health and sexuality is vital and not of consistent quality. There needs to be a balance between the potential for sexual abuse and meeting the sexual health needs of people with LD, including LGBT groups.
- The attitudes of staff and carers can influence how well the sexual health needs of people with LD and LGBT are met. Additional training is suggested for nurses and other professionals.
- LD health messages on sexual health and sexuality must be clear and explicit rather than ambiguous.

4.7.2 The position in Southwark

For people who are eligible for support, Southwark responds to the needs of people with learning disabilities who are gay, lesbian, bisexual or transgender through its assessment and support planning process. These are person centred and encourage individuals to describe their own needs and determine and arrange their own support arrangements by the use of a personal budget provided by the council. This approach is designed to allow people to live their lives in ways that they choose.

Similar approaches are developing in health services through the use of personal health budgets.

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27 Stevens, Bethany Examining emerging strategies to prevent sexual violence: Tailoring to the needs of women with intellectual and developmental disabilities, Journal of Mental Health Research in Intellectual Disabilities, April 2012, vol./is. 5/2(168-186), 1931-5864;1931-5872 (Apr 2012)

28 Douglas Scott, Susan Sexuality and learning disability. In Burtney, E. and Duffy, M. (eds) Young People and Sexual Health: individual, social and policy contexts, Basingstoke, Palgrave Macmillan, 2004

29 Armstrong, Yolande Audit of sex and relationships education and sexual health provision for disabled children and young people Bradford Safeguarding Children Board, 2010


4.7.3  **What else needs to be done?**

All agencies involved in providing care and support to people with learning disabilities from the LGBT community need to ensure that they respond to their individual needs appropriately and without discrimination.

To achieve this staff will need ongoing skills and awareness training on LGBT issues and how they relate to people with learning disabilities. They will then be better equipped to provide appropriate advice and support to this group and their families.

Staff to be included in the training will include:
- GPs
- Specialist LD nurses/therapists
- Social workers/brokers
- Support workers
- Advocates
- Teachers

Agencies will be monitored on how they are responding to the needs of to people with learning disabilities from the LGBT community.
Chapter 5. Health and wellbeing

This chapter focuses on the physical and mental health of people with learning disabilities in Southwark. It ranges from overall indicators of health status to more specific problems that people with learning disabilities might face. Much of the epidemiological evidence comes from national sources but local data has also been included where possible. In particular some data on the use of local services is helpful as an indicator of where the needs of people with LD may be greater or where people might not have equitable access to services.

People with learning disabilities have significantly poorer health than their non-disabled peers and are more likely to die at a younger age. Although people with learning disabilities have a greater need for services they have been found to have poorer access to services. A number of reports in recent years have highlighted the low priority and focus given to health and healthcare for people with learning disabilities:

- *Equal treatment: Closing the Gap* highlighted failing in access to healthcare and providing appropriate treatment for people with learning disabilities.

- *Death by Indifference* described the circumstances surrounding the death of six people with learning disabilities while they were in the care of the NHS.

- *A life like no other* found that adults with learning disabilities are particularly vulnerable to breaches of their human rights in healthcare.

- An independent Inquiry was held in response to *death by indifference* and a report of that Inquiry (*Healthcare for All*) made ten recommendations.

5.1 Physical health

People with learning disabilities have a lower life expectancy than people who do not. However life expectancy for people with learning disabilities has been increasing. The leading cause of death for the general population is from cardiovascular diseases; for people with learning disabilities the leading cause of death is respiratory disease rather than heart disease. All cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population.

5.1.1 Lifestyles

*Smoking and alcohol use*

The major health risks of smoking (and the reduction in health risk from quitting smoking) are well known. There is very little information on smoking and alcohol use amongst adults with learning disabilities. However of adults who use learning disabilities services a smaller proportion smoke tobacco or drink alcohol compared to the general population. A survey of people with learning disabilities found that one in five (19%) people with LD smoked cigarettes compared to an estimated 22% of the general population (Source: Health Survey for England 2009). The survey of people with learning disabilities found that people with learning disabilities were more likely to smoke if they:

- had low support needs
- were poor

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32 Eric Emerson and Gyles Glover *Health Checks for People with Learning Disabilities: 2008/9 & 2009/10*
33 Eric Emerson and Susannah Baines, *Health inequalities and people with learning disabilities in the UK: 2010*
34 Eric Emerson and Susannah Baines, *Health inequalities and people with learning disabilities in the UK: 2010*
35 Eric Emerson Sally Malam, Ian Davies & Karen Spenser, *Adults with learning difficulties 2003/04*
did not see friends with learning difficulties very often
lived in more deprived areas
were men
were White
did fewer different types of community activities
were younger
saw friends who do not have learning difficulties more often

It is estimated that amongst the 5,700 people with learning disabilities in Southwark 1,080 will be smoking (assuming 19% prevalence).

Physical activity
Regular physical activity is important for both physical and mental health. It is currently recommended that adults engage in 30 minutes or more of moderate or vigorous activity on at least 5 days a week. The Health Survey for England 2009 reported that 34% of the general population met these recommendations and a further 32% participated in 30 minutes or more of moderate or vigorous activity on one to four days a week.

There is very little information on physical activity amongst people with learning disabilities. The national survey of people with learning disabilities asked about people participating in physical activity three or more times a week and found that nearly one in six (15%) did this. The survey also found that people were more likely to exercise at least three times a week if they:
- were younger
- had lower support needs
- did a wider range of community-based activities
- were men
- were Black
- did not see friends with learning difficulties very often

While physical activity may be achieved by involvement in non-formal activities such as gardening and housework, opportunities for people with learning disabilities to participate in formal physical activities is often more difficult to access. People with learning difficulties may encounter problems due to access (physical), lack of transport, lack of support staff, limited finances and lack of easy to read information.

Assuming that 15% of adults with learning disabilities are participating in physical activity three or more time a week, 855 people with learning disabilities in Southwark will be doing this and 4,845 will be not.

