Joint Strategic Needs Assessment for Adults with Learning Disabilities

Final Version

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NHS Brighton & Hove and Brighton & Hove City Council

Contents

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1. Introduction

People with learning disabilities are people first, with the right to be treated with dignity and respect. They do not want to be defined solely by their learning disability as they may have many other identities, such as friend, neighbour, relative and colleague. They also have the right to enjoy the same opportunities and responsibilities as all local citizens – access to suitable housing, achieving good health outcomes, and leading active and fulfilling lives in our city.

We also recognise that people with learning disabilities often suffer many disadvantages and poor outcomes. This can in part be due to intellectual, medical and physical impairments, but it is also due to disabling barriers, negative attitudes and social exclusion that also need to be overcome.

The term learning disability is useful in identifying some of these barriers, identifying the problems and solutions, and in planning responses. However, we must make sure we recognise people also have a gender, age, ethnicity, faith and sexuality and may have other disabilities, impairments or disadvantages that are of equal or greater importance.

Much of what needs to change is within our wider society. We need to offer greater access and better outcomes in housing, health, education, leisure and employment opportunities, alongside specialised support for those who need it. To achieve this we need a better understanding of the needs and outcomes of people with learning disabilities. This Joint Strategic Needs Assessment will help to make this happen locally [1,2,3].

2. Key Issues and gaps

It is estimated that 5,053 adults in Brighton and Hove have a learning disability, with 1,065 of these having a moderate or severe learning disability. The size of the local learning disability population is expected to increase at a higher rate than the general population, due to improved life expectancy of people with disabilities. The number of people with learning disabilities in total is predicted to increase by 5.1% in the next 10 years and 11.6% in the next 20 years, with the highest proportional increase predicted in older people and those with the most severe learning disabilities[1].

In 2009/10 there were 798 people with learning disabilities receiving social care funding from the Brighton and Hove (B&H) Learning Disability budget. It is estimated that there will be an increase of 54 – 135 people with LD eligible for social care support locally in the next 5 years and of 89 – 244 people by 2020[48,49].

It is estimated that seven in ten people receiving adult social care funding have significant health or social care needs in addition to their learning disability. These additional needs, with estimated numbers of people affected are:

• Challenging behaviour	25%	(200 people)
• Severe challenging behaviour	6%	(50 people)
• Autism	20%	(160 people)
• Mental health needs	15-20%	(120-160 people at any one time)
• Early onset dementia	> 1.6%	(at least 13 people)
• Substance misuse	> 1.2%	(not known, at least 10)
• A history of offending	7-14%	(according to national surveys)
• Parenting responsibilities		(not known)

2.1 Key issues identified in this JSNA are described below

Commissioning and services planning

There are limited accessible data available to inform commissioning of services. Minimum data sets should be developed for recording and analysis of data, including costs and outcomes, to help inform future service planning.

There are also limited opportunities for effective sharing of data and information between the many different organisations supporting people with LD. There is a need to review how data and up to date information are shared between organisations to improve effective partnership working.

There is a need to review the support and care pathways for people with LD and specific additional needs including:

- Early onset dementia
- Challenging behaviour

- Parents with LD and their families
- People with LD in offending services
- People with LD and substance misuse
- People with LD from BME populations

Housing and social care

Locally, 70% of the commissioning budget is spent on accommodation and support, including 62% spent on residential care and 8% for supported living options. There is national evidence showing good outcomes and lower spending in authorities that offer more supported living options compared to residential care.

More than 100 people with learning disabilities are placed in residential care outside of Brighton and Hove, with 40 living outside of Sussex, indicating insufficient range of accommodation and support services. Young people with challenging behaviour are at a particular risk of being placed out of area.

There is a specialist Learning Disability Housing Options post that provides advice and support to people who need housing, which has started to improve access to mainstream housing locally. However there are still areas for improvement:

- There is insufficient specialist accommodation to meet need of people with LD and complex need locally, which means people are often placed out of area at increased cost.
- There are insufficient supported living options to meet need.
- There is a need to review pathways and barriers to housing in order to help people with learning disabilities who are temporarily housed in residential care to move on to other supported living or mainstream options.

Transition

Locally, a transition team manages the transition of young people with learning disabilities to adult services. However, those with the most complex needs are often placed out of area, not currently covered by the local team and there is also a need to review fairness in access to transition planning across the city. Research shows that supporting young people effectively can reduce unemployment and mental ill health in adulthood with reduced costs as a result.

There is a need to review transition planning in partnership with local schools and social services and ensure young people with learning disabilities across the city are trained in basic skills and supported to increase independence, employment opportunities, health and wellbeing.

Choice and Personalisation

Social services are using detailed person centred plans which contain information that could inform effective service commissioning. Commissioners and services should establish systems for sharing this information on the needs and outcomes of adults with learning disabilities.

Individualised budgets have been available within the learning disability service since the pilot commenced in August 2007. This has led to a significant increase in the number of people receiving Direct Payments from 12 in 2007 to a total of 137 people (17%) in 2009/10.

Carers

Of the people with LD known to social services locally, 28% of people were living with their families (LDPB Annual Report 2009). As life expectancy of people with LD is increasing, it is estimated that there will be an increased need for support when carers becomes too old or frail to carry on their carer's role.

There are currently a lack of mechanisms to collect and update information on the needs of carers and people supported by them and there is a need to put systems in place in order to inform planning and commissioning for this group.

Employment

15% of adults aged 18 to 69 with learning disabilities known to social services are in paid employment, which is higher than the national and South East rates. There are a higher percentage of men in supported employment compared to women locally. The national target is 40% in employment by 2025[15]. Research and pilots shows that employment is cost-effective and can improve behaviour, health, wellbeing and independence for people with LD.

Locally, there is a Supported Employment team, which reports that they have a potential to support more people with LD into employment with better partnership working between organisations and employers.

There is a need to engage more employers and voluntary organisations to employ people with learning disabilities, including looking at how the public sector can be better exemplar employers.

There is also potential to increase people's ability to work by delivering training on basic skills needed for employment, including how to use public transport and independence in the community.

Good health

People with learning disabilities have a higher than average risk of health problems, due to barriers to accessing services, a lack of accessible information as well as genetic factors associated with health conditions related to the learning disability. As life expectancy improves, more people with learning disabilities will experience the same age-related chronic illnesses seen in the general population, including cancer and diabetes.

There are several examples of best practice locally to improve access to mainstream health services, including a Community Learning Disability Health Facilitator, a hospital learning disabilities liaison team, and a mental health nurse leading on LD. These developments have led to improvements, including more people with learning disabilities receiving annual health checks and health action plans at GP practices, better support for people with LD admitted to hospital and better services to meet the needs of those with a learning disability and mental health need.

However, there are still areas for improvement identified, including:

- Improved access to health improvement services such as weight management and physical activity programmes.
- Better uptake of health screening services in response to low uptake rates.
- Increased take-up of annual GP health checks and good quality health action plans.
- Work with GPs with lower than expected prevalence rates to ensure this does not reflect inequity in access to care.
- Continued work to raise awareness across all mainstream health services.

3. Recommendations for Commissioning

Commissioning and service planning

1. Revise the learning disability commissioning strategy to provide a clear plan to reshape services, including accommodation and support options, to meet the current and future needs of local people.

2. Design a better system for how information on needs is collected.

3. Devise a protocol to ensure that local needs are shared between services and commissioners to inform planning and commissioning.

4. Monitoring data provided by services should include costs and outcomes so that their cost effectiveness can be evaluated by commissioners.

5. Commissioners should involve people with learning disabilities and their carers to inform service planning of both mainstream and specialist learning disability services.

Information

6. Design an easy read information leaflet covering main service contact points and review how to make it easy accessible for users, carers and staff across services.

7. Improve local arrangements to simplify how people are sign posted to services and to ensure the information that is offered is accessible.

Housing and social care

8. Develop a clear pathway for people with learning disabilities to improve access to mainstream housing and supported accommodation options, in particular for those placed in residential care.

9. A detailed assessment of future accommodation and support needs, and the types of housing and services required, should be carried out to inform future commissioning.

10. There should be a disinvestment in residential care services that fail to deliver good outcomes for people with learning disabilities so that resources can be reinvested in supported living models.

11. Expand the range of supported living options to meet the needs of people with mild learning disabilities who have additional needs, such as mental health and substance

misuse problems, and to enable people in residential care to move on to greater independence.

12. To reduce the number of out of area placements, expand the range of specialist accommodation services for those with complex and challenging needs, seeking agreements with other authorities where appropriate.

13. Explore housing and accommodation options within mainstream older people's services in response to the increasing number of older people with learning disabilities.

14. Continue the expansion of personalised budgets so that people have more choice in how they live.

Employment

15. Engage more employers and increase expectations that people with learning disabilities can work in a variety of settings.

16. Offer training on basic skills needed for employment to increase people's ability to work.

17. Review equity of access to supported employment for men and women.

Community Learning Disability Team

18. Modify the work of the transitions team to focus on those with the most complex needs.

19. There is a need to improve the coordination of referrals to supported living schemes to maximise use of local vacancies.

20. Identify care management resources to support move on to greater independence.

21. Individuals' support needs should be robustly reviewed on an annual basis so that the support provided is at the right level and cost to meet people's needs.

22. Clear service pathways should be established for parents with learning disabilities and people with learning disabilities who are offenders.

23. Make better use of the knowledge and expertise of the challenging behaviour team to improve commissioning and the dissemination of best practice to services.

24. Information on needs identified within carer's reviews should be collated and regularly reviewed to inform service commissioning.

25. Review practical support and short breaks for carers to ensure fair and appropriate allocation of respite resources.

Good health

26. Continue to raise awareness of learning disability amongst healthcare staff across services.

27. Continue to work with GP practices that have fewer than expected people with learning disabilities registered to ensure they are identifying and supporting people appropriately.

28. Continue to deliver action to increase the uptake of health screening.

29. Increase the proportion of people receiving regular learning disability annual health checks and continue to support practices to develop effective health action plans.

30. Ensure healthy living services are accessible for people with learning disabilities, including healthy eating, physical activity and weight management services.

31. Ensure that where appropriate adults with learning disability have good access to community services for chronic lung conditions and fall prevention in order to reduce risk of hospital admission.

Mental health support

32. Continue to train mental health, primary care and specialist learning disability staff in how to care for people with learning disabilities and mental health problems.

33. Improve links between mental health and learning disability teams and assess the impact of the new community mental health nurse post.

34. Review how young people with learning disabilities and mental health problems are identified and supported to reduce the risk of mental health problems in adulthood.

35. Review the quality and costs of specialist health placements for people with learning disabilities and mental health problems and consider options for more local alternatives.

Hospitals

36. Continue to deliver action underway to support meeting the requirements of the Mental Capacity Act.

37. Review how hospitals record details of adults with learning disabilities to ensure good access to the support offered by the learning disability liaison team.

4. Who is most at risk and why?

4.1 Introduction

Definitions

The Department of Health (2001) defines learning disability as:

"*A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) along with;*

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

- An onset of disability which started before adulthood, with a lasting effect on development."

The term "Learning Disability" does not include people with learning difficulties such as dyslexia. Many UK services favour a more bio medically-based definition, such as the ICD -10 definitions. The ICD-10 definition incorporates the presence of an impaired intelligence, defined as an Intelligence Quotient (IQ) level of 70 (WHO 2007)[5], requiring a formal IQ assessment by a psychiatrist. Due to the normal distribution of IQ levels, an estimated 2% of the national population will have a learning disability, as 2% of the population will fall 2 standard deviations outside the normal distribution[5].

The newly-established Learning Disability Observatory has with Department of Health (DH) developed a definition of LD to inform their work. This definition states that an adult could be considered to have a LD if they have one of the below statements:

- a Special Educational Need (SEN) assessment by educational services or attended a special school for LD
- scored below 2 standard deviations on a general cognitive functioning test in child- or adulthood (consideration taking into account bilingual individuals)
- registered on a local disability register
- significant difficulties in literacy and numeracy
- a positive assessment by a validated LD screening test

In practice

Locally, different services use differing models. Social care and housing services assess need rather than ability when allocating support services. The specialist health care services use a formal IQ assessment together with assessment of ability to cope independently. An IQ assessment has to be carried out by a psychologist.

4.2 Populations with higher risk of learning disabilities

Some groups of people have higher risk of learning disabilities, such as people with Down's syndrome. Some people also have significant additional needs over and above their learning disability that puts them at a higher risk of negative outcomes without appropriate support.

In particular there are:

Higher rates in men compared to women

- Males are more likely than females to have both mild and severe learning disabilities (1.2 males: 1 female and 1.6 males: 1 female respectively), because some conditions associated with learning disability are linked to the Y-chromosome, only present in males. These ratios decrease with age as women live longer[8].

Higher rates in South Asian communities

- Prevalence rates for severe learning disabilities are higher in South Asian groups in the UK, with rates three times higher among 5 to 34 year olds compared to other ethnic groups[9].

Association with social class and family instability for mild learning disabilities

- The presence of mild learning disabilities is strongly associated with parental social economic class and family instability. No relationship is found between these factors and severe learning disabilities[8].

4.3 Patterns of health need

In general, people with learning disabilities experience worse health outcomes than the general population. The reasons for this are multifactorial, including genetic and biological factors related to the cause of their learning disability, but also wider social determinants of health such as education, housing, deprivation, and lower levels of health literacy or poor service outcomes.

Mortality

- People with learning disabilities have shorter life expectancy. There is a strong correlation between severity of learning disability and life expectancy (median life expectancies of 74.0, 67.6 and 58.6 years for people with mild, moderate and severe learning disabilities)[10].

- People with Down's syndrome have a shorter life expectancy than people with learning disabilities in general, though life expectancy in this group is increasing[11].

- Respiratory disease is the main cause of death for people with a learning disability [12], in contrast to the leading causes of death in the general population, which are heart disease, stroke and cancer [13].

Long term conditions

- Due to increasing life expectancy, more people with learning disabilities will experience the same age-related illnesses seen in the general population. For example, the incidence of cancer amongst people with learning disabilities is rising[12]. Long term conditions such as Type 2 diabetes will also become more common.

- People with learning disabilities have higher rates of gastrointestinal cancer compared to the general population (48%-59% vs. 25% of cancer deaths in these populations). This may be due to the high prevalence of helicobacter pylori infections in people with learning disabilities[12].

- The risk of developing dementia is higher in adults with learning disabilities[12].

- People with learning disabilities are more likely to be obese, and less likely to participate in physical activity or eat a healthy diet[14].

- One in three adults with LD has unhealthy teeth and gums[12].

- A higher than average proportion of people with learning disabilities have difficulties eating, drinking and swallowing, which have implications for health, safety and wellbeing. 40% of adults who have problems swallowing experiences recurrent chest infections[12].

- Adults with LD have higher levels of osteoporosis and lower bone density. Studies have also reported a high incidence of accidents, falls and injuries amongst adults with LD[12].

Barriers to services and information

There are a range of barriers to access health care services for adults with Learning Disabilities including:

- insufficient levels of accessible information, services, facilities, and transport [14,15].

- failure of services to make adjustments to improve access.

- "diagnostic overshadowing", whereby symptoms of physical ill health are mistakenly attributed to the individual's learning disability, for example, expression of pain mistaken for aggression.

- negative attitudes amongst healthcare staff[12].

A number of studies have reported low uptake of health screening and health promotion activities[12]. Limited opportunities to gain knowledge may mean that people with learning disabilities have limited understanding about health risks and are unable to determine healthy lifestyle choices.