Nutrition and obesity
There is considerable evidence that people with learning disabilities are more likely than those in the general population to have nutritionally-related ill health, and that this is less recognised by support staff and professionals than when it occurs in the general population. Less than 10% of adults with learning disabilities have a balanced diet containing fruit and vegetables.

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Several studies have shown that obesity is more common among people with learning disabilities. One study looking at health checks on people with learning disabilities found that 35% of people with learning disabilities were obese compared to 22% of the general population\textsuperscript{39}. Obesity is related to specific learning disability conditions e.g. Prader-Willi syndrome and due to poor nutrition and sedentary lifestyles.

It is estimated that amongst the 5,700 people with learning disabilities in Southwark 2,000 will be obese (assuming 35% prevalence). Southwark is about to undertake a piece of work exploring the local issues of diet and nutrition in people with learning disabilities. This piece of work will explore evidence of good practice both within the borough and outside it, investigate what data is collected locally and make recommendation on how this can be improved and what health promotion services could reasonably be offered.

**Sexual health**

Evidence\textsuperscript{40} suggests that people with learning disabilities may face particular barriers in accessing sexual health services, and the informal channels through which young people learn about sex and sexuality.

5.1.2 Chronic conditions

**Respiratory disease**

Respiratory disease is possibly the leading cause of death for people with learning disabilities (46%-52% of total deaths), with rates much higher than for the general population (15%-17% of the total)\textsuperscript{41}.

**Coronary Heart Disease**

Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20% of the total), with rates expected to increase due to increased longevity and lifestyle changes associated with community living\textsuperscript{42}. People with Down's syndrome are at higher risk of congenital heart defects.

**Epilepsy**

The prevalence rate of epilepsy amongst people with learning disabilities has been reported as at least twenty times higher than for the general population\textsuperscript{43}. The frequency of epilepsy increases progressively with more severe intellectual impairment. It has been estimated that the prevalence of epilepsy in people with mild to moderate learning disabilities is 15% whilst it is estimated to be 30% within those with severe learning disabilities.

Literature indicates that epilepsy in people with learning disabilities is generally more difficult to treat and often resistant to drug treatment. Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality.

\textsuperscript{39} Kerr, M. Improving the general health of people with learning disabilities. Advances in Psychiatric Treatment (2004): 10: 200-206

\textsuperscript{40} Eric Emerson and Susannah Baines, Health inequalities and people with learning disabilities in the UK: 2010

\textsuperscript{41} Eric Emerson and Susannah Baines, Health inequalities and people with learning disabilities in the UK: 2010

\textsuperscript{42} ibid

\textsuperscript{43} ibid
Sensory Impairments
There is a greater frequency of hearing and sight problems in people with learning disabilities than the general population. Approximately 40% of people with learning disabilities are reported to have a hearing impairment and are 8 to 200 times more likely to have a vision impairment compared to the general population.\(^\text{44}\)

Bearing in mind the increased risk of hearing and vision problems it is important that people with learning disabilities regularly have eye and hearing tests. However, a survey of people with learning disabilities\(^\text{45}\) found just over half (52%) of those surveyed had received an eye test in the past year and 21% had had their hearing tested.

Diabetes
There is very little information on diabetes in people with learning disabilities. A study undertaken in the Netherlands has shown an increased risk of diabetes in people with learning disabilities. Some of the risk factors for diabetes, such as obesity, poor diet and inactive lifestyle are more common amongst people with learning disabilities, which could suggest that diabetes may be more prevalent in this group than the general population.

Dysphagia
Swallowing and nutritional problems have a high prevalence among people with learning disabilities. Difficulties with eating, drinking and swallowing have implications for health and wellbeing. Dysphagia can lead to poor nutritional status, dehydration, and asphyxiation.

Oral Health
Good oral health is important for all and impacts on the overall quality of life but dental ill health is more common in people with learning disabilities than the general population. One in three adults with learning disabilities and four out of five adults with Down’s syndrome have unhealthy teeth and gums.\(^\text{46}\) It has also been reported that adults with LD living with families have more untreated decay and poorer oral hygiene and that adults living in residential services have more missing teeth.

Information on the oral health of people with learning disabilities is generally poor. This year the annual Adult Dental Health Survey is including a booster sample of people with learning disabilities. This should give some useful information on this group of adults and their oral health. The data will however reflect the national picture and not the local situation.

Screening
Several studies have reported low uptake of health promotion or screening activities among people with learning disabilities, including screening for cervical and breast cancer. A number of reasons have been suggested including not offering the screening, perceived difficulties of performing the test, cognitive difficulties in understanding the benefits of screening and getting adequate consent.

It is not known what the local coverage of people with learning disabilities is for cervical and breast screening.

\(^{44}\) Ibid
\(^{45}\) Eric Emerson, Sally Malam, Ian Davies & Karen Spenser, Adults with learning difficulties 2003/04
\(^{46}\) Eric Emerson and Susannah Baines, Health inequalities and people with learning disabilities in the UK: 2010
5.1.3 Use of health services

Primary Care
The trend towards people with LD living in the community rather than in long-stay institutions over recent decades has meant that their primary health needs are met by GPs. A survey of people with learning disabilities found that almost all were registered with a GP (99%) and that three out of four (78%) had seen a doctor with the last year\(^{47}\).

All general practices are expected to keep registers of adults with learning disabilities as part of the Quality and Outcomes Framework (QOF). In Southwark there were 623 adults recorded on the general practice learning disabilities registers in 2010/11 (see Section 3 - Population). There are several other conditions also considered in QOF that are particularly important for people with learning disabilities, such as obesity, epilepsy, coronary heart disease. Currently Southwark is unable to identify how many people with learning disabilities have each of these other conditions.

Annual health checks
Evidence suggests that the provision of health checks in primary care for people with learning disabilities is effective in identifying previously unrecognized morbidity\(^{48}\). Health checks are a good tool in helping reduce health inequalities faced by this group of adults.

In 2009 the Department of Health stated that PCTs should offer GP practices in their area the opportunity to provide health checks for people with learning disabilities as part of a Directed Enhanced Service (DES) scheme. The DES was originally agreed for two years (2008-9 and 2009-10) and has been extended for at least another year (2010-11). TheDES specification on the health check included that the check was undertaken by a provider with appropriate training and was based on a local protocol that included the following:
- a review of physical and mental health with referral through the usual practice routes if health problems are identified
- health promotion
- a review of chronic illness
- a physical examination
- a review of epilepsy
- a review of behaviour and mental health
- a syndrome specific check
- a check on the accuracy of prescribed medications
- a review of co-ordination arrangements with secondary care
- a review of transition arrangements where appropriate.

The baseline for the checks specified in the DES is the number of “Learning disabled clients known to Councils with Adult Social Services Responsibilities: those clients who are assessed or reviewed in the financial year and who have received a service, as well as those who are assessed and/or reviewed but who have not received a service. In addition, include learning disabled clients who should be reviewed by the CASSR in a financial year but are not.”

Nationally, 72,782 people with learning disabilities were reported to have received a health check in 2010/11 (49% of people with LD). This is an increase of 24% from 2009/10 and 118% from 2008/9. In London 37% of people with LD had received a health check.

\(^{47}\) Eric Emerson, Sally Malam, Ian Davies and Karen Spencer Adults with learning difficulties in England 2003/04
In Southwark the baseline for the checks has been the number of people on the general practice LD register but a project is in progress to look at those known to social services (see above). In 2010/11, 34% (197 out of 623) of people on Southwark’s learning disabilities register had received a health check. This was a 2% reduction on the proportion receiving a health check in Southwark in 2009/10.

There is no uniformly recorded data on the health checks that can be analysed to monitor the health of people with learning disabilities in Southwark at the population level. However the Improving Health and Lives observatory has recently produced an audit tool for health checks. This useful audit tool helps practices look at how they are currently carrying out the health checks and reflect on how they could improve.

**Health Action Plans**

A health action plan is defined by the DH as:

> “the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the individual and the range of services and supports they need if they are to have better health... the plan is primarily for the person with learning disabilities and is usually co-produced with them.”

Each patient with a learning disability is supposed to have a health action plan. However in Southwark it is not known how many local patients actually have one of these plans.

**Secondary care**

It has been estimated that 26 percent of people with learning disabilities are admitted to hospital annually, compared to 14 percent of the general population. The secondary use service (SUS) dataset provides information on all patients admitted to NHS hospitals in England. However, there is no single data item in the dataset that identifies people with learning disabilities completely. People with learning disability can be identified if they are given a diagnosis either specifically of a learning disability, or of a condition causing this. However, many admissions by people with learning disabilities will have no reference to the adult having a learning disability.

This section looks at hospital admissions for Southwark residents over three years (2008/09 to 20010/11) where there has been some recording of the following conditions:

- Autism Spectrum disorders (ICD-10 F84)
- Down syndrome (ICD-10 Q90)
- Fragile X (ICD-10 Q99.2)
- Mental Retardation (ICD-10 F70-F79)
- and Asperger’s syndrome (ICD-10 F84.5)

It must be noted though that many admissions for people with learning disabilities will not be included here as there will have been no recording of it on the hospital admissions minimum dataset.

Over the last three years there has been an increase in admissions for people with a learning disability diagnosis (Table 5.1). In particular there was a large increase admissions for males between 2009-10 and 2010-11. This includes people that may have been readmitted. Table 5.2 shows the actual number of people admitted in the three years. The numbers are not large with 76 people being admitted to hospital in 2010-11.
Table 5.1: Number of Spells for five conditions associated with LD, Southwark residents:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>45</td>
<td>50</td>
<td>107</td>
<td>202</td>
</tr>
<tr>
<td>Females</td>
<td>31</td>
<td>40</td>
<td>54</td>
<td>125</td>
</tr>
<tr>
<td>Total</td>
<td>76</td>
<td>90</td>
<td>161</td>
<td>327</td>
</tr>
</tbody>
</table>

Source: SUS admitted patient data set 2008/09 to 2010/11

Table 5.2: Number of people admitted for five conditions associated with LD, Southwark residents

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>33</td>
<td>30</td>
<td>53</td>
<td>116</td>
</tr>
<tr>
<td>Females</td>
<td>20</td>
<td>20</td>
<td>23</td>
<td>63</td>
</tr>
<tr>
<td>Total</td>
<td>53</td>
<td>50</td>
<td>76</td>
<td>179</td>
</tr>
</tbody>
</table>

Source: SUS admitted patient data set 2008/09 to 2010/11

Figure 5.1 shows the number of total number of admissions over the three year period. The majority (117) of people had just one admission over this time period.

Figure 5.1. Number of admissions of Southwark patients for five conditions associated with LD over the 3 years

Source: SUS data 2008/09 to 2010/11
Table 5.3 shows that just over 50% of the patients were under 15 years old on their first admission in the three year period. Almost half of the patients (46.9%) were White and just over a third (35.2%) were Black or Black British (Table 5.4).

Table 5.3. Age of patients (based on age at first admission), 2008/09 to 2010/11.

<table>
<thead>
<tr>
<th>Age</th>
<th>Males</th>
<th>Females</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>67</td>
<td>27</td>
<td>94</td>
</tr>
<tr>
<td>15-24</td>
<td>22</td>
<td>13</td>
<td>35</td>
</tr>
<tr>
<td>25-34</td>
<td>6</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>35-44</td>
<td>4</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>45-54</td>
<td>6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>55-64</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>65-74</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>63</td>
<td>179</td>
</tr>
</tbody>
</table>

Source: SUS admitted patient data set 2008/09 to 2010/11

Table 5.4. Ethnic group of patients, 2008/09 – 2010/11.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of people</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>84</td>
<td>46.9%</td>
</tr>
<tr>
<td>Asian or Asian British</td>
<td>4</td>
<td>2.2%</td>
</tr>
<tr>
<td>Black or Black British</td>
<td>63</td>
<td>35.2%</td>
</tr>
<tr>
<td>Mixed</td>
<td>9</td>
<td>5.0%</td>
</tr>
<tr>
<td>Chinese or Other Ethnic Groups</td>
<td>9</td>
<td>5.0%</td>
</tr>
<tr>
<td>Not known</td>
<td>10</td>
<td>5.6%</td>
</tr>
</tbody>
</table>

Source: SUS admitted patient data set 2008/09 to 2010/11
Finally, Table 5.5 shows the primary diagnosis of those people admitted during that time. While this gives a broad indication of reasons for hospitalisation, further analysis would be needed to help assess whether patterns are significantly different from the wider population and the extent to which some admissions could be avoided.