The Mental Capacity Act
The National Patient Safety Agency has reported concern about patient consent in people with learning disabilities related to cases where clinicians sought consent from a carer, rather than taking the time to gain consent from the person with LD, in line with the Mental Capacity Act[12].

4.4 People with learning disabilities with additional needs

Needs analysis carried out in 2008-10 locally suggests that at least 70% of adults with learning disabilities known to social services in Brighton & Hove have specific significant health needs or diagnoses in addition to a learning disability. These include developmental conditions, such as Down's syndrome or autism, physical and sensory impairments, long term health conditions, mental health conditions, and behavioural needs, such as challenging behaviour. Many clients have more than one additional significant need and this can present multiple barriers to meeting their housing, health, social and employment needs. This section describes some of the better known and more common additional needs.

4.4.1 Profound intellectual and multiple disabilities

Some of the most complex clients are those with profound intellectual and multiple disabilities. The DH defines these people as among the most disabled individuals in our community. They have a profound intellectual disability, which means that their IQ is estimated to be less than 20, with severely limited understanding as a result. In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism[16].

People with profound intellectual and multiple disabilities need high levels of support at high cost. Families frequently suffer distress due to a lack of services, and poor co-ordination of the various services[16]. Key to good service provision is adequate supplies of equipment and a strong relationship with social workers and commissioners[16].

4.4.2 Challenging behaviour

The term "challenging behaviour" describes behaviour of such intensity, frequency, or duration, as to threaten the quality of life and/or the physical safety of the individual or others. It may result in restrictive responses or exclusion[17].

10 to 15% of people with learning disabilities nationally express challenging behaviour. Age-specific rates peak between 20 to 49 years. The causes of challenging behaviour are complex and difficult to determine but can in some instances be a response to environmental factors or to pain associated with medical disorders[12].

A national report identified a number of problems with the way services are commissioned and delivered to people with challenging behaviour. A lack of planning and availability of appropriate support has led to many people with challenging behaviour being moved to out of area placements. This can be disruptive to the individual and their families, and makes it difficult to control costs and ensure service quality[18].

4.4.3 Autism

Autism is a lifelong condition, marked by three characteristics: difficulties with social communication, social interaction, and social imagination (difficulties in seeing things from others perspective). Autism is not a learning disability, but its estimated that 20-33 % of adults with learning disabilities known to councils in England also have autism[32]. People with autism may come into contact with a variety of specialist and mainstream services in social care, housing and health, but details of their autism are not systematically collected, and the impact of autism may be overlooked. The lack of specific information results in a lack of specialised services[19]. Although mainstream services or learning disability services may be able to meet the needs of some people with autism, for others specialist services will be needed.

4.4.4 Black and Minority Ethnic Groups

There is a large body of national research and policy literature about people with learning disabilities from Black and Minority Ethnic communities, which consistently identifies social exclusion and disadvantage in these groups[20, 21]. People with learning disabilities from Black and Minority Ethnic groups often face 'double discrimination' and experience insufficient and inappropriate services. Causes for this include policy and services which are not culturally sensitive, incorrect assumptions about certain ethnic groups' values, language barriers, and discrimination[15]. A national report concluded that needs analysis and service development for people with learning disabilities from Black and Minority Ethnic communities was limited[20].

4.4.5 Parents with learning disabilities

Parenthood may place extra stress on a person with a learning disability and their need for support can increase as a result. Policies and practice generally focus either on the children, or the parents, rather than the family unit. Currently, services often only intervene when there are child protection issues. Research shows that parents with learning disabilities need specialised support and access to social support networks. Research also shows a lack of resources and expertise that is focused on supporting the family unit to succeed[22].

Good Practice Guidance on Working with Parents with a Learning Disability (2007) highlights that there is a need to commission appropriate services to meet this need, with adults and children's services taking joint responsibility in supporting the family unit[23].

4.4.6 Learning disabilities and mental health

People with mild learning disabilities have an estimated 35-75% risk of mental ill health, which can limit their functioning and quality of life [4]. Young people with undiagnosed learning disabilities may suffer unemployment and higher rates of anxiety and depression, which can lead to long-lasting psychological harm in adulthood with extra costs to society[24]. Mental ill health can be missed if professionals attribute symptoms and signs to the learning disability, rather than recognising mental ill health. Mental ill health problems may present differently in people with a learning disability[25].

People with a learning disability and a mental health problem are most at risk of admission to hospital and residential care. Effective treatment and support services are crucial to

reduce the dependency on institutions and to avoid creation of new, costly long-stay placements[4].

4.4.7 Early onset dementia and Down's syndrome

Dementias are degenerative brain diseases which are irreversible and progressive. They can alter a person's ability to perform daily tasks. People with Down's syndrome are at particularly high risk of developing dementia: 54.5% of people with Down's aged 60-69 years old are affected, compared to 5% of the general population[26]. People with Down's have an earlier average age of onset of dementia (age 54 compared to age 65 in the general population) and the time from diagnosis to death is less than 5 years [26]. Dementia is associated with a range of potentially challenging behaviours and health problems[12]. Early symptoms of dementia are often different in people with learning disabilities, complicating diagnosis [26]. The life expectancy for people with Down's syndrome is increasing and is now over 50 years old [26]. With 15-20% of people with learning disabilities having Down's syndrome it is likely that the prevalence of dementia in this population will increase in the future.

National reports highlight a need for early baseline assessment of cognitive function in people with Down's syndrome together with awareness training to social care and health staff, including GPs, to enable earlier diagnosis and treatment of dementia [26].

4.4.8 Learning Disabilities and substance misuse

It is estimated nationally that people with mild LD have higher levels of substance misuse than their peers[33]. Many of these people will not be known to or assessed as having LD by local services. This can often be a complex and sometimes challenging group to support, especially when combined with mental health problems. People with learning disabilities that have substance misuse issues (alcohol and/or drugs) are very vulnerable and are at risk of abuse and exploitation, and involvement in criminal activity. Parents with LD and substance misuse issues may lose their parental responsibilities. Substance misuse may represent "self-medication" due to negative experiences in life.

This group may not be sufficiently supported by learning disability or substance misuse services alone and without the right support they may be unable to manage or overcome their substance misuse issues, sometimes staying within substance misuse services and temporary accommodation for years. Traditional recovery models often do not support these clients appropriately[27].

There is a need to develop new, ways of supporting people using multi-disciplinary approaches and one-to-one sessions rather than traditional group work[27].

4.4.9 People with Learning Disabilities who offend

It is estimated that 20 to 30% of offenders have learning disabilities or learning difficulties[15]. There is a lack of clear pathways for support for people with learning disabilities who also have an offending history that puts themselves or others at risk. This is evidenced in specific client cases where specialised services are not available outside of offender services. There are also barriers to people with learning disabilities who have an offending history or are assessed as being at risk of offending, where the perceived risks can restrict their independence.

5. The Level of Need in the Population

5.1 Introduction

It is estimated that 2% of the general population have a learning disability, due to normal distribution of IQ levels. This means that in Brighton & Hove there are an estimated 5,053 adults aged 18 or over with learning disabilities, of whom 1,065 are estimated to have moderate or severe learning disabilities[1].

Information systems held by local health and social care services indicate that:

- There were 949 people recorded as having a learning disability on the local GP practice registers in 2009/10, equivalent to 0.4% of adults aged 18 and over.

- 798 people with learning disabilities received adult social care services from Brighton and Hove City Council in 2009/10.

This indicates a difference in adults known by services to have a learning disability and the estimated number of adults with a moderate and severe learning disability living in the city of B&H. The GP register prevalence rate observed in Brighton and Hove is the same as for the South East Coast Strategic Health Authority and England (0.4%) and this scale of under-recording is evident nationally as well as locally[28].

The difference between the figures may be due to the following reasons:

- National estimates are based on the normal distribution of IQ, which might not reflect the true picture and does not consider functional ability.

- People in local residential care whose placement is funded by local authorities other than Brighton and Hove will not generally be known to local social care services, but will usually be registered with a local GP.

- Under-recording of people who are in contact with services.

- People with moderate learning disabilities may cope without additional support, either living alone or with family. However, they might have various degrees of unmet support need, for example support to find or stay in employment and access to mainstream services, or require support when their family carer gets ill or too old to provide care.

Prevalence of GP-recorded learning disability was only weakly correlated with practice-level deprivation in Brighton and Hove. However, the local children register (Compass) shows a higher number of people with learning disabilities registered from the more deprived areas of Brighton & Hove (section 8.2).

5.2 Prevalence by age and GP practice

5.2.1 National estimates of number of adults per age groups locally

The highest estimated number of adults with LD in Brighton & Hove is in the 18-44 years age group (table 1).

Table 1: People estimated to have a learning disability, by age in Brighton and Hove 2010: All learning disability and moderate or severe learning disability (based on national estimated prevalence).

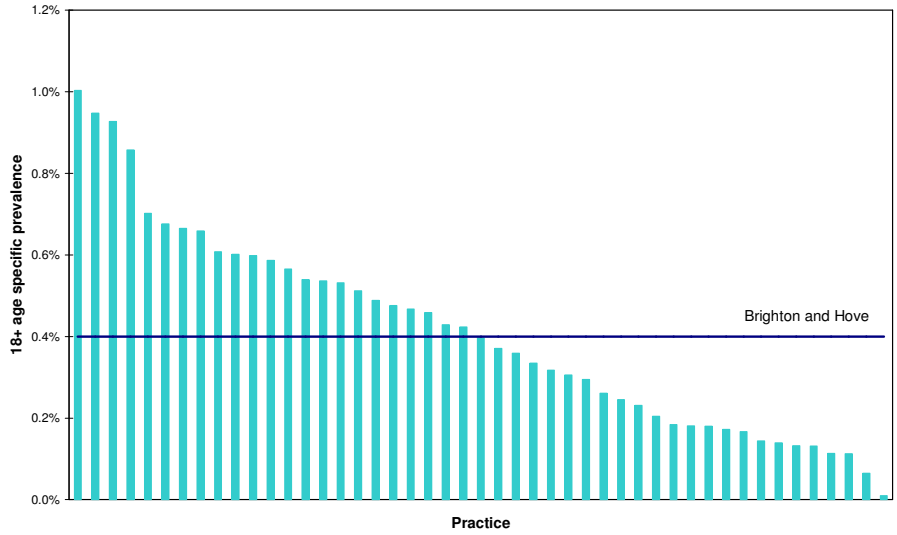
Age group	Learning disability: mild, moderate and severe	Learning disability: Moderate or severe
18-24	1,005	229
25-34	1,006	198
35-44	1,031	259
45-54	748	169
55-64	530	115
65-74	358	58
75-84	250	26
85+	124	12
18+	**5,053**	**1,065**

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) [1]

5.2.2 Local data on number of adults with LD registered with individual GP practices

There is considerable variation in the number of adults with learning disabilities in relation to total number of adults registered per practice (prevalence) between GP practices locally (Fig. 1)[29]. This could be due to differences in practice populations, for example related to social deprivation or the location of residential care homes. It could also be due to under recording in GP practices. The Health Facilitator (section 6.3.4) should work with practices with lower levels of registration to ensure this does not reflect inequality in access to care.

Fig 1. The number of adults with learning disabilities recorded by individual GP practices in relation to number of adults registered with each practice (prevalence) in 2009/10.



Source: NHS Information Centre 2009/10[29]

5.3. Age and sex distribution of adults with LD known to social care locally

There were 798 people with learning disabilities receiving social care services locally in 09/10. Below are data on 655 of these people, by sex and age band.

Table 2. Sex and age distribution of people with LD known to social care services locally
The table includes 82% of the people with LD receiving social care services in 09/10.

	Male	Female	Total
18-24	76 (21%)	52 (18%)	128
25-34	61 (17%)	45 (15%)	106
35-44	80 (22%)	44 (15%)	124
45-54	64 (18%)	49 (17%)	113
55-64	52 (14%)	56 (19%)	108
65-69	15 (4%)	16 (5%)	31
70-74	8 (2%)	16 (5%)	24
75-79	4 (1%)	6 (2%)	10
80-84	2 (1%)	5 (2%)	7
85+	0 (0%)	4 (1%)	4
Total	**362**	**293**	**655**

5.4 Adults with a moderate or severe learning disability living with a parent

According to national estimates there are 404 adults with a moderate or severe learning disability, aged 18-64 years, living with a parent in Brighton and Hove. The estimated number of people living with a parent falls with age, with a majority being under 44 years old (table 3)[30].

Table 3: People aged 18-64 years estimated to have a moderate or severe learning disability and be living with a parent in Brighton and Hove 2010.

Age group	Number
18-24	150
25-34	103
35-44	101
45-54	40
55-64	10
Total (18-64 years)	**404**

Source: Projecting Adult Needs and Service Information (PANSI) [1]

The proportion of people living with a parent known to services is lower than this: 28% (223/798) of people with LD known to services locally live in the family home (table 5).

National reports estimate that 25% of people with LD only become known to services when their carers become too old or too frail to continue to provide care for them. There is a need for local services to identify these cases earlier to improve future planning of housing and care[30].

5.5 People with learning disabilities with additional needs

5.5.1 Profound intellectual and multiple disabilities

According to estimates by the Department of Health, in a population such as Brighton and Hove there will be 75-80 people with profound intellectual and multiple disabilities in 2010 expected to rise to 105 by 2026.

Of young people reaching adulthood each year around 3 people are in this group, rising to 5 per year by 2026[16]. Local social care service IT systems do not identify level of need, so the exact number of people with profound intellectual and multiple disabilities using services is not systematically updated.

5.5.2 Challenging behaviour

Research suggests that 40-45 people in a population such as Brighton & Hove will present a serious challenge at any one time[31].

Local needs information suggests that around 25% (200) of the clients receiving social care services exhibit challenging behaviour, as reported by service staff. The proportion is higher for those placed outside of Brighton and Hove, rising almost 40% (42 of 109). Locally the open caseload of our Behaviour Support Team, who works with the city's most challenging clients, averages at around 50 clients.

5.5.3 Autism

Autism is more prevalent in men than women. An estimated 20-33 % of adults with learning disabilities known to councils in England also have autism[32]. Local needs surveys suggest that approximately:

- 20% (150-160) of people using learning disability social care services are on the autistic spectrum.

5.5.4 Black and Minority Ethnic Groups (BME)

Of the adults with learning disabilities receiving social care services locally 91% were of British White Origin and 9% of any other ethnicity (2010). 4.5% of the children and young people (0-19 years old) registered with The Compass children's register in 2010 were of Asian ethnicity. There was no information found to establish if there are any cultural or social barriers to accessing services or under recording in the BME population locally.

5.5.5 Parents with learning disabilities

Information on numbers of parents with learning disabilities is not known nationally, and not collected systematically locally. Health visitors from two local children centres estimate that their caseload includes 1-2 parents with LD per health visitor, giving an estimated number of 9 - 18 parents that might have LD registered with these two centres alone. There are a further five children centres locally that have not reported numbers. This indicates inconsistent recording and collation of information on level of needs of parents with LD and their families.

There is a need to formally collect information on the number of parents with LD and their families and to review level of need and support for parents with learning disability and their children and care pathways locally.

5.5.6 Learning disabilities and mental health

The local needs survey suggests that around 15-20% or 120-160 of adults with learning disabilities receiving social care services have a current mental health need. This is lower than national estimates, indicating that it is likely that there are a high number of adults with learning disabilities and mental health problems that are undiagnosed, with a possible negative impact on their ability to function independently in the community.

5.5.7 Early onset dementia and people with Down's syndrome

Local needs surveys suggest that around 25% (200) adults with learning disabilities receiving social care services have Down's syndrome. People with Down's syndrome have higher risk of developing early dementia.

Locally, there are no consistent recording of number of people with LD and dementia, but there were at least 13 people with dementia known to the Community Learning Disability Team in Dec. 2010. There might be people with undiagnosed dementia, since symptoms differ from the general population and might go undiagnosed.

5.5.8 Learning disabilities and substance misuse

People with LD and substance misuse problems are a vulnerable population. The exact number of people locally is not known and there is a need to review the care pathway and support for these clients locally.

A local study identified eight people supported by both the Community Learning Disability Team and substance misuse services in August 2010, five men and three women. All of them had suffered abuse (physical, sexual, emotional and/or financial) now or in the past[25].The cases identified highlighted issues around the lack of suitable services due to the risk of abuse from others or from the person with a learning disability. Substance misuse service staff also did not feel adequately trained or equipped to treat this population effectively. The case studies also concluded that there was a lack of rehabilitation programmes tailored to the needs of people with LD, since current programmes rely on group work and material requiring a level of literacy not suitable for people with LD. There was also a need identified to co-ordinate working between teams and a need for suitable accommodation services. Most of the people who had been offered suitable housing with support had gone on to decrease their substance misuse[25].

The study concluded that these are clients at high risk who require support from several services, using new methods tailored to people with LD [25].

5.5.9 People with Learning Disabilities who offend

There were no clear numbers of how many people in offending services have LD locally. Lewes prison reported that approximately 15% of offenders have learning disabilities or learning difficulties. The court nurse at Lewes Crown Court has started using a tool kit to screen whether people might have a learning disability, in which case they will be referred for assessment by the Community Learning Disability Team.

More work is required to establish numbers of offenders from Brighton & Hove who may have a learning disability, to establish pathways and to consider their needs in custody and in the community.

6. Current services in relation to need

6.1 Introduction

Support Services for adults with learning disabilities range from: mainstream to specialist health, social care, housing, employment, voluntary and other support services. There has been improvement in service delivery and quality of support in the last couple of years locally, in line with national recommendations. There are examples of best practice, including the community health facilitator post and hospital liaison nurse team as well as a community mental health nurse lead on learning disabilities. There has also been a significant expansion in self directed support and a specialist housing officer to support people to access mainstream housing. Many of the improvements have been made by training of mainstream staff to increase awareness on how to improve access for adults with learning disabilities, by providing advice to mainstream staff on an on-going basis and providing support for individuals and carers.

According to national guidelines adults with learning disabilities should access mainstream services as far as possible and mainstream services should make relevant, appropriate and reasonable adjustments to facilitate access[14].

6.2 Learning Disability Partnership Board and local commissioning of specialist services

Brighton and Hove City Council act as lead agency for the commissioning and assessment of social care and specialist health services for people with learning disabilities locally. The city council and local health services have a commitment to work in partnership to improve the lives of people in Brighton & Hove.

Brighton & Hove has set up a Learning Disability Partnership Board to help take forward local priorities as required in the White Paper *Valuing People Now*[12]. The Learning Disability Partnership Board meets regularly and is chaired by a member of the council and a person with learning disabilities. Half of the members of this board/group are family carers and people with learning disabilities. The other half consists of representatives from the NHS, local authority adult social care and housing, the Children and Young Peoples Trust, other support and service providers as well as voluntary organisations.

The aim of the partnership board is to provide a voice for people with learning disabilities and their carers to influence local plans and wider strategies to improve access to mainstream services and improve inclusion in the community locally.

The Learning Disability Strategy 2009 - 12

In response to national guidelines and strategies, in 2008 Brighton & Hove developed a three year Learning Disability Commissioning Strategy. The strategy set out an agenda to deliver more choice and control to adults with learning disabilities through self-directed support, a wider range of personalised services and better access, opportunities and outcomes in health, housing, work and meaningful activities[34].

The strategy also acknowledged that partnerships with the Council, housing providers and the voluntary and private sector are key to delivering change. The strategy was informed by consultations with people with learning disabilities and carers (Section 9.2).

6.3 Health Care Services

Below are descriptions of some of the different health care services that support adults with learning disabilities locally.

6.3.1 General Practice (GP) services

Local Enhanced Service for adults with people with learning disabilities

To improve access to GP services and care for adults with LD a Local Enhanced Service (LES) has been established informed by national guidance. This aims to ensure that all adults with learning disabilities in Brighton and Hove are offered the opportunity to receive a regular, comprehensive health check and a resulting health action plan.

47 out of 48 GP practices have signed up to provide the Local Enhanced Service; the remaining practice is the University practice, which does not have any patients with a learning disability.

Since the start of the LES in 2007, there has been an increase in individual health checks of people with LD from 81 to 376. The percentage of people with LD who received a health check in 09/10 was higher compared to the national average (Table 4).

Table 4. Percentage of people with LD known to services who received an annual health check 09/10 in relation to national average.

	Number of annual health checks	Number receiving social care support	Percentage received health checks	Number on GP registers (QOF)	Percentage received health checks
B&H	369	779	47%	949	39%
England*	58,919	145,130	41%	179,064	33%

Source: *Valuing People Now and local GP practice and social care service data (09/10)

A qualitative audit of health checks was conducted by a health facilitator (section 6.3.4) in 2009/10. This showed that:

- There were a large number of new health needs identified including overweight, eye, foot, skin, teeth and diet issues, diabetes, high cholesterol and high blood pressure as well as cervical smear tests being overdue.

- More work is needed to ensure that meaningful health action plans are produced as a result of the annual health checks.

The data collected suggests that health checks are effective in terms of identifying unmet health needs. If the resulting health action plans are effective this will improve health and

reduce the risk of complications and long term conditions. However, to enable health action plans to be fulfilled there needs to be equitable access to support available, such as healthy living services.

GP practice data to inform the Big Health Service Check 2010

The South East Coast Strategic Health Authority requires each PCT and local authority to complete and submit a self-assessment of their health care services for people with learning disabilities, known as the Big Health Service Check. This is carried out on an annual basis to enable improvement to be demonstrated. A survey was sent to all GP practices locally to provide some of the data required for the Big Health Service Check. 24 out of 48 GP practices responded to the survey. The data returned relates to the 12 months from July 2009 to June 2010.

The data returned related to 656 adults (aged 18 years and above) and 81 children (under 18 years old), a total of 737 people. This is equivalent to 70% of the 949 adults with learning disabilities recorded in GP practices registers (QOF data 09/10). Some of the data provided for this survey has been used in the following sections to describe the health needs of local people with LD.

6.3.2 Long term conditions

The Big Health Service Check survey indicated that, of the 737 people for whom information was available:

- 433 had their body mass index (BMI) recorded and 152 were recorded as obese (21%), but only 62% of people recorded as obese were recorded as having received dietary advice.

- 120 (16%) people with LD were reported to have epilepsy, 84 (11%) asthma and 66 (9%) mental health problems.

- 28 people had diabetes and 82% of these had received an annual diabetes review.

- 12 people had coronary heart disease, and 75% of those had received a review in the past 12 months.

6.3.3 Health screening services

The Big Health Service Check survey indicated that of the people eligible for screening services 18% were recorded as having received bowel cancer screening, 28% breast cancer screening and 29% cervical cancer screening. Of the people with diabetes 57% had received diabetes retinopathy screening.

These are very low figures in relation to the uptake in the general population of 76% for cervical screening, 70% for breast cancer screening[35] and 62% for diabetes retinopathy screening and the minimal national targets of 70% for breast, 80% for cervical screening and 70% for diabetes retinopathy screening uptake. Bowel cancer screening is a new programme nationally and locally which may explain the low proportion of people who have been screened. There is no national target for bowel cancer screening yet.

It is important that campaigns to increase uptake of screening includes people with learning disabilities together with targeted efforts to increase screening uptake in this population. Low uptake of screening can be due to a multitude of different factors including information, understanding, and awareness of importance, procedure and benefits, as well as fear, and practical issues such as transport and staff skills.

Cervical screening guidance has been developed by the LD Health Facilitator (section 6.3.4) and Cancer Health Promotion Specialist, with input from practice nurses, to improve access to cervical screening for women with learning disabilities. The guidance is aimed at practice nurses and was distributed to GP practices during October to November 2010. Similar guidance will be developed for bowel and breast cancer screening in 2011.

6.3.4 Health Facilitator

A Health Facilitator was appointed in 2007 to support GPs and other community based healthcare professionals to improve health by raising awareness of the needs of people with learning disabilities. The health facilitator is part of the Community Learning Disability Team.

The Health Facilitator also provides training to primary care and community health care services to raise awareness about how to make reasonable adjustments to ensure access to mainstream services for people with learning disabilities.

There are plans for the future to extend awareness training to include healthy living/health promotion services as described in section 6.3.7.

6.3.5 Dentistry

There are currently 52 general NHS dental practices in Brighton & Hove. It is not known how many adults with a learning disability access a mainstream dental practice. Of the people with LD who responded to this year's Big Health Service Check survey (see section 9.3), 75% reported that they had visited a dentist regularly and 87% that they thought their dentist was good at supporting people with LD. However, the survey only represents 13% of the population with LD know to social care services and might be biased in terms of people that responded being more likely to be aware of services.

Sussex Community NHS Trust provides a Special Care Dentistry service available to adults with a learning disability in Brighton & Hove. As part of this contract, the Oral Health Promotion Team provides oral health promotion guidance, information and training to those organisations and carers working with people with learning disabilities. Adults with LD may be seen by either a general dental practice or the Special Care Dentistry service depending on their disability and level of oral health need.

Issues relating to oral health and access to dentistry for the local LD population were highlighted in last year's LES audit and the South East Big Health Service Check. As a result, a plan of action is underway. This includes provision of information about the oral health needs of people with a learning disability at an Oral Health Champions event organised by NHS Brighton & Hove and a joint review of the access and barriers to local mainstream and specialist dentistry services by Oral Health Promotion/Special Care Dentistry in partnership with the Health Facilitator.

6.3.6 Optometry

It is known that people with learning disabilities have a high level of eye issues and unmet health need related to eyes (as identified in the LES audit). Review of the current access to local mainstream and specialist optical services is planned for 2011.

- In this year's Big Health Service Check survey (section 9.3), 90% of respondents were reportedly happy with the services received from their optician.

6.3.7 Healthy living services and health promotion

People with learning disabilities have more health needs compared to the general population, including high prevalence of overweight and obesity, poor diet and often less access to physical activity opportunities and meaningful activities.

Good health begins with promoting wellbeing and preventing ill health and this is the same for people with learning disabilities: healthy active lifestyles have to be the starting point for all[14].

The LD Health Facilitator and PCT health promotion lead have drawn up plans to increase access to healthy living services as described below:

- To review options to include needs of people with learning disabilities on referral and monitoring documentation for Stop Smoking, exercise referral scheme, Health Trainers and Brighton & Hove Food Partnership services.

- To explore options for monitoring referral and uptake rates of these services by people with a learning disability.

- To explore options for Health Trainers to provide small groups on healthy eating and physical activity in local learning disability services.

- Provide learning disability awareness training for staff from the local exercise referral scheme, Health Trainers, Brighton & Hove Food Partnership, the Stop Smoking and the alcohol and substance misuse services and cancer screening health promotion team.

The focus initially will be on addressing issues in relation to weight management and physical activity services, and then on raising awareness of the services available to local adults with LD and their carers and support staff.

Relationships and sexual health

Building and maintaining relationships can help improve health and wellbeing[14]. A recent 3 year study in the UK found that there is a lack of specialist information and support for building relationships and sexual health available to people with LD, their parents and professionals[36]. A two day training course on sexual health for people with LD was offered to professionals in Brighton and Hove in 2010. The aim was for participants to become a lead for their service on the Personal Relationships Lead Network and undertake personal relationships and sexuality work with their service's clients with support and supervision

from community LD nurses. This training will now be delivered on an annual basis. There is a need to evaluate the impact and outcome of this training and any need for further support.

6.3.8 Mental Health

Nationally, it has been recognised that people who have a learning disability do not always receive the same quality mental health services as the general population. Historically there have sometimes been disagreements between mental health and learning disability teams as to who should support them. The 'Green Light for Mental Health' service improvement toolkit seeks to improve this by encouraging local self-assessment and good practice. The local progress on Green Light has shown good performance and sets actions for further work[38].

A local needs survey suggests that around 15-20% or 120-160 of adults with learning disabilities receiving social care services have a current mental health need.

The Royal College of Psychiatrists estimates that the prevalence of mental ill health in people with learning disabilities could be anywhere between 35-75%[4]. This highlights the importance of ensuring that members of staff are trained in picking up and diagnosing mental health issues in people with learning disabilities.

Locally there is a part-time Community Mental Health Nurse (0.6 whole time equivalent (WTE)) with a lead in learning disabilities to support fair access and appropriate support in mental health services. The nurse spends about a third of her time supporting clients, one third providing advice to colleagues who support people with LD and the remaining time training other mental health access teams across the city.

There is also a specialised psychiatrist (0.6 WTE) for adults with learning disabilities who works in the community and on wards as well as three psychologists. A psychologist is needed to formally assess if a person has a learning disability as well as to support people with mental health problems.

6.3.9 Hospital Services

The national "Healthcare for All"[40] report highlighted a need to improve quality of care and outcomes for people with LD admitted to hospitals. This requires improving awareness of staff, improving understanding of expression of symptoms in adults with LD and ensuring relatives, who are sometimes better at diagnosing changes and symptoms in people with LD, are listened to[39].

Learning Disability Liaison Team

Locally a Learning Disability Liaison Team (LD LT) was established in 2009. This service is commissioned by the PCT and team members are employed by Sussex Partnership Trust. The team covers all sites within Brighton and Sussex University Hospitals, including the Royal Sussex County Hospital, Hove Polyclinic and the Princess Royal Hospital. The team comprises 2 WTE nurses. This service has been cited nationally as good practice within Valuing People Now.

The team offers support to individuals, their families and carers with any form of hospital admission or appointments before, during and after hospital visits as needed. Support can involve explanations of procedures, providing accessible information as well as supporting staff to ensure they comply with the Mental Capacity Act and help ensuring safe discharge. The team also work closely with the hospital staff providing advice to ensure that reasonable adjustments to patient care have been considered.

The team provide training as part of the mandatory equality and diversity training for all new staff, except for medical doctors.

The team operates an open referral system and receives referrals from wards, families, carers, and professionals. They rely on other people being aware of the services and referring patients to them. The team do not have access to the hospital clinical information system, which makes it difficult for them to ensure that all people with LD in need are offered their support. The way in which learning disability is recorded electronically on the information system needs to be reviewed to ensure that all those in need can be identified.