Table 5.5 Primary diagnosis of admissions during 2008-09 to 2010-11

<table>
<thead>
<tr>
<th>Disease</th>
<th>Number of admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certain infectious and parasitic diseases</td>
<td>7</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>2</td>
</tr>
<tr>
<td>Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism</td>
<td>5</td>
</tr>
<tr>
<td>Endocrine, nutritional and metabolic diseases</td>
<td>2</td>
</tr>
<tr>
<td>Mental and behavioural disorders</td>
<td>40</td>
</tr>
<tr>
<td>Diseases of the nervous system</td>
<td>52</td>
</tr>
<tr>
<td>Diseases of the eye and adnexa</td>
<td>5</td>
</tr>
<tr>
<td>Diseases of the ear and mastoid process</td>
<td>14</td>
</tr>
<tr>
<td>Diseases of the circulatory system</td>
<td>6</td>
</tr>
<tr>
<td>Diseases of the respiratory system</td>
<td>39</td>
</tr>
<tr>
<td>Diseases of the digestive system</td>
<td>23</td>
</tr>
<tr>
<td>Diseases of the skin and subcutaneous tissue</td>
<td>3</td>
</tr>
<tr>
<td>Diseases of the musculoskeletal system and connective tissue</td>
<td>10</td>
</tr>
<tr>
<td>Diseases of the genitourinary system</td>
<td>13</td>
</tr>
<tr>
<td>Pregnancy, childbirth and the puerperium</td>
<td>8</td>
</tr>
<tr>
<td>Certain conditions originating in the perinatal period</td>
<td>2</td>
</tr>
<tr>
<td>Congenital malformations, deformations and chromosomal abnormalities</td>
<td>40</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified</td>
<td>19</td>
</tr>
<tr>
<td>Injury, poisoning and certain other consequences of external causes</td>
<td>25</td>
</tr>
<tr>
<td>Factors influencing health status and contact with health services</td>
<td>9</td>
</tr>
</tbody>
</table>

Source: SUS admitted patient data set 2008/09 to 2010/11

5.1.4 What else needs to be done?
Key priorities should be to:
- Improve the level of recording of learning disabilities in primary care
- Collect data on the number of people with LD receiving health checks and improve coverage if necessary
- Develop ways of extracting health and health-related data (such as smoking prevalence, screening uptake, body mass index etc) from LD registers in order that health improvement efforts can be targeted effectively
- Review hospital admissions to ensure that people with LD are being recorded where appropriate and to review the potential for avoiding unnecessary admissions
5.2 Mental health and wellbeing

5.2.1 Background
It is now understood that people with learning disabilities experience the same range of mental health problems as the general population but are more likely to experience mental health issues than those without learning disabilities\(^{49}\). The White Paper “Valuing People” highlights this as a key area for which people with learning disabilities need support. An added difficulty is how the symptoms of mental health problems can sometimes present themselves differently or be missed due to other issues such as autism in people with learning disabilities.

The Royal College of Nursing published guidance relating to mental health and learning disabilities\(^{50}\). This highlighted the prevalence of different mental health problems among people with learning disabilities and is the source of the following summary:

**Attention deficit hyperactive disorder (ADHD)**

Levels of ADHD are higher in people with learning disabilities, with 3% of those with borderline and 12% of those with mild learning disabilities reported to have ADHD. This figure may be higher still, but may be misdiagnosed as personality disorders or as bipolar affective disorder. The reasons for higher levels of ADHD could be that adults with learning disabilities are at a developmental stage where the symptoms of ADHD are particularly prevalent.

**Affective Disorders**

The reported prevalence rate of affective disorders in people with learning disabilities varies widely, but a recent study found the overall prevalence of these disorders to be 6.6%.

For depression in people with mild learning disabilities, who have good communication skills and can recognise and articulate their emotions, similar assessment methods are used as those for the wider population. Where an individual does not self-report their symptoms, services have to rely on behavioural signs for diagnosis.

Bipolar disorder is estimated to be higher in people with learning disabilities. Deb and Hunter observed cyclical changes in behaviour in 4% of people with learning disabilities.

**Anxiety**

There is a great deal of variation in the reported prevalence rates of anxiety disorders, although the incidence is thought to be higher in people with learning disabilities; a recent study reported a rate of 3.8%. Anxiety disorders are seen in equal proportions in both genders of people with learning disability, compared with the wider population where incidence is higher in women.

Problems like social phobias may not be noticed if a person has a restrictive environment, is under close supervision or receives support when they are in the community. Anxiety may also be a symptom of another mental health problem, such as depression or psychosis, which has gone undiagnosed.

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\(^{49}\) Cooper SA et al. 'Mental ill-health in adults with intellectual disabilities: prevalence and associated factors' British Journal of Psychiatry 2007 190: 27-35

\(^{50}\) Royal College of Nursing. "Mental Health Nursing of Adults with Learning Disabilities" RCN 2010.
**Delirium**
There are no exact prevalence figures for delirium in people with learning disabilities. This condition can go undetected or misdiagnosed as psychotic illness. Delirium may present more frequently in people with learning disabilities due to the increased risk of infections seen in this group. There is also a risk of toxic reaction due to the introduction of, or changes in, medications, especially in people with metabolic disorders.

**Dementia**
Higher prevalence rates of dementia exist in people with learning disabilities: 21.6% compared with 5.7% in those above 65 years. The prevalence of dementia is further increased in people with Down's syndrome, where Alzheimer's disease is seen in much higher rates and at an earlier age.