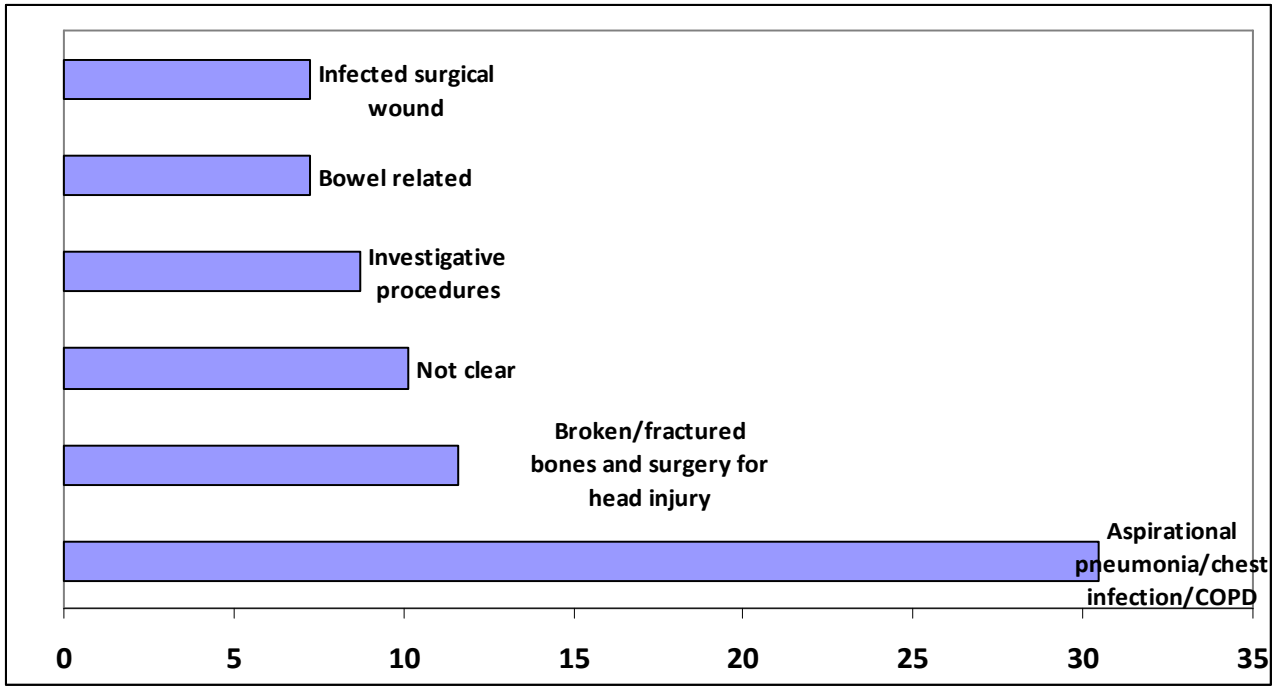
During the first six months of 2010 the team received 102 referrals, of which 89% received care at Royal Sussex County Hospital, 10% at Princess Royal Hospital, Haywards Heath and 3% at Hurstwood Park Neurological Centre. About a third of the patients referred to the services were over 56 years old.

Of the people seen, 15 individuals (14%) had repeat admissions.

The most common admission reasons were aspirational pneumonia/chest infection/ chronic obstructive pulmonary disease (30%) followed by accidents, broken bones and head injuries combined (12%) (fig 2). Other reasons for hospital admissions not shown in the figure below included cancer, status epilepsy, urology, chronic conditions and gynaecology. The figure only shows people with LD known to the LD Liaison team.

Fig 2. The six most commonly reported reasons for admission to hospitals for people with LD locally

The figure only shows number of people with LD referred to the hospital liaison team nurses. Liaison team data from 1st Jan – 6th July 2010.



Graph adapted from: "Summary of services offered by the Learning Disability Liaison Team" 2010.

6.4 Social Care Services

6.4.1 Introduction

Adult social care services are commissioned by Brighton & Hove City Council (BHCC) and delivered by different providers. Eligibility for services is based on assessment of needs for support and risk to health and wellbeing if no support is offered. Services range from providing residential care for people who cannot live independently and specialised supported accommodation for people with more complex needs, to providing outreach practical support in the person's home, advocacy services and support for carers, including respite breaks. Accommodation support is described in section 6.5.

6.4.2 Community Support

Community Support refers to outreach support that is delivered to clients in their own home. It can include personal care, support with independent living and support to access the community. Community Support is arranged through generic providers of 'home care' services, through specialist providers or in a range of ways with the use of personal budgets and direct payments.

6.4.3 Day Services

Day Services include specialist services to support people with more complex needs, such as physical disabilities, sensory impairment and challenging needs. Day activities range from educational and pre-employment sessions to leisure and recreational activities. Whenever possible people are supported to access a wide range of community resources.

Brighton & Hove City Council directly provides day services to 134 clients in 5 day services and the private and voluntary sector provide day services to 114 clients (a combined total of 31% of people with LD known to social services).

6.4.4 Community Learning Disability Service

The Community Learning Disability Service is an integrated service, jointly funded by the Brighton & Hove City Primary Care Trust (BHC PCT) and Brighton & Hove City Council 'pooled' budget. The team members are employed by Brighton & Hove City Council and Sussex Partnership Trust.

The Community Learning Disability Services consists of:

- Care Management and Social Workers (12.2 WTE)
- Transition team (3WTE)
- Nurses (6.3WTE)
- Behaviour Support (2WTE)
- Occupational Therapy (1WTE)
- Speech and Language Therapy (1.8WTE)
- Physiotherapy (1.7WTE)
- Psychology (1.9WTE)
- Psychiatry (0.6WTE)
- Senior Management (1.33WTE)
- Administrative support

The Community Learning Disability Team (CLDT) reported issues in general around the predicted increase in number of clients for the future and capacity within the team. It was felt that there was a need to review procedures for referrals, data collection and reporting to make work as effective as possible to better cope with increases in demand for support services. Below are some other main issues around support and demand reported from the community learning disability team.

Care management and social workers

The team provides person centred assessments of need. Social workers:

- provide initial assessments of need and support.
- provide immediate response to clients, carers and providers requests for support.
- support the effective use of personal budgets.
- conduct carer's assessments.
- deal with safeguarding concerns and safeguarding investigations to reduce risk of harm from and to vulnerable adults as well as providing sign-posting to people who are not eligible for social care support to advice and information.

Transition team

The transition process from children to adult services is complex and it was reported that it was often difficult to identify specialist provision. Concern about future demand has been raised by the team. Caseloads are increasing year on year and one of the posts that are currently funded by another organisation (Connexions Service) is likely to cease in April 2011. A review of the work of the team is underway to focus resources on those with the most complex needs.

Nurses

The community learning disability nurses support adults with learning disabilities who have complex needs and are unable to access mainstream services. The team consists of 2 community nurses, 3 nurses who work in the hospital liaison team (section 6.3.9) and 1 health facilitator (section 6.3.4). The team support individuals to achieve or maintain good levels of health and wellbeing by carrying out health assessments and care planning. They also work with mainstream health services to support them in making reasonable adjustments, via direct client work, consultations or training sessions. They can also provide support to other provider services on how to support people with learning disabilities to manage own health and wellbeing. Waiting time for first assessment with the community nurses are 4 weeks, with first treatment within 18 weeks. An increasing focus for the team is to help mainstream services enhance their awareness of the needs of people with learning disabilities and their responsibility to undertake reasonable adjustments.

Behaviour support

The behaviour support team is part of the psychology support team at CLDT. The behaviour support team provides assessment and plans aimed at reducing levels of challenging behaviour in clients. Other professionals can refer clients to the team and the waiting time for a first assessment is 4 weeks or less. The team also provides training to other healthcare staff in dealing with challenging behaviour.

Currently the team reports that it is stretched for capacity and emergency referrals often take precedence over already high priority cases, with a risk of less effective interventions as a result. It was thought that there is a need for a review of type of support delivered to improve effectiveness and increase reach. The team is currently developing tools to monitor quality standards and to share best practice through a local challenging behaviour network.

Occupational Therapy (OT)

There is one part-time occupational therapist, who works in partnership with physiotherapy and other health professionals delivering care to people with LD. The occupational therapist provides services directly to individuals, including eating and drinking assessments for people with swallowing problems, short interventions for people with posture problems and bathing clinics as well as training to other staff. A first assessment of individuals is offered within 4 weeks of a referral to the service. Occupational therapy has also secured additional funding to provide specialist drinking utensils and cups to enable immediate provision of these utensils to clients to reduce risk of swallowing incidents in the home. Disorders related to swallowing problems (aspirational problems) are one of the most common reasons for people with LD being admitted to hospital (fig. 2).

Speech and Language Therapy (SALT)

The team provides communication and audiology assessments and support for eating, drinking and swallowing problems. They provide direct support as well as training for family and carers. The team works in partnership with other support services to ensure complex health needs are met. The team reports that it has experienced an increase in referrals every year and are stretched to capacity. As swallowing problems are one of the main reasons for admission to hospitals for people with LD, there is a need to review working arrangements to meet increasing demand for SALT services in the future.

Physiotherapy
The physiotherapy team delivers support to adults with LD and complex needs who have mobility and muscoloskeletal issues. They work jointly with other support services for example wheelchair clinics and clinics supporting people who have problems swallowing. The team carries out assessments and delivers direct support as well as setting up clinical pathways for individuals to access complex posture care, aquatic therapy, intermittent case load management and access to mainstream services and liaison with relevant services. This can include equipments stores with mobility aids and other support. The waiting time to the team is less than 4 weeks.

Psychology
The psychology team offers assessment and treatment of people with LD and psychological difficulties, directly and/or through those who support them. The team also offers training and consultancy to other professionals to increase understanding of supporting people with LD and psychological difficulties. They can also formally assess if a person have a learning disability. All people referred to the service in 2009/10 were seen within 4 weeks. Within the services there were about 50 clients seen by a psychologist and further 25-50 cases seen by a trainee or volunteer supported by the service.

Psychiatry
This service provides diagnosis and support for adults with LD and mental health disorders that are residents in Brighton & Hove. Referrals to the service are by referral from GPs or other doctors. There are currently 3 inpatient beds specifically for people with LD available at Mill View hospital in Hove. There is a part-time psychiatry consultant for the Brighton and Hove area, which means that there is no consultant cover for part of the week. National guidelines recommend 1 psychiatrist per 80,000 residents, which for Brighton and Hove would be 2.8 psychiatrists[4].

With an expected increase in number of adults with learning disabilities there is a need to review current working arrangements to meet increasing demand and to maximise benefit and outcomes for individuals within available resources.

6.4.5 Respite services
Respite services offer short-term breaks for people with learning disabilities who live with unpaid carers. Respite can take a number of forms: short term residential care, family placement, and outreach.

- Brighton & Hove City Council has its own residential respite service, offering short breaks to 14 people at a time, including 2 places that are used as emergency respite for people in crisis.

- There is a waiting list for this service, with some clients waiting for over a year.

- Other residential respite services are spot purchased from independent providers for individuals as the need arises.

6.4.6 Advocacy support

Advocacy supports people to speak up and represent their best interests. Advocates aim to help people make positive changes and realise their rights as citizens. Advocacy for people with learning disabilities is mainly provided through two specialist agencies on a long term basis. Issues that frequently require support include housing, employment, finance and relationships. Many issues require detailed and intensive support. Both local advocacy agencies run waiting lists and there is unmet need especially for those with complex needs. A review of advocacy services is planned for 2011/12.

6.5 Housing

6.5.1 Introduction

People with learning disabilities live in a variety of types of accommodation. Many live with their family, some rent and a small proportion own their own home. Others live in some form of supported accommodation[42]. There is research showing lower spend and better outcomes in local authorities offering more supported living options compared to residential care. The emphasis in Valuing People Now is on using person centred planning and the local housing strategy to identify and improve choice of accommodation[43].

6.5.2 Local picture

Approximately 70% of the local social care services budget is spent on accommodation, including 63% on residential care and 8% on supported living (section 7.2). It was estimated in 2004 that the shortfall in accommodation to meet people with learning disabilities housing need in England was 50 places for every 100,000 of adult population, equal to just over 100 places in Brighton & Hove[44]. This figure includes people in residential care that could move on, people who are living with family due to no other choices and young people reaching adulthood.

Needs surveys conducted locally in 2008-10 by the Community Learning Disability Team and Learning Disability Commissioning Team suggested that about 40-50 people in residential care do not have personal care need and therefore may be suitable to move to supported housing.

Compared to national data for people with LD, there is a higher than average percentage of people with learning disabilities living in rented accommodation locally, which is positive (Table 5).

Table 5. Percentage of adults with LD in different types of accommodation nationally and locally

	General population (nationally)	People with learning disabilities (nationally)	People with learning disabilities in Brighton & Hove*
Own their own home	70	No data	0.3
Rented accommodation	29	15	22
Live in the family home	No data	50-55	28
Shared lives placements (settled accommodation)	No data	No data	9
Residential care or other unsettled accommodation	No data	30	33

Source: Valuing people Now (2009-12) and * Learning Disability Partnership Board annual report 2010.

6.5.3 Housing Options

Since 2008 people with learning disabilities (including those that do not receive social care) have been able to access support from a specialist Housing Options officer. This role supports people to maintain existing and access new tenancies, to bid for properties through the Homemove Choice Based Letting scheme[43] and improve access to housing information. In 2009/10 the officer supported 18 people with learning disabilities to access own tenancy for the first time. This role is now being developed to also support people moving on from residential care.

Further work should be undertaken to review numbers of people of people with learning disability on the housing register and to identify their outcomes.

6.5.4 Residential care

Residential care provides 24 hour care and support in care homes that are registered and regulated by the Care Quality Commission. Although many residential care placements are long term, it is classed as 'unsettled accommodation' as people do not have a legal right of occupancy.

National policy aims to move people on from residential care to settled accommodation, such as supported living models or independent, mainstream housing where this is appropriate to meet their needs.

In Brighton and Hove there are 37 residential care homes for people with learning disabilities, with 280 placements. The local market has a number of large independent sector providers with several care homes and the local authority provision of five care homes[41]. 130 placements are used for Brighton and Hove funded clients, with the rest either vacant or used by other authorities. . 46% of locally funded clients are placed outside of the city (Table 6).

Table 6. Residential care placements of adults with LD from Brighton and Hove

	Brighton & Hove	*Other areas of Sussex*	*Outside of Sussex*	*Total*
Number of people:	130	65	44	239
Percentage of people:	54.4 %	27.2 %	18.4 %	

Source: Hendriks 2010[41]

- There is a shortfall of specialist services for people with additional physical or sensory needs, challenging behaviour, severe autism or age related dementia locally to meet needs. This means that people with LD and these additional needs are often placed out of area.

- There is also a gap in forward planning to ensure places are available locally when needs arises, for example when carers becomes too frail or too old to carry on providing care and housing.

- In addition, there is also a shortfall of supported living options that represents good value for money that can be a barrier to people moving on locally[41].

6.5.5 Supported housing

This refers to specialised support provided in accommodation that has a separate tenancy agreement. In some cases support and housing is provided by one organisation. More usually, the support and accommodation are provided separately and the clients have an independent tenancy agreement with the housing provider. In this case it is called 'Supported Living'.

In Brighton and Hove there are 32 supported housing schemes for people with learning disabilities, with 145 places. The council manages 9 of these supported living services (39 places). Brighton and Hove City Council currently use 108 of the supported housing places; the others are used by other authorities or are vacant. Supported housing is a growing market as people choose to live more independently and demand for it can be high. Service commissioners report that there are shortfalls in supported housing for people with low to moderate needs, as well as for those with complex or challenging needs, mental health problems and substance misuse problems. This can lead to an overuse of residential care or other less appropriate placements.

6.5.6 People living with family

The high percentage of people with LD living with families will present a future challenge for accommodation services, as the life expectancy of people with LD is increasing, when their carer gets older and are no longer able to provide care and housing. Detailed analysis of this group is a priority in order to inform future commissioning plans.

6.5.7 Shared Lives

A Shared Lives service is a placement in a family home, with accommodation, care and support being provided by that family. There are two Shared Lives services in the city.

Brighton & Hove City Council's Shared Lives Scheme works with 30 approved carers that can currently provide up to 30 full-time placements and 22 respite placements. The Grace Eyre Shared Lives Scheme supports 23 Brighton and Hove clients in long term arrangements. Options are currently being explored to expand the use of the shared lives as floating support and respite.

6.5.8 People with additional needs

The number of people with learning disabilities who have complex needs requiring specialist accommodation and support is projected to increase over time, due to an increase in life expectancy, due to improved health care and support.

Recent analysis of need suggests that there is a need for specialist provision for people with autism, challenging behaviour, mental health problems or substance misuse problems locally, to improve support and reduce need for costly, out of area care placements. In addition there is a need to commission accommodation services that can meet the needs of frail, older people with learning disabilities and those that need nursing care and/or support with mobility or dementia[45].

6.5.9 Barriers for the local housing market

109 people (45%) funded by Brighton & Hove are placed in other authorities (section 6.4.2). This is partly due to clients remaining in historical placements and partly due to a lack of specialist provision and forward planning.

A barrier to developing the local supported housing market is the concept of 'ordinary residence'. Under ordinary residence legislation, people placed locally in supported housing by other authorities are entitled to claim local benefits and subsequently the cost of their support will have to be met by the host authority. Ordinary residence however does not apply to those placed in residential care as the placing authority retains funding responsibilities regardless of where people are placed.

This presents a financial risk where clients move to Brighton & Hove or where clients placed in local residential care by other authorities move out of their care home or where the care home changes its registration. There is therefore often a financial disincentive for Brighton & Hove to remodel care homes to tenancy based accommodation models, unless agreements around funding can be made with other authorities.

Other barriers include the higher cost of housing and lower levels of appropriate social housing stock, compared to other areas. People with LD are vulnerable to abuse from others, due to the condition of LD and often social housing is provided in areas with higher risk of abuse to this vulnerable population. An increase in semi-supported smaller group housing models in areas with lower risk of abuse can reduce risk and social isolation as well as improving awareness and acceptance in general population and inclusion in the society, as evident by research[59] (section 11.2).

6.5.10 Positive progress

- **Westbourne Development**

A new mixed tenure development provides 10 supported housing units and 14 units of respite for people with a learning disability. The supported housing units provide shared accommodation for five younger people with learning disabilities and 5 one bedroom flats for people with physical disabilities and complex needs.

6.6 Employment Support Services

There are several services locally that directly support children and adults with learning disabilities, into supported voluntary and mainstream employment:

- **Connexions** – provides information, advice and guidance to young people with special educational needs aged 13 to 25 years.
- **Supported Employment Team (BHCC)** The team support disabled people of all ages into work and can provide on-going support to people once they are in work. They have specific criteria for referral.
- **Care Co-ops** – Manages a number of programmes to adults with long-term mental health problems and people with learning disabilities, these include an employment and training programme to support clients into voluntary or paid work. They also have a community farm project at Stanmer Park and can offer work placements within their 20:20 café.
- **Grace Eyre Foundation** – Manages a number of programmes for adults with disabilities, this includes an Employment Project to help people into both voluntary and paid work. They also offer work experience placements within their in-house café.
- **Disability Employment Advisers, Jobcentre Plus** – work with adults who need additional support to access employment because of their disability, including referral to supported programmes and Access to Work (which advises disabled people and their employers how they can overcome work-related obstacles resulting from their disability).

6.6.1 BHCC employment support team

The team works with 75 employers in the city to support people with LD to gain employment.

Table 7. Number of adults supported by the BHCC employment support team (2009/10)

Type of work	Number of adults with LD	Number of these supported by Special Educational Training
Paid employment	126	92
Voluntary work	134	15
Total	**260**	**107**

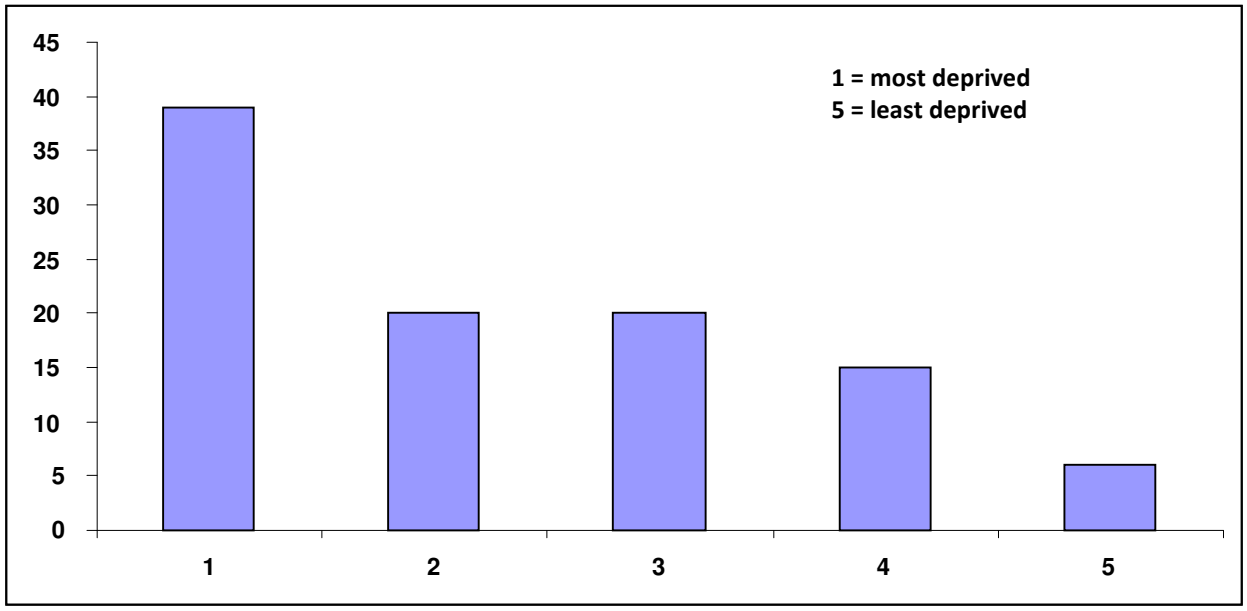
Source: BHCC employment support team

Locally, 105 out of 720 adults (14.9%) aged 18 to 69 with learning disabilities known to adult social care were in paid employment at the time of their most recent assessment or review (2009/10). The national target is 40% of people with LD in paid employment by 2025[15]. The local figure is considerably higher than the average rates for England (6.4%) and the South East (9.7%) and B&H is ranked 10th out of 151 Councils. The proportion of men in paid employment is higher than women; 17.9% (75/425) compared with 11.2%; (35/295). This

partially reflects the pattern seen nationally (7.2% vs. 5.4%) and in the South East (10.5% vs. 8.7%), however the difference between men and women is greater in the B&H population[46].

Between April and September 2010, the BHCC employment support team supported 80 people with LD into paid employment. Of these 71% were men and 29% women. The median age was 43 years old (range: 21 – 67). A majority of people lived in the more deprived areas of Brighton & Hove (fig. 3) and the median number of hours worked per week was 16.5 hours (range: 2 – 42 hours)[47]. There were a higher percentage of people in supported employment (April – Sept. 2010) from the most deprived areas of Brighton & Hove (fig. 3). This is likely to reflect that a high number of people with LD live in more deprived areas locally.

Fig 3. Percentage of people with LD in supported employment by area of socio-economic deprivation locally



Data source: The Employment Support Team, B&H City Council (Data from April – Sept 2010) and Index of multiple deprivation (IMD) scores, Chris Dorling, Information analyst, NHS B&H.

The local employment support team reports that more resources are needed to engage employers and to support individuals, to increase the number of people with LD in employment.

They also report that more effective partnership working with other organisations and services could help young people and adults to develop skills necessary to gain employment e.g. basic skills in health and safety and in using public transport to get to and from work.

6.7 Self-Directed Support for people with learning disabilities

In line with national recommendations[12] people with learning disabilities are being supported in a number of ways to gain more choice and control through self-directed support (SDS).

- Self Directed Support has been available to people with learning disabilities since a pilot project in 2007/8. In 2009/10 there were 137 people with self-directed

packages of support (17% of social care clients with LD), most using a system of Direct Payments.

- By September 2010, 28 people with learning disabilities had a Personal Budget, giving them choice and control over how they spend their agreed funding. This is 3.5% of all the adults with LD receiving adult social care services.

- There have also been services set up under 'Individual Service Fund' (ISF) arrangements, which allows individual clients to have a greater say over how their service is delivered, and there has been a pilot of four people accessing day services using ISFs.

The Federation of Disabled People is commissioned to offer a supported account service to help people access and manage their personal budgets. To support awareness and understanding of the process, several information and support services have been set up including: an SDS Information Pack produced for people with learning disabilities, carers and professionals; information on SDS available on websites and newsletters; and a new website called the 'Big Bridge' is being developed (www.thebigbridgebrighton-hove.org) to provide information for people with learning disabilities so they can have more choice and control. There have also been several events delivered about SDS for people with learning disabilities, providers, and professionals and an SDS Peer Support Group has been developed.

6.7.1 Further areas for development

- Work is on-going to develop and improve the processes that support SDS, for example in contracts and payments.

- The process is also being improved for young people as they reach adulthood, to make sure that the handover of support from children to adult services is as smooth as possible.

- As processes are refreshed and improved, training and awareness sessions will be updated for professionals, clients and families.

- Options are being explored for how to perform the 'brokerage' role most effectively.

- Work is on-going to align the local council's current IT systems to support the developing SDS processes.

6.8 Safeguarding Vulnerable Adults

People with learning disabilities are amongst the most vulnerable within our society and the safety of people with learning disabilities is of paramount importance. Due to the nature of learning disabilities many face risk of exploitation and abuse, ranging from physical, sexual, financial to neglect. Locally, the Community Learning Disability Team's social work team responds to reports of suspected abuse. In 2009/10 the team were alerted to 284 cases of suspected abuse. This was a 47% increase in reporting of suspected cases compared to previous year. However, after investigation, so far only 70 of the cases have been

confirmed. There are another 48 cases still to be investigated. This is a similar number of cases as for the previous couple of years, indicating that people are more aware and better at reporting suspected abuse, but the number of actual abuse cases has not increased.

6.8.1 Type of abuse, perpetrators and location

A majority of confirmed cases related to physical abuse (71%), followed by financial (9%), psychological (8%), sexual (8%) and neglect (4%). A majority of reported incidents were reportedly carried out by service users (130 cases) followed by members of staff (51 cases) and others. The settings where the abuse took place included: residential services (29%); in the community (17%); day services (12%); supported living services (10%); home (8%); school (7%); and other locations.

This highlights that people with learning disabilities can be vulnerable to abuse and also that some can be a risk to others, which has implications for providing appropriate facilities for support to minimise risks to users and others. Improvements can include training of staff, good, quality care and environmental factors such as accommodation.

6.9 Transition: when young people move from children to adult services

Person-centred transition planning can improve choice and control for people with LD and can be used to support young people with learning disabilities and other additional needs to get jobs and live full lives as adults. Valuing People Now says that by 2012, all young people will have person-centred transition plans focusing on health, housing, jobs, friends and relationships and social inclusion. In order for this to happen, young people and their families need to receive expert advice and information from age 13/14 about the options available to support their aspirations.

There is a local transitions team that manages transition between children and adult services. Person-centred review processes have been introduced in five special schools in Brighton. However, not all special schools are yet covered within the remit of the council's transition team.

The Council also commission Amaze to employ a Transition Development Worker who provides information, advice and support to parents as their children move into adulthood and who works with professionals in the city to improve support to young people and their families through the transition phase.

The statutory duty to co-ordinate transition planning lies with schools which mean that Person Centred Transition Planning has to have the full backing of the head teacher to ensure it happens. This means that it is important to ensure that all schools adopt this new, person centred transition model with the same commitment of involving young people and their families in the process. There is also an issue in local transition planning around young people who are placed out of area. These people tend to have the most complex needs but who are not currently within the remit of the transitions team.

6.10 Support for carers

According to the 2001 Census there were six million carers in the UK with 3 out of 5 of us expected to be carers at some point in our lifetime. Carers provide an important role in our

society and are estimated to save the British economy £87 billion a year. However, it is also recognised that carers can suffer high levels of stress and mental health problems because of problems being exacerbated by their caring responsibilities.

National research shows that 27% of people caring for others for more than 20 hours per week suffer from mental health problems. Those caring for a spouse or partner or for a sick or disabled child are of highest risk of mental health problems. Research also shows that more women than men are at risk of mental health issues, especially when caring for someone in the same household. People doing very demanding caring or who care for people with dementia are most at risk of mental health issues.

6.10.1 Carers of people with learning disabilities

The needs of carers should be seen as separate to those of the person with a learning disability and an assessment of those needs should be undertaken. Carers in particular frequently express their concern about the lack of planning for the future (Valuing People 2001).

The community learning disability team estimates that there are approximately 110 carers over 65 years old locally who are caring for someone with a learning disability and more information regarding their needs should be regularly updated to inform future planning and commissioning.

6.10.2 The Carers Assessment Service

There are a number of services to support carers, including a carer's centre that provides a range of support and advice services. There is also training to help carers with their caring role, including back care advice and a backup plan service. Every carer of a person with learning disabilities is entitled to a carer's assessment, which looks at the overall care setting, and considers how any identified needs can be met. The Community Learning Disability Team includes a carer's assessor worker (0.6 WTE) although all care managers and social workers can complete carer's assessments. Through the carers assessment there are some key needs and issues for carers that have been identified by the Community Learning Disability Team as described below.

- There is a demand for residential respite that exceeds local supply.
- There is a lack of support for people with Autism & Asperger's Syndrome, which impacts on their carers.
- There is a lack of provision for people with learning disabilities and dementia.
- There is a lack of supported housing for people with lower levels of need.

6.10.3 Brighton & Hove Carers Survey 2009

The Carers Centre for Brighton & Hove was commissioned by Brighton & Hove City Council to carry out a survey to help improve services for carers of adults in Brighton & Hove. The

following data is summarised from 79 people who responded to the survey and cared for someone with a learning disability.

Views of practical support
Services that carers would like to use for their cared ones were, in order of highest response rates: short breaks where the cared for person is taken out, short breaks in the home; supported employment; day centre or day activities; and home care/home help. 34% also reported that existing transport services did not support their caring role.

Views of carer's assessments
40 people (51% of respondents) reported that they had had a carer's assessment, but only 13 people that the assessment made a change to their caring role.

6.10.4 Carers Grant
Brighton & Hove City Council receives funding from the Carers Grant to help carers with short breaks or support services. There are 28 carers of people with learning disabilities that are receiving funded services from the Carers Grant, in terms of, for example, equipment, education, leisure activities, funding for a holiday, transport costs or a short break for the person with LD being cared for.

The amount of the grant is limited. Funding also goes toward the Carers Centre that provides a preventative support service for carers. In addition to this, 28 places are funded at Cherish Young Adults holiday scheme and a number of sibling carers are supported through funding to the Young Carers Project (exact numbers not available). Also to be funded are Mindfulness Cognitive Behavioural Therapy retreats and self-management courses for carers.

7. Funding and workforce

7.1 Introduction

There is a Brighton & Hove Learning Disability Workforce Development Strategy 2009 – 2012 which sets out the priorities for the local workforce. It is driven by the vision in Valuing People Now for workforce development, which recommends that the workforce across public services is given the appropriate support and training to equip them with the values, skills and knowledge to deliver the priorities for all people with learning disabilities.

The strategy notes that there is a need to engage a number of stakeholders to realise this vision and there is a need to work in close partnership with people with learning disabilities to design and deliver training. The Workforce Development Sub Group of the Learning Disability Partnership Board leads the implementation of the strategy. The priorities of the local strategy are:

1. Recruit and retain an excellent workforce
2. Develop new ways of working
3. Developing skills and knowledge of the workforce
4. Leadership and management
5. Developing excellence in leading for change
6. Partnership working

It is estimated that there are more than 1000 people in the learning disability social care workforce locally; this includes all staff in housing, care homes, social care staff and others. Many of these are part-time staff and high proportions are women. The turnover rate is 19% and the vacancy rate is 2.7% overall, which is lower than the national average turnover rate. The most common stated reason for leaving a job was stated as pay (Source. NMDS-SC January 2010).