Dementia may progress more rapidly in people with learning disabilities, although this could also be because early symptoms go unnoticed in people whose routines such as hygiene and dressing are supported by a carer.

**Eating disorders**
Anorexia nervosa and bulimia are less common in people with learning disabilities than in the wider population, but hyperphagia and pica are more prevalent. However, in people with mild learning disabilities, prevalence rates may be similar to those seen in the wider population. Over eating is particularly associated with Prader-Willi syndrome.

**Obsessive Compulsive Disorder (OCD)**
The prevalence of OCD in people with learning disabilities is thought to be 3.5%. It is difficult to give a clear diagnosis of OCD without the person demonstrating a subjective struggle not to carry out the compulsion. For some, carrying out what looks like a compulsion may be a pleasurable activity.

It may also be difficult to differentiate between a true compulsion and stereotyped movements, mannerisms or complex tics. Compulsions and stereotypic behaviour are often seen in people with autism and may distort the diagnostic picture.

**Personality disorder**
Personality disorders are considered to be more prevalent in people with learning disabilities, though it is often difficult to subdivide personality disorders into different groups. Cooper et al found a prevalence of 1%.

Before giving a diagnosis of personality disorder, clinicians must take into account an individual’s circumstances and conditions such as autism.

**Post Traumatic Stress Disorder (PTSD)**
There is little research on PTSD in people with learning disabilities. We can assume that people with learning disabilities can develop PTSD just as they can develop other mental health problems, particularly given the high levels of neglect and abuse that people with learning disabilities often suffer. PTSD may present as aggression or occur along with other mental health problems.

**Psychotic illness**
Non-affective psychotic disorders have a raised prevalence in people with learning disabilities. Hatton found rates of between 2% and 6% when examining prevalence figures. Cooper et al found a prevalence of 4.4% for the range of psychotic disorders. People with learning disabilities are less likely to use illegal psycho-active drugs, so induced psychosis is not as commonly seen as in the wider population.
Some people may show behaviours that lead observers to believe wrongly that an individual is responding to hallucinations. For example, the echoed speech seen in people with autism may give the impression they are holding a conversation, when in fact they are repeating fragments of speech they heard earlier.

**Schizophrenia**

The prevalence of schizophrenia in people with LD has been found to be three times that of the wider population, with Deb et al reporting that the prevalence rate lies between 1.3% and 3.7%. Schizophrenia has an earlier onset of 22.5 years in people with learning disabilities compared to 26.6 years in the wider population.

Like all psychotic illness, a diagnosis of schizophrenia is difficult in people with severe/profound learning disabilities and reduced communication skills. A decline in someone’s social functioning and self-help skills may be masked if they receive support from carers. Even when symptoms such as poor hygiene or a lack of self-help skills are identified, the assessor could attribute them purely to the individual’s learning disabilities, and steer away from a diagnosis of schizophrenia.

**Substance misuse**

Levels of drugs and alcohol misuse are lower than in people without learning disabilities, but are an emerging issue of concern. A small but increasing number of people with learning disabilities living independently can, and do, develop substance misuse problems, and are sometimes targeted due to their vulnerability.

It is important to recognise that there is a distinct difference between a person having a mental illness and a learning disability, although the two may often be confused. Mental health problems can develop after childhood, can change over a period of time and some can be temporary. Learning disabilities, on the other hand, permanently affect intellectual function and are usually evident from birth or early years.

There can be many reasons for this vulnerability to mental health problems in people with learning disabilities including health, societal or quality of life factors. People with learning disabilities are vulnerable to social exclusion, depression and stress, as well as physical, verbal and psychological abuse, and this may contribute to develop mental health issues. Some specific types of learning disabilities may also be associated with particular mental health problems e.g. Downs Syndrome and dementia.

In addition, people with learning disabilities may not be able to communicate their problems and feelings, leading to frustration on behalf of the person and misdiagnosis by those supporting them. Changes in behaviour may be overlooked or misunderstood and as a result behaviour which challenges services may occur. In some cases, previous or current lack of access to psychiatric/psychological services can exacerbate problems. However, if mental health issues are identified in people with learning disabilities, there can be effective interventions such as medication, psychological help, counselling and therapy. Valuing People therefore places an emphasis on social inclusion in mental health services. People with learning disabilities should use the same services, resources and facilities as the rest of the population; “As with their other health needs, people with learning disabilities should be enabled to access general psychiatric services whenever possible”.

5.2.2 The position in Southwark

**Community Based services in Southwark**

The mental health services for people with learning disabilities in Southwark are managed by the South London and Maudsley NHS Trust (SLaM). They offer a range of community based
services which are integrated with local community health services but which can offer specialist input to meet the needs of people with learning disabilities when required.

Southwark Mental Health in Learning Disabilities (MHLD) is the specialist, community-based service at the York Clinic, in Guy’s Hospital. This provides outpatient mental health assessments and advice on services and treatment options to help people with learning disabilities maintain their health and independence. The team includes psychiatrists, community psychiatric nurses (CPNs), counsellors and behavioural support specialists who work with other health and social care teams as part of the Mental Health Learning Disability Service (MHLD) Neurodevelopment Division.

The Psychological Services Team also provides community-based psychological assessment, advice and treatment. They work with adults who have mental health problems and learning disabilities who may have emotional, behavioural, social, communication or physical difficulties. It supports people with a range of mental health problems, including depression, anxiety and phobias. They also work with people who have experienced trauma, abuse and relationship problems.

Non-community based services
Southwark also has access to 4 inpatient beds at the Bethlem Royal Hospital for adults with learning disabilities who require specialist assessment and treatment due to complex or atypical mental health issues. Using needs-led, person centred support in non-secure accommodation the service is designed to avoid lengthy hospital admissions and the need for readmission.

Those supporting adults with learning disabilities in Southwark also have access to The Estia Centre. The Centre is an integral part of local services for people with learning disabilities provided by the South London & Maudsley NHS Trust. It provides training, and is a research and development resource for those who support adults with learning disabilities and additional mental health needs.