There is an extensive programme of learning disability related training delivered through the Adult Social Care & Health directorate of Brighton & Hove City Council. Training is delivered to staff across the public, private and voluntary sectors. Training is also available to family carers. Training is developed with the direct involvement of the client group wherever this is applicable and possible, and new opportunities to involve people in more training areas are being explored.

7.2 Brighton & Hove City Council learning disability budget

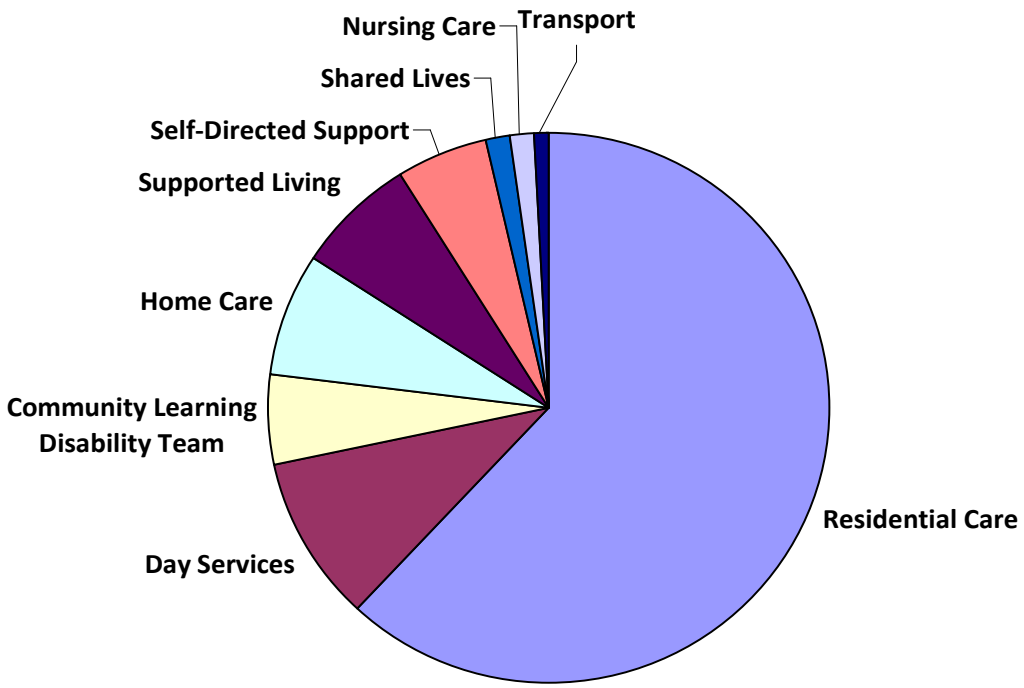
There area lack of systems currently being used to evaluate services in regards to outcomes and cost effectiveness, although a pricing tool, the Care Funding Calculator has started to be used for a sample of high cost placements. The overall cost of social care services (including specialist health services), and breakdown by service type, is indicated below (table 8 and figure 4).

Table 8. Adult learning disability social care service budget by service type, Brighton and Hove 2010/11

Service Type	Budget 2010/11	
	(£)	(%)
Residential Care	21,113,350	62
Day Services	3,347,970	10
Community Learning Disability Team	1,716,700	5
Home Care	2,497,130	7
Supported Living	2,362,050	7
Self-Directed Support	1,838,340	5
Shared Lives	426,150	1
Nursing Care	500,690	1
Transport	266,920	1
GRAND TOTAL	34,069,300	

Fig. 4 Proportion of social care service expenditure by service type, Brighton and Hove 2010/11

70% of the social care service expenditure locally for adults with LD over 18 years old is spent on specialist accommodation and support services, including 62% for residential care and 8% for supported living options.



8. Projected service use and outcomes in 3-5 years and 5-10 years

8.1 Projected prevalence

Estimates suggest that the prevalence of people with learning disabilities in England will increase over the next few years, driven by three main factors:

- Increased survival rates among young people with severe and complex disabilities, due to improved medical care.

- Increased longevity among adults with learning disabilities, due to improvements in medical care and reduced mortality.

- The increase in proportion of younger adults who belong to South Asian communities, as these communities have a higher prevalence of severe learning disabilities.

8.1.1 Estimated increase in prevalence in Brighton & Hove

- It is estimated that there will be a 3.0% increase in the numbers of adults with learning disabilities in the next five years and a 5.1% increase within the next 10 years in Brighton & Hove.

- The rates of increase in prevalence are projected to be higher amongst those with moderate and severe learning disabilities, with a 3.7% increase within the next 5 years and a 6.6% increase within the next 10 years (Table 9).

- This is equivalent to an increase of 70 people with moderate or severe learning disabilities in the next 10 years. It should be noted that projections of the increase in need for social care support exceed this figure (see 8.1.2).

This data is based on national prevalence rates that are applied to Office for National Statistics population projections for Brighton and Hove.

Table 9. Estimated numbers of adults with learning disabilities and estimated increase in populations between 2010 and 2030, by severity of condition.

	2010	2015	2020	2030	Change between 2010 and 2015	Change between 2010 and 2020	Change between 2010 and 2030
Learning disability	5,053	5,204	5,313	5,637	3.0%	5.1%	11.6%
Moderate or severe learning disability	1,065	1,104	1,135	1,225	3.7%	6.6%	15.0%

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

This means there is likely to be an increase in demand for local accommodation and specialised support for people with moderate to severe learning disabilities of working age. As well as a likely increase in demand for support for carers for this client group including practical support, mental health support and respite breaks.

Figure 5 below shows that the highest proportional increase in prevalence of adults with LD is expected in people over 55 years old. This will have particular significance for service planning as older adults with learning disabilities are more likely to have greater health and social care needs compared to the general population.

It is also likely that there will be an increase in diseases associated with an older age, such as cancer, diabetes and coronary heart disease. This, in combination with low identification of long term health conditions and low uptake of chronic disease reviews and cancer screening in this population is a risk.

Fig 5. Percentage change in estimated number of adults with learning disabilities by age in 2010 - 2030 in Brighton and Hove and England[1]

The graph shows that the greatest proportional increase in prevalence is expected in people aged 55-64, 65-74 and 85+ locally.

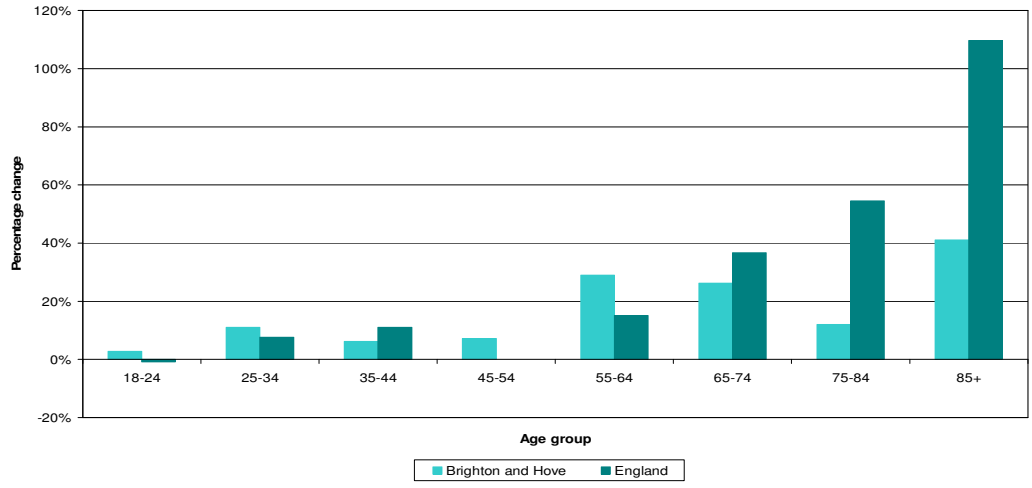
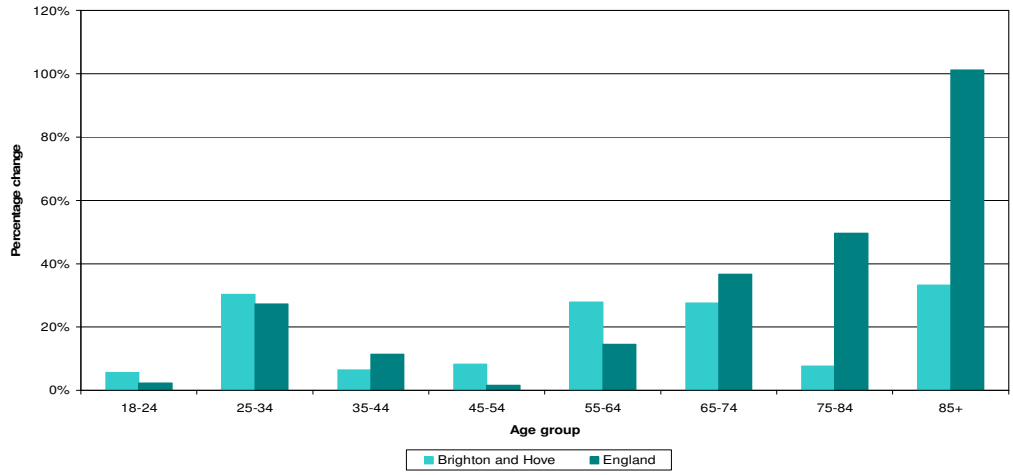


Figure 6 shows that the highest increase in prevalence of moderate or severe learning disabilities is expected in people over 55 years old and also in younger people aged 25 – 34 years old. This younger age group are more likely to have a high prevalence of other needs, such as challenging behaviour.

Fig. 6 Percentage change in estimated number of adults with moderate or severe learning disabilities by age in 2010 - 2030 in B&H and England[1]

The figure shows that the highest proportional estimated increase in prevalence is expected in the 25-34 year old age group and in people over 55 years old. The increase in the 25-34 year and 55-64 year age bands is expected to be higher in B&H compared to the national average increase.



8.1.2 Projected future need for social care services for adults with learning disabilities in England

The Centre for Disability Research, commissioned by Department of Health, has published a report estimating future needs for social care services for adults with learning disabilities[48].

This estimates that the need for social care services for adults with LD in England will change over the next 15 years driven by factors including:

- Decreasing mortality among people with LD; especially in older age ranges and among children with severe and complex needs.

- The impact of changes in fertility in the general population.

The report uses a complex model to estimate a range (lower, middle and upper) of increase in need for adult social care. The estimates are based on assumptions with varying robustness. The model is based on the number of current service users, projected demographic changes, and expected number of new entrants to adult social care.

The model was run for three scenarios using different assumptions regarding future eligibility criteria for adult social care for children with LD as they reach adulthood. The scenarios were that services would be provided to new entrants with:

i) Critical or substantial needs only
ii) Critical or substantial needs and 50% of new entrants with moderate needs
iii) Critical, substantial and moderate needs

The figures below are based on scenario i) as this is consistent with current eligibility criteria locally.

8.1.3 Future needs for social care services for adults with learning disabilities in Brighton and Hove

Applying the projections to the population of adults with learning disabilities known to social services in Brighton & Hove (798 people) suggests that:

- In the next 5 years there will be between 852 - 933 adults with LD eligible for social care services, an increase of 54 – 135 people.

- In the next 10 years there will be between 887 – 1042 adults with LD eligible for adult social care services, an increase of 89 – 244 people.

Table 10. Estimated number of people eligible for social care services (using scenario that new entrants with critical or substantial need are eligible for services)

	Estimated eligible users: Lower	Estimated eligible users: Upper	% Anual change: Lower	% Annual change: Upper
2010	798	798	1.6	3.7
2011	811	828	1.4	3.3
2012	822	855	1.3	3.1
2013	833	882	1.2	2.9
2014	843	908	1.1	2.7
2015	852	933	1.0	2.4
2016	861	957	0.9	2.4
2017	869	980	0.8	2.2
2018	876	1002	0.7	2.1
2019	882	1023	0.6	1.9
2020	887	1042	0.6	1.9
2021	892	1062	0.6	1.9
2022	897	1082	0.7	2.0
2023	903	1104	0.7	2.0
2024	909	1126	0.7	2.0
2025	915	1149	0.8	2.1
2026	922	1173	0.8	2.0
		Average:	3.1	1.0

The study concluded that these estimates are conservative because they do not take into account where people have mild LD plus other needs, such as mental health, where the combination of factors may result in meeting eligibility for social care.

It also noted that demand for support may increase due to a range of factors that will act to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women. These include:

- Increase in lone parent families.
- Increasing rates of maternal employment.
- Increase in the percentage of older people with LD (whose parents are likely to have died or be very frail).
- Changing expectations among families regarding the person's right to an independent life.

8.1.4 Estimated increase in number of adults with profound multiple learning disabilities in Brighton & Hove

The Centre for Disability Research, commissioned by Department of Health, has also published a report including projections of the increase in the number of adults with profound multiple learning disabilities[49].

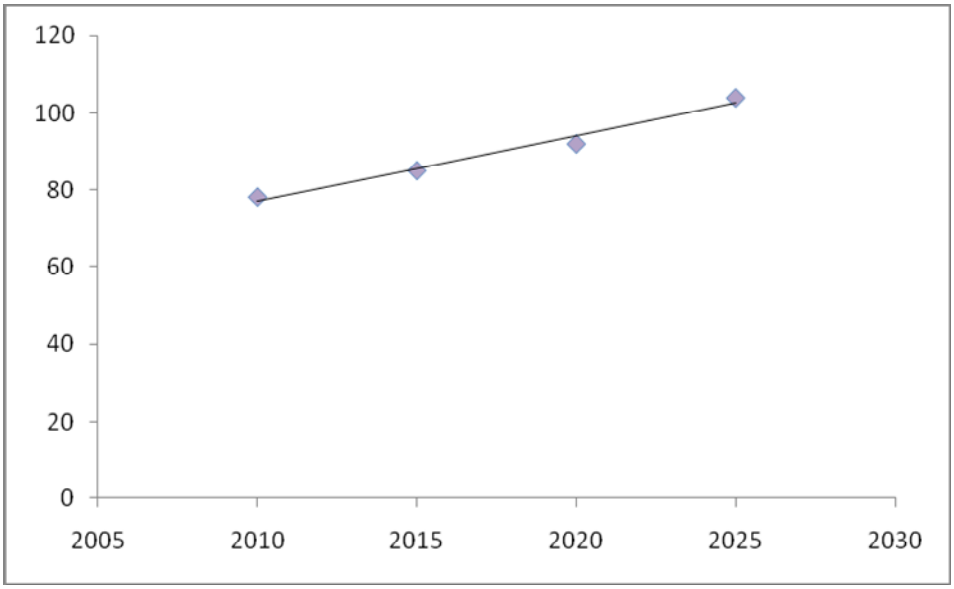
The study suggested a sustained and accelerated growth in the numbers of adults with profound multiple learning disabilities (PMLD) in England in the next 15 years, with an average annual increase of 1.8%. The rate of increases grows markedly towards the end of the period due to increases in birth rates in the general population[49].

In an average area in England with a population of 250,000, the same size as Brighton & Hove, the analyses suggested that[49];

- The number of adults with PMLD receiving health and social care services will rise from 78 in 2009 to 105 in 2026.
- The number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026.