Southwark also have a number of people placed outside of the borough in specialist mental health placements. These are placements designed to meet the needs of people who were no longer able to remain in their local community. These residential placements range from secure to non-secure placements but were chosen due to a lack of appropriate local resources or an over-subscription to local resources.

The “Green Light for Mental Health” is a framework and self audit toolkit for improving mental health support services for people with learning disabilities. It provides a picture of what services should be aiming to achieve, including quality outcomes, and a self assessment checklist. This toolkit aims to make sure that principles of inclusiveness and inclusion around mental health services for adults with learning disabilities are put into practice.

Southwark has produced an action plan giving an update of progress on the 12 Green Light Tool Kit Indicators, along with targets to improve upon current standards across services both inside and outside of SLaM. Key areas of work are:

- Review care pathways for people with LD, particularly for those using multiple services. Workshops and training will cover eligibility and agreements between services on criteria and boundaries.
- Supporting Community Mental Health Services to meet the needs of those with Asbergers more effectively
• Increasing the level of involvement of people with LD through a variety of activities including community events
• Piloting a Patient Experience Tracker (PET) scheme
• Links with carers groups and guidance specifically for carers Improving carer involvement and a family and carers “listening” event for all mental health service users.
• A ‘flag’ for service users with learning disabilities is being developed to highlight people with an LD who are care co-ordinated in Adult Mental Health services. Standards for care planning for people ‘flagged’ are being developed Review of transition protocols between services.
• A scoping exercise to look at whether culturally specific services are equipped to include people with LD.
• Looking at options for including people with a learning disability in the current workforce to ensure it is representative.
• Development of current initiatives such as the Tuesday Group, a service user group designed to help people stay mentally well and an LD awareness programme run by the Estia Centre to support the promotion of good mental health amongst people with LD
• Piloting the provision of appropriate mental health promotion resources to people with an LD, linking with research being conducted by the Estia Centre into ‘self help’ packs.

5.2.3 What else needs to be done?
Southwark via its Partnership Board, and partnership with SLaM, is committed to improving the services aimed at meeting the needs of people with learning disabilities experiencing mental health problems. Ensuring that any changes meet the needs of service users is key to this. Therefore work with user groups and incorporating user experience into the future planning and commissioning of mental health services needs to be strengthened.

Southwark is currently undertaking a review of the service specification with SLaM. This review needs to highlight some key areas for change and improvement, namely:
• A more person centred approach to service user assessment and support.
• Greater emphasis on user experience and ensuring this shapes how the service is delivered in the future.
• More detailed outcomes for service users and a more monitoring that they have been achieved.
• Better and more detailed recording and reporting of reasons for admission to help inform future needs

A review of out of borough residential placements has already been completed and a plan has been agreed for people to return to Southwark to live if they choose to. In order to ensure the needs of these people with mental health issues are met effectively further work needs to be done in the following areas:
• The development of specialist supported living to help people with mental health issues resettle in the borough with appropriate support. Work with SLam to further develop step-down accommodation from the in-patient services.
• Further work with the community based mental health support services to ensure that support systems are in place to help those returning to the borough to resettle successfully.
• Better and more comprehensive systems for recording and sharing mental health diagnosis should be put in place. This will help inform commissioning and planning and ensure that services are responsive to future needs.
Chapter 6. People with additional needs

People with learning disabilities can be more likely to have other conditions that bring extra challenges for themselves and their carers. This chapter highlights three important areas of need; people with LD who also have autism, people with profound and multiple needs and people who have challenging behaviour. Each of these sections includes some background information such as evidence data and national policy, outlines the position in Southwark and concludes by highlighting some issues that require particular attention.

6.1 People with autism and learning disability

6.1.1 Background

Autistic Spectrum Disorder (ASD) is a lifelong developmental disorder characterised by impairments in social interaction, social imagination and communication. The spectrum includes autism and Asperger’s syndrome.

People with ASD may have a range of very different needs; some people may be non-verbal or have a severe learning disability, whilst those with Asperger’s syndrome often have an average or above average IQ.

Characteristics of ASD include:

• Difficulty with social relationships
• Difficulty with understanding others’ intentions or viewpoints
• Difficulty with both verbal and non-verbal communication
• Difficulty with interpersonal play and imagination
• Difficulty in understanding sub-texts and abstract meanings
• Repetitive patterns of behaviour
• Resistance to change in routine
• Hypersensitivity to stimuli (e.g. sound, touch, pain, light, etc)

ASD is often under-diagnosed, under-reported and misdiagnosed, largely due to the social and communication difficulties listed above.

People with a learning disability and diagnosed autism, are mostly likely to have a high level of need and be known to social services. Their needs will be met by the CLDS. There is also another cohort with mild or borderline learning disabilities who have queried or unknown autism and who may not be known to services. There are also people with higher functioning autism, who do not have a learning disability. They too may not be known to services but are not covered by this JSNA.

The Autism Act was enacted in November 2009 and required local authorities and the NHS to make provision to meet the needs of adults with autistic spectrum conditions. The Secretary of State published an Autism Strategy called ‘Fulfilling and rewarding lives’ in March 2010.

The Autism Act is the first legislation designed to address the needs of one specific impairment group. It is underpinned by the fundamental principles of equality and human rights. Its starting point is existing government policies including health, social care, employment, justice and communities.

There are four key strands:

• training of staff who provide services to adults with autism
identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
planning of the provision of services to people with autism as they move from being children to adults
local planning and leadership in relation to the provision of services for adults with autism

6.1.2 The position in Southwark
There are currently 53 adults with a diagnosis of autism in receipt of social care services. All of the day services commissioned in the borough work with people on the autistic spectrum and are able to make appropriate adjustments as required. The remainder of this section uses three of the key national strands to outline the situation in Southwark.

Training of staff who provide services to adults with autism
Improving training around autism, and increasing its availability for all public service staff is at the heart of the strategy. Southwark Council’s Organisational Development team are working with training providers to develop and purchase suitable e-learning training for council staff and commissioned providers.