The study highlights that rates are likely to be higher in areas with a younger age profile or with a large population from a South Asian background, especially from Pakistan. Brighton & Hove has a younger age profile, but a relatively small population of people from a South Asian background. The projected rates will not be influenced by level of socio-economic deprivation. The study also states that the projections are based on assumptions and the highest uncertainty lies in estimates of changes to mortality rates[49].

Fig 7. Estimated Number of Adults with Profound Multiple Learning Disabilities in Brighton & Hove 2010 – 2025



8.1.5 Adults with learning disabilities living with families

A national report estimated that about 60% of adults with learning disabilities live with their families. The White Paper *Valuing People* (2001) estimated that one third of people with learning disabilities living in the family home are living with a carer aged 70 or over[50].

The report also states that these family carers have often been caring for decades with very little or no support from services. As a result many families with older carers are unknown to services and will only become known where there is a crisis, for example when a carer dies or becomes too frail to continue in their caring role.

- **The Community Learning Disability team estimates that there are more than 110 carers over 65 years old locally known to services.**

Valuing People suggests that 25% of people with learning disabilities become known to statutory agencies in later life when their older family carer is no longer able to continue to care[50].

The report stated:

- That identifying older carers and people not yet known to services needs to be a priority in order to plan services and support effectively. There is a need for learning disability services to make stronger links with older peoples social and health care services to provide a joined up approach to supporting older family carers.

- A high priority for LDP boards should be to develop more effective systems for identifying older family carers as well as recording and collating information.

- Mechanisms need to be established to ensure that information collected by different agencies is co-ordinated and collated.

- Works need to be continued and increased to support the establishment of carer's registers with GP practices.

8.2 Transition of children with learning disabilities into adult services

Local authorities have a legal obligation to keep registers of disabled children in their area. The Compass is the register of disabled children in Brighton & Hove and is held independently by Amaze for B&H City Council. The register is voluntary.

- In 09/10 there were 634 children registered with Compass as having mild to severe/profound or multiple learning disabilities.

- 31% of them reportedly have autistic spectrum condition, 20% emotional and behavioural difficulties and 24% mental health problems.

- There are 556 young people registered with Compass with mild to profound learning disabilities that will become adults (reaching 18 years old) within the next six years.

- Of these 182 were recorded as having moderate learning disabilities and 122 as having severe to profound learning disabilities.

8.2.1 Information about the young people aged 16-19 years old registered with Compass

The data analysed below was collected from a self-registration form that people with LD or their carers fill in to join the register.

- 19% were registered as having mild, 31% moderate and 23 % severe or profound or multiple learning disabilities (remaining 26% as having a specific learning difficulty such as dyslexia).

- 73% were boys and 27% girls. 91% were of white and 8% of BME background.

- A high percentage live in the more deprived areas of the city, with the highest number of children with LD known to Compass living in East Brighton, Moulsecoomb and Bevendean. These are all areas of higher than average socio-economic deprivation.

- A high percentage was recorded as having additional need and in need of practical support (fig. 8 and 9).

Fig. 8 Additional needs of young people with LD aged 16-19 years old in Brighton & Hove
The figure shows number of young people with mild to severe and profound learning disabilities, registered with the Compass children register. Note that some might have more than one additional need.

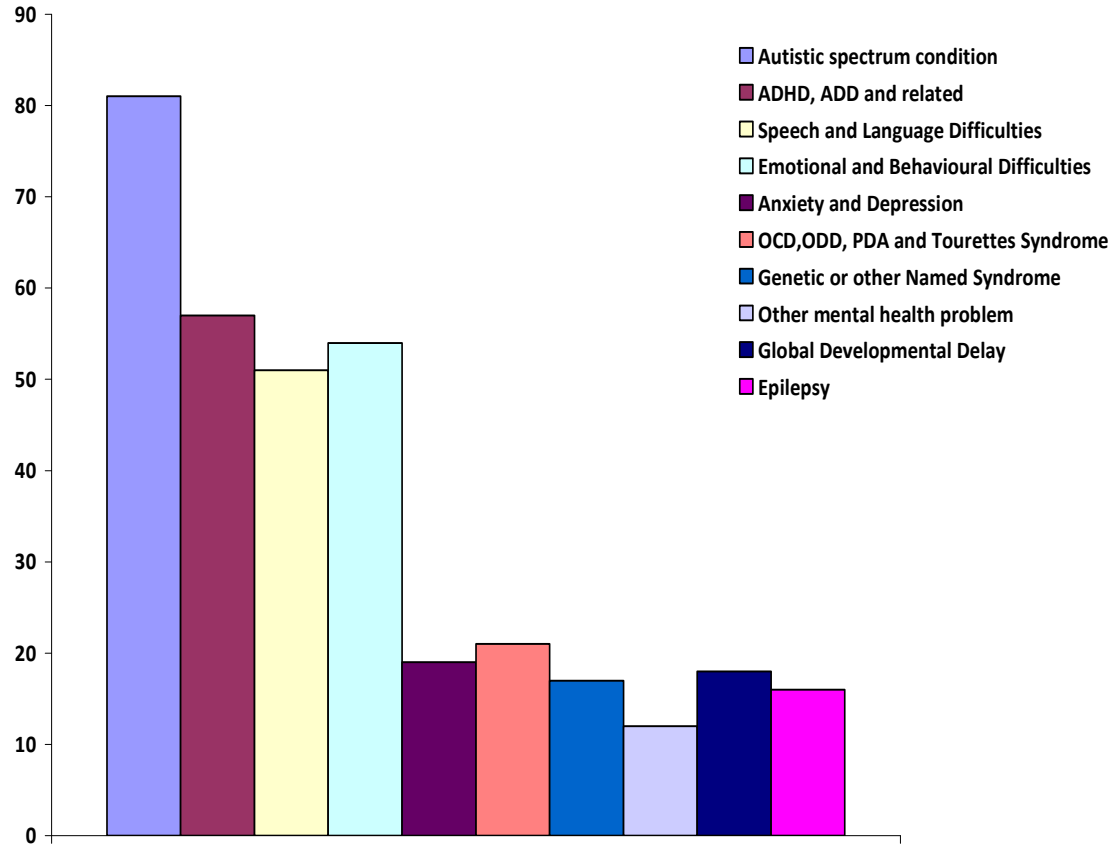
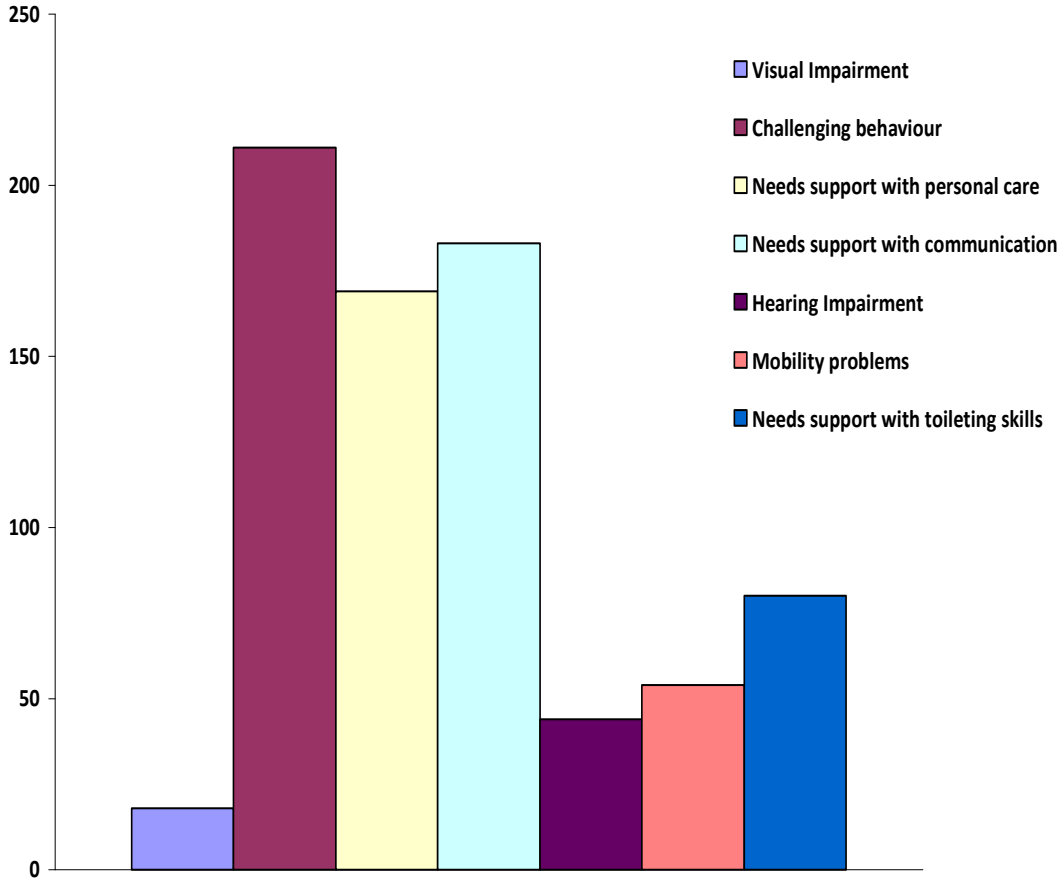


Fig.9 Number of young people aged 16 – 19 years old and additional needs

The figure shows number of young people aged 16 – 19 years old with mild to severe and profound learning disabilities, registered with the Compass children register in Brighton & Hove.



9. Views of public

9.1 Introduction

Views from people with learning disabilities, family and carers on health and social care support and services are collected regularly to help shape services, act on any major issues and help inform service planning.

In 2008, there was a three month consultation with people with LD and their carers to inform the local Learning Disability Strategy. There was also an extensive survey of the health and wellbeing and needs of carers in 2010. Views are also collected from parents, carers and young people for the Compass children register.

Since 2009 a survey of views on health care services has also been carried out to inform the annual South East Coast Big Health Service Check. Views from services users and carers are summarised briefly below.

9.2 Consultation for the Learning Disability Commissioning Strategy (2009-12)

A range of group discussions and written feedback involving people with learning disabilities, carers, professionals and related stakeholders informed the strategy.

The main overall themes that emerged were:

Involvement: People with learning disabilities and families wanted to be involved in all commissioning projects and developments.

Support: Support for people with learning disabilities should be tailored and appropriate for their individual needs. Support should be available for all types and levels of need and advocacy should be available for those that need it.

Information: People wanted accessible information and advice about services and pathways.

Person centred planning: Person Centred Plans should be used as key information to develop commissioning priorities.

Choice: There should be meaningful choice in each area of a person's life including for example support, care, housing, health and learning.

9.3 Survey to inform the South East Coast Big Health Service Check 2010

A survey was distributed to people with learning disabilities, carers and care staff to collect views on health care services locally. The survey was distributed via a range of services including care homes and day centres. Views were also collected at several meetings and a "Big Health Service Check" day. In total, 128 people with LD and 39 carers/support staff gave feedback. The former figure is equivalent to 13% of people on the GP registers. This may mean that the responses are not representative of the population of people with learning

disability. It is possible that the people that responded are the people most likely to be informed about services and most likely to attend services as appropriate.
A summary of the views collected is presented below.

Primary care
A majority were happy with the support received from GPs (86%), dentists (87%) and opticians (90%). 73% reported that they had received a health action plan from their GP.

Hospital care
67% of users and 77% of carers felt that the hospital was good at helping people with a learning disability.

60% of people who had been to the hospital in the last year had also received support from the learning disability liaison team and 93% of those said that the liaison nurses were good at helping people. 86% of carers/support staff who had received support from the learning disability liaison nurses also said that the liaison nurses were good at helping people.

Mental Capacity Act
86% of carers/support staff indicated they had been involved in making decisions about the health care of the person they care for and 30% of carers/support staff indicated that they had been asked to give consent on behalf of the person they care for.

According to the Mental Capacity Act, no-one should be asked to give consent on behalf of another adult.

9.4 Learning Disability Hospital Liaison Team satisfaction survey

The LD Liaison Team sends out satisfaction surveys to staff, carers and patients. However, the response rate has been very low. In the last year only 12 people responded to the survey (4 patients with learning disabilities, 3 family members, 3 carers and 2 members of staff). The surveys that returned indicated that:

- A majority rated the LD Liaison Team services as good to excellent.
- The main issues relating to the hospital stay reported by users and carers were:
  - not being able to go to the toilet when needed
  - uncertainties around length of stay, when they will be discharged
  - transport home when discharged
- A member of staff reported that when a support worker accompanied a person with LD in hospital, the hospital staff stepped back and left a lot of care to the carer.
- Another member of staff that responded thought the LD Liaison Team nurse was a great asset in co-ordination of the care and safe discharge of a patient with LD.

9.5 Views of parents of children with a learning disability

The Compass children register collects information from children and their parents as part of the registration process. The views collected suggest a high need for support amongst children with LD in the city. Parents/carers reported that 52% of young people aged 16-19

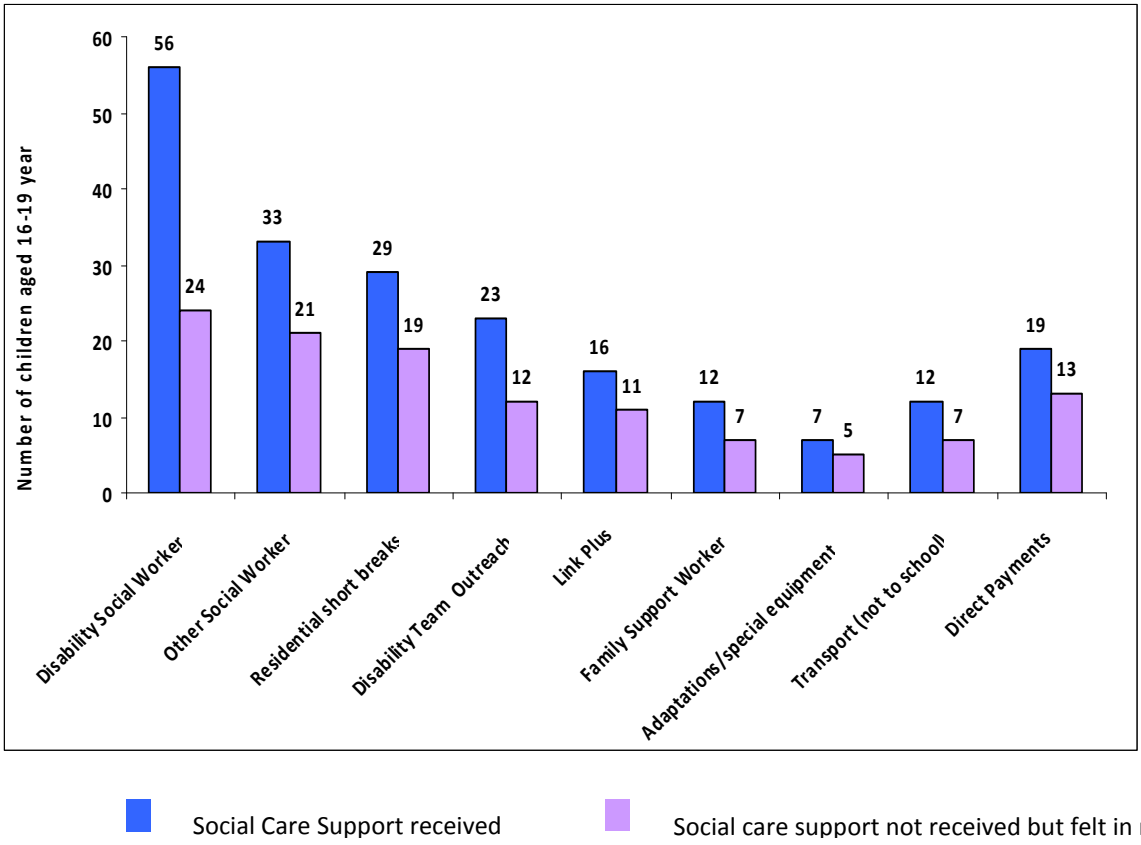
years old were in need of constant supervision. A high number also reported perceived unmet needs in form of social care support workers, residential breaks, transport and personalised budgets. The following data relate to young people aged 16-19 years old.