SLaM provides autism awareness training for all its staff. In addition they offer training on working with people who have learning disabilities in Adult Mental Health Services. This aims to increase knowledge, skills and confidence in providing mental health care to people with learning disabilities. SLaM also commissions the Estia Centre for more detailed specialist training as required.

Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
Southwark Council has a clear pathway for diagnosis of autism, from initial referral through to assessment of needs for both children and adults. SLaM also has a clear pathway with all adult referrals coming via their GP through to SLaM.

A NICE clinical guideline for adults with autism is scheduled to be published in July 2012. Commissioners will collaborate with local providers to discuss how the Guidelines can be adopted.

Service Planning and Transition
Most people on the autism spectrum in Southwark are diagnosed as children with very few being newly diagnosed as adults. Each year at transition all children receiving social care services and known to the Autism Support Team in education are FACS assessed by adults social services.

Southwark Council complies with statutory guidance on transition planning in relation to social services responsibilities for children and young people as set out in the Special Educational Needs Code of Practice. The borough has a transition team to smooth the progression into adults and a transition board. This includes:

- Adults social services
- Adults commissioning
- Children’s social services
- Children’s commissioning
- Education
• Health
• Connexions

The transition team ensures that all parents and young people are informed of their right to a community care assessment and inform carers of the right to a carer's assessment. The transition team ensures that the young person with autism, their families and carers are always involved in transition planning.

6.1.3 What else needs to be done?
NHS Southwark is developing local commissioning plans for health services for adults with autism in particular to improve access to health care. A robust action plan is in place to deliver this.

There is a need to improve data collection and in particular Southwark is working to gather better data on:

• The number of adults known to have autism in the area
• The range of need for support to live independently
• The age profile of people with autism in the area – including those approaching 65 or above working age
• The number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time

Southwark has a strong Learning Disability Partnership Board and many of the organisations, services and stakeholders work with both people with Learning Disabilities and Autism. Southwark plans to use specific themed Learning Disability Partnership Board meetings to act as the local autism partnership board.

6.2 People with complex needs

6.2.1 Background
The term 'complex needs' refers to a range of multiple and additional needs that some people with learning disabilities may have. Included in this group are people with profound and multiple disabilities. People with learning disabilities, especially those with severe disability and the most complex needs, are some of the most vulnerable members of our society. They often have a reduced life expectancy, and they also have significantly worse health than others in the population.

People with complex support needs may not have the same opportunities for independence and choice. People should have person centred plans which are developed with them and which set out their individual support requirements so they are able to receive services that meet their expectations and needs.

6.2.2 The position in Southwark
In depth work was undertaken in 2009/10 to identify the people with learning disabilities in Southwark that are already in services and who have complex needs. This has shown that 61% of the 585 current users have a learning disability alone. The remaining 39% have more than one complex need, for example a physical and/or sensory disability, dementia, epilepsy, Down's syndrome, or other need.
Complex needs require well coordinated services and support from a variety of different organisations. These complexities are also reflected in the commissioning of services which are funded through different funding streams. Southwark therefore understands the importance of both the sharing information with health partners so that assessments and planning of services are efficient and effective.

A large number of the borough’s service users with complex needs are placed in specialist residential care services outside of the borough. Southwark’s five year accommodation strategy has driven a number of changes in ensuring that those people with complex needs have access to local services so that in the future fewer people will need to be placed outside of the borough.

The strategy is focussed on ensuring that people with learning disabilities have access to the same life opportunities as everyone else, including access to ordinary housing regardless of an individual’s level of capacity or support needs. Local work also includes a review of respite and carers support services.

People with complex needs are encouraged through person centred support planning to be directive about their housing needs where they want to live, whom they want to live with and the care and support they receive.

This has included developing a housing strategy with a key aim of reducing the number of people who are placed outside of the borough, by the development of suitable services able to work with people with challenging needs that are available locally and

6.2.3 What else needs to be done?

Recommendations for the future are that-

- Principles of personalisation should be embedded within all aspects of planning, commissioning and delivery of support services for people with complex needs, including the roll out of personal budgets and individual service funds for those residing in residential care.

- Personalisation strategies should include implementation of person centred planning, support planning and carers impact assessments for all adults with complex needs.

- Partnership arrangements between health professionals in mainstream and specialist learning disability services are needed to ensure that people with more complex needs access the best care and treatment in the full range of health services.

- Independent supported living can be enjoyed by people with very high or complex needs (as well as those with fewer needs) with support tailored to their particular requirements.

- Work will be done to ensure that the adult social care workforce strategy is modernised to reflect the needs of people with learning disabilities, including tailoring more innovative care and support for people with complex needs.

- A targeted approach should be taken to improve the uptake of carers assessments and carers personal budgets for those who care for adults with complex need.
Appropriate high-quality provision should be commissioned to ensure that people with learning disabilities and long-term health needs are able to stay living in the community or to return to their community.

Work should be undertaken to strengthen Southwark’s policies on complex needs and embed them within other policies. Southwark is working towards meeting the 10 principles set by the Care Quality Commission.

6.3 People who services identify as challenging

6.3.1 Background

Challenging behaviour is defined as "behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities".  

However, "When the term ‘challenging behaviour’ was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. In the ensuing years, there has been a drift towards using it as a label for people. This is not appropriate ………".

The National Development Team for Inclusion recommends using the term ‘people services label as challenging’ to emphasise the importance of placing the responsibility with services rather than the individual.

Estimates of the number of people identified as challenging services vary but the Mansell Report estimates that about 24 adults with a learning disability per 100,000 total population present a serious challenge at any one time. The numbers of young people who challenge services and are in transition to adulthood are believed to be increasing.

Most of the behaviour identified as challenging to services includes known physical aggression, the destruction of property, self-harm, fire-setting, and sexually inappropriate behaviour. A few people identified as challenging will present such a challenge more or less all the time and will become well-known to local services, but many people will move into and out of this group depending both on changes in their characteristics and on how well services meet their needs over time.

The Mansell Report identified three general responses in local areas to meeting the needs of people identified as challenging:

- ‘Removers’ do not want to develop locally the competence to serve people whose behaviour presents a challenge. They seek instead to place people who cannot be served locally in out-of-area residential placements, often at considerable expense.

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51 Emerson E et al ‘Developing services for people with severe learning difficulties and challenging behaviours’. University of Kent 1987.
52 Department of Health. ‘Services for people with learning disability and challenging behaviour or mental health needs - Mansell Report’ DH Revised October 2007
‘Containers’ do seek to provide local services but seek only to contain people in low-cost (and therefore poorly-staffed) settings.

‘Developers’ seek to provide local services which really do address individual needs, and therefore give higher priority to funding services which, with more staff and more training and management input, are more expensive than ordinary community services.

6.3.2 The position in Southwark
Southwark’s response to people who challenge services has been mixed. For a group of people who transferred from the old long stay hospitals, and people who lived in services previously run by the Council, many of whom are identified as challenging, Southwark can be identified as a ‘Developer’ borough.

Southwark has worked with a number of providers to support the needs of these people. This initially included supporting small community based residential services at significantly greater cost but in the belief it would provide better outcomes. This work has represented a partnership between the Community Learning Disabilities Team (a joint social care and health team who have provided input from social workers, occupational therapists, speech and language therapists and learning disabilities nurses) and the Behaviour Support Team (part of SLaM, who have also offered specific training via the Estia Centre).

However, for other people who were not part of this cohort Southwark has acted as a ‘Remover’, placing people in often high-cost out of borough placements sometimes with one to one support as a solution to meet their challenges.

Southwark has revisited its approach to supporting people who challenge and as identified by Royal College of Psychiatrists54:

“Rather than relying on attempts to alter a person’s behaviour by changing service models, or through ‘treatment’, it is evident that commissioners and managers should be designing services that promote a person’s quality of life in spite of the intensity or frequency of their behaviour”

There is recognition that supporting people to live as ordinary a life as possible, designing support around the individual, in their own communities, near or with their families and with an appropriate support system, is key to achieving better outcomes. This approach has begun in Southwark and some of the key steps undertaken include:

- Adopting a person centred approach to people who challenge.
- Promoting and utilising personal budgets for people who challenge.
- Reviewing all current residential placements and identifying, with individuals and circles of support, those who wish to return to live in Southwark and planning these moves.
- Adopting a positive attitude to risk-taking and risk management.
- Working with new providers to develop local supported living services designed around people who challenge.
- Supporting people who challenge and live in residential services in Southwark to change to supported living environments using an Individual Service Fund model, increasing their choice and control over their lives.

6.3.3 What else needs to be done?
This approach to a more individualised risk-tolerant way of supporting people who challenge is, although progressing, still in a development stage. More work needs to be done to embed this approach. Some of the risks to its progress are:

- The potential higher (at least initially) cost of developing more individualised services in a financial climate of funding reductions and savings targets.

- The ability of those involved to maintain a positive attitude to risk-taking and stick to this approach, if and when things go wrong.

The work identified around people who challenge is also part of an overall strategy aimed at personalisation and improving outcomes, rather than a specific plan aimed solely at people who challenge. Some specific steps therefore need to be taken to ensure the progress of this area of work:

- That the NDTi’s “Guide for commissioners of services for people with learning disabilities who challenge services” is adopted and used to shape a specific plan around delivering better outcomes for people who challenge.

- That information about people who challenge is gathered centrally so that the full impact of current service models can be assessed.

- This information can then also be used and compared to the outcomes for people using alternative methods of support and the evidence used to demonstrate the success (or not) of a more person centred approach.
7. Priorities for action

7.1 Introduction
This report has provided key information on adults with a learning disability in Southwark. The purpose of JSNA is to guide the development of strategy and services to ensure that local resources are used to best effect for local people. These resources include the funding available to local agencies but also the wider resource of the time, energy and commitment of local people. The JSNA should help to foster a collective sense of the priorities for people with a learning disability in the borough.

Learning disabilities is an under-researched field and there is less hard evidence of effectiveness and cost effectiveness than for some other topics. On the other hand there is a vibrant rights-based approach developing and many examples of people with learning disabilities having much more involvement in decisions about the support they want. An important activity to complement this report is the gathering of client’s views on service requirements and on the wider issues affecting people with LD.

7.2 Key priorities for action
Most sections of this JSNA contain detailed recommendations or have flagged up some important next steps. These cover a multitude of different issues and are not all repeated here. Instead this section identifies some key overall themes for attention as follows:

Information
There is no common register of people with LD across health and social care in Southwark, hospital activity figures under-report the number of people admitted and it can be difficult even to identify how many people are funded to live in residential care. Caseload information systems do not routinely provide some of the vital data for planning and for ensuring that services are equitably provided. Improving the coverage, quality and sharing of information will be critically important in developing evidence-based commissioning.

Future planning
Southwark will see a large increase in the number of people with LD at a time when public sector spending is being curtailed. The tension between growing need and restricted resources increases the need for clear priorities, realistic expectations and creative solutions while pursuing the personalisation agenda. Detailed modelling of future need (including activity levels and costs) can help to plan resources and make choices explicit.

Awareness and rights
Although wider population awareness and national policy may be improving, people with LD are still subjected to discrimination and hate crime, lower access to some services and low employment levels. Further work needs to continue to ensure that equity is achieved and discrimination opposed. Better support, information and training for professionals, carers, families and people with LD (for example on hate crime, on offending, on meeting LGBT needs and promoting and enabling people with LD to have a healthy sex life) will be needed to support effective targeted action.

Accommodation
Many people with LD still live outside the borough and in the type of residential care that may not be appropriate for their needs. Continued development of supported living means that real choice can be exercised and can also bring financial savings.
Health inequalities
In general, people with LD face worse health and higher mortality rates than the population as a whole yet only a small proportion are identified on GP registers. An equitable NHS would ensure that health improvement interventions, screening programmes and other services reflect these higher levels of need and provide additional support as appropriate. Again better recording and information on utilisation of services is important.