GP and dentist services

- Of 276 carers that felt it was applicable, 71% felt that their GP had good grasp of the child's need, and 23% that the GP did not.

- 88% of respondents were registered with a dentist and 89% was satisfied with the treatment by their dentist.

Fig.10 Perceived unmet social care support need (age 16 – 19 years old)
The graph shows number of young people and the social care support they receive and number of children not receiving social care support they feel in need of (self-reported data from The Compass children register 2010).



9.6 Views of carers of people with learning disabilities

The Carers Centre for Brighton & Hove was commissioned by Brighton & Hove City Council to carry out a survey to help improve services for carers of adults in Brighton & Hove. The survey was sent to an estimated 1,700 individual carers and an additional four focus groups were held with carers in 2009. The following data is summarised from the 79 people who responded to the survey and cared for someone with a learning disability, some of whom cared for more than one person with LD. Of the 88 people with learning disabilities these

people cared for, 73 lived at home with their carer and a majority of people cared for were over 18 years old. The findings of this survey are reported below.

Practical support needed
Services carers would like to receive to help them in their caring role (ordered by number of responses, from highest to lowest):

- short breaks were person cared for were taken out
- short breaks in the home
- supported employment
- day centre or day activities
- home care/home help

Carer's assessments
40 respondents (51%) reported that they had had a carer's assessment, but only 13 reported that the assessment had made a change to their caring role.

GP services
56% did not know that they could register as a carer with their GP and 51% reported that they had not received any caring information or practical help from their GP.

Health and wellbeing of carers
30% felt that the caring role had a major impact on their lifestyle and had led to high levels of stress and some health issues and only 16% felt that their caring role only had a small impact on their life. A high proportion of people reported that they were losing sleep over worry (55%), were unable to concentrate (35%), constantly under strain (45%), unable to enjoy every day activities (42%), felt unhappy or depressed (41%), not feeling happy (25%) due to their caring role.

Top five things that reportedly could improve wellbeing for carers:

- Information on managing stress
- Practical advice and help on managing stress
- Receive practical support from others in my caring role
- Have time to socialise
- Have time to myself

10. Views of professionals

In order to inform this JSNA a brief survey was conducted of health and social care professionals who work directly with people with learning disabilities. 63 questionnaires were distributed by e-mail to health and social care staff and 26 responses were received. Questions were arranged around three broad areas: A Place to Live, Good Health and Fulfilling & Active Lives.

10.1 A Place to Live

Respondents reported that there is a lack of choice for people with learning disabilities who need a specialist accommodation service. Whilst it has been recognised that there is more 'independent living' available, it is short of what is needed. There is a need for more Supported Living that can provide independent living with the security of on-site (often 24 hour) support, as an alternative to residential care. There is a need for both self-contained and shared accommodation. This would be helped by more support being available to help people move to more independent living options, including having trials or training facilities.

In addition, specialist accommodation is lacking for people with a range of particular needs: challenging behaviour, autism, sensory loss, physical disabilities, epilepsy, substance misuse, ex-offenders, mental health and dementia. Where people's needs are more complex there were fewer choices available. Staff felt that this can lead to people being placed in less appropriate placements or outside of Brighton & Hove. Particular unmet needs were identified, for example:

"A service for young adults (generally females) in the city who are prone to getting into relationships in which they find it hard to keep themselves safe and assert themselves. Some type of psychological work to help them develop their self-confidence and self-protections skills is needed as they are prone to being taken advantage of" - Social Worker

In addition to a basic lack of availability and choice, there are other barriers that prevent people achieving good outcomes in where they live. The most common barrier reported was a lack of pro-active support for people who are moving home. It was noted several times that when people did move, it was usually due to a crisis, which led to placements being made in whatever vacancies existed at that time. For example:

"In theory there should be a choice where people move to, but in practice I have found this to be limited. This seems to be due to the fact that people are only allocated a worker once they need to move, so it needs to be done on a fairly quick basis. This means that clients are placed dependant on what is available at the time and what vacancies need to be filled, rather than being able to wait for a good quality service or what best suits their needs & preferences." – Care Manager

The quality of residential care was described as variable and inequitable. For people in poorer quality care homes there are no opportunities to move on to better accommodation if that is more expensive to fund. There were too many care homes that were not offering the support for people to be independent and choice and control over the way their services were delivered.

It was also felt that the options available were dictated too much by the providers of those services. This has led to a 'service led' market rather than a 'needs led' market, with availability often dominated by poorer providers. It was also felt that some people may not be encouraged by their families to leave home and be independent, due to a lack of options or aspiration, or because the persons benefits were too important a part of the household income.

In terms of access to general social housing options, it was felt that even though improved there remained a number of barriers, such as: prioritisation of different types of needs in allocation to social housing and housing available often located in inappropriate areas for people with LD particularly vulnerable to isolation, exploitation and abuse. Furthermore, the process of gaining housing often based on quick decisions, which was sometimes difficult for people with learning disabilities to make, practically, intellectually and emotionally.

10.2 Good Health

In general, the support for people with health needs was perceived to be good, with significant progress in recent years. The availability of a health facilitator and hospital liaison nurses were repeatedly mentioned as having made a real difference in improving access to care. Some felt that further work was required to improve understanding of people with learning disabilities in mainstream health services – hospitals, community services and GP practices. There were also several comments suggesting more was needed to support healthy lifestyles – such as healthy eating, opportunities to be active and routine health screening.

In mental health, whilst it was noted that there has been some progress (including the recruitment of a nurse LD lead in the mental health teams), there was still a strong theme that people with learning disabilities have poorer access and outcomes when they have mental health needs. There was a lack of clarity of process and practice when someone had a mental health need as well as a learning disability. Examples included: when accessing community services, on discharge from mental health units, and a general lack of services for people with dementia. Individual respondents suggested that there was a need for more preventative, responsive psychological interventions and support to prevent people becoming isolated and depressed.

There was also a significant gap cited in supporting people to have intimate relationships, promote sexual health, family planning and parenting skills. Everyone who commented on these areas felt they were all under supported and there was a need for services to offer more to help people form and maintain personal relationships. There were better links developed with children's services to ensure families that included parents with learning disabilities got the right support, but there was a need to improve on existing practice.

10.3 Fulfilling and Active Lives

A few people mentioned learning opportunities and commented that while learning opportunities have improved, there was still a need for greater range of learning activities. This should also be supported by more consistent approaches to supporting learning and communication in other services, using approaches such as active support and intensive interaction. The opportunity to work was repeatedly mentioned as an unmet need. There

was a very consistent picture of what the issues were here, which included a lack of aspiration (starting at school) and a lack of options in paid and voluntary work. Repeatedly cited issues were:

- A lack of capacity in the Voluntary Work Project (currently run by one part-time worker and with a large and growing waiting list, with waiting times up to and over a year)

- A lack of capacity in the Supported Employment Team

- A gap in supporting people to gain the necessary skills to meet the requirements of the Supported Employment Team

Some respondents also commented that there was a lack of a clear pathway into employment and there was a lack of support once people were in employment. Several people said that the local authority should be doing more as an employer to set an example by employing people with learning disabilities.

"Jobs that seem to not exist which my clients would like to access are mainly in the care industry; many are caring and compassionate of those who are more disabled than them, they have many skills which go unused." - Social Worker

In general, there was a theme that the range and quality of leisure activities was good, but that the same opportunities were not available to all and some services were not flexible enough. Modernisation of day services and the increased use of self-directed support to access activities were seen as positive, as long as an option of activities was made available. Several people said that, whilst many people with learning disabilities had active lives, this still fell considerably short of genuine social integration. In addition to the above areas, there were a number of comments that related to the way that services were commissioned. Personalisation and the use of Individual Budgets were described positively, but it was noted that they were only mechanisms to improve services if the choices available could meet people's needs effectively. This would still require professional input in order to support families, safeguard people and shape services. This involves a clearer definition of what the role of professionals is (in assessment, commissioning, contracts and provision) and how this informed the overall picture:

"I think there should be something that sets a general vision for the city rather than, at present, a set of important but not cohesive set of goals". -
Service Manager

11. Expert opinion and evidence base

11.1 Introduction

Adults with learning disabilities are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. The previous government's three year strategy, *Valuing People Now*[15], recognises that more work is needed to implement the recommendations from the White Paper *Valuing People*[50] from 2001, especially around personalisation, meaningful daytime activities including employment, fair access to good quality health care services as well as giving people with LD more choice about where they live.

Valuing People Now recommends that people with learning disabilities should participate in society as fully as possible with a voice regarding decisions about their care. It also contains key targets for those in receipt of services such as:

- 5% increase in proportion with tenancies or home ownership
- 40% in paid employment by 2025

Other key targets from the strategy are to set up person-centred plans and personal budgets to enable choice and control and health and wellbeing as well as informing effective commissioning.

The national strategy highlights four groups of people with learning disabilities that are least often heard and most often excluded, and local work needs to ensure that these groups are included in planning and support. These include people with more complex needs, people from BME and newly arrived communities, people with autistic spectrum conditions and offenders in custody and in the community.

Valuing People Now built on some of the recent national reports and guidance about health and social care for people with LD. Reports and findings included;

- *Services for people with learning disability and challenging behaviour or mental health needs* (also known as the Mansell Report 2007), Department of Health good practice guidance with actions to effectively meet the needs of people with challenging behaviour. The guidance emphasised the continuing neglect of the needs of people with LD whose behaviour is seen as 'challenging', many of whom remains placed 'out of area', often in costly services that are of poor quality, for long periods of time.

- *Healthcare for all* (2008), an independent inquiry into access to healthcare support and appropriate and reasonable adjustments to general health services. The report states that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities with a focus on weight management, dysphagia, epilepsy and resolution of pain and distress[4y].

- The *Six Lives* report (2009)[51], by the health service and social care ombudsmen, responded to complaints brought by the charity Mencap on behalf of the families of six people with learning disabilities who died whilst in NHS or local authority care in 2003/05. The report shows that on many occasions basic policy and guidance were not observed, the needs of people with learning disabilities were not accommodated and services were uncoordinated. It also highlighted insufficient training of staff, misconceptions and risk of institutional discrimination of adults with LD. The report demonstrated a need for training and a stronger leadership throughout the health and care professions.

11.2 Studies including cost-effectiveness analysis

There is a limited amount of research on the cost-effectiveness of different models of care for people with learning disabilities. The lack of cost effectiveness analysis is a barrier to making effective and appropriate policy and practice decisions[52]. A short evidence review of learning disability support studies, pilots and best practice that included cost evaluations was undertaken. With limited evidence found, all reports considered of relevance to the local JSNA are summarised below.

Costs related to services for people with learning disabilities are considerable. A recent UK study found that the average annual cost of social care and housing per person with LD over 60 years old, was £41,080. 74% of this cost was accommodation[53]. A study from the US found that the cost increased in those with more severe disabilities, hearing impairment, physical disorder and mental illness. Mental illness was associated with an additional cost of £10,504 per year[53].

- **The high cost of accommodation shows the importance of reviews of local housing options and reviews of people able to move from residential care locally and out of area to good, quality, more cost-effective options with better outcomes, such as supported living.**

- **It also supports forward planning to reduce risk of expensive, emergency placements of people with LD in expensive accommodations.**

- **Furthermore, the need for support, such as mental health and employment support, to help people live more independently.**

- **And the importance of evaluating housing and support in terms of outcomes and cost effectiveness.**

11.2.1 Housing

Reports have shown lower spend in authorities with lower use of residential care for people with learning disabilities[54]. Department of Health has issued key recommendations to develop and expand capacity of local services to avoid out of area placements and establish local partnerships to improve best practice[55].

A study from US that compared costs and quality of life for adults with low support needs did not find any major differences in lifestyle outcomes between adults with LD living in fully

staffed or semi-supported living accommodations. However, they found that people living in semi-supported living models had better choice and community activities outcomes and the cost was lower. But people in fully staffed accommodations, for example residential care homes, had better outcomes for money management and some health indicators.

- **This study suggested that semi-supported living was more cost-effective than residential care, but attention is needed to ensure people in semi-supported living were provided with enough health and financial advice support[56].**

11.2.2 Challenging behaviour and different models of accommodation

In regards to cost-effectiveness and quality of life for people with challenging behaviour, one study from the US found that individual residential support for people with LD and challenging behaviour can be more cost-effective than group residential care support[57].

Another study looked at the stress and morale of staff in care homes for people with LD, where the majority of residents had challenging behaviour. The study found that group settings were associated with higher levels of staff stress. 25% of staff in group settings experienced emotional distress and over 33% were likely to actively seek new employment. The high levels of staff stress and turnover were not related to the clients' behaviour, but a lack of staff training and support[58]. This study highlights that good staff training and support can help reduce staff turnover and stress, which is also likely to improve quality and consistency of care and reduce the cost of continuously having to recruit and train new staff.

Another study found that neighbours of smaller care homes were more likely to view community care for people with learning disability as a good policy (76%) compared to neighbours of larger group settings (53%) and believe there were benefits to the neighbourhood from having the group home in the areas (46 vs. 29%)[59].

11.2.3 Person Centred Planning

There is limited evidence on the impact or cost of person centred planning. A UK study found small positive changes in the areas of social networks, community based activities and choice, after introduction of person centred planning. The study included 65 people with learning disabilities from different areas of the UK. The direct costs of introducing the planning were £674 per participant[60].

11.2.4 Employment support

Having a job and settled accommodation are important factors in tackling poverty and social exclusion. A study examining the Kent County Council Supported Employment Service Studies highlighted examples of people with LD with positive experiences of work. A quote from a family carer of a person with complex needs stated that the person with LD benefited considerably; after finishing specialist college and moving into residential care, the person has found employment and moved into his own bungalow. His challenging behaviour and health and wellbeing have subsequently improved[15].

- **This study suggests that employment support can improve wellbeing, reduce challenging behaviour and need for residential care, with financial savings as a result.**

- **Early indications suggest that for every person supported into work there is an average annual saving of £1,290 to the council and of more than £3,500 to the taxpayer[61].**

11.2.5 Benefits

Getting accurate and accessible benefits advice is important to people with LD and their families. Devon has a Making It Pay project, where people with LD who want to work get a "better off" calculation which looks at all their benefits and ensures that they get what they are entitled to. They then get a breakdown of how much they would get if they were in work, which has so far always been more[12].

11.2.6 Health care

Health check interventions were found to be more cost-effective and cheaper compared to general care in a recent study[62]. Overall there were a limited number of studies on the cost effectiveness of health care.

Psychological interventions

There were limited studies focusing on cost-effectiveness. One study, where offenders with LD were taught a cognitive-behavioural mindfulness intervention showed decreased verbal and physical aggression. Moreover, no medication or physical restraint was needed for at least 12 months post training for study participants. This resulted in a 96% cost reduction compared to 12 month before and after the intervention[63].

Psychological support has also been recommended in other studies including people with LD and challenging behaviour. One study found that pharmacotherapy alone was not good value for money[64]. This was corroborated in another study that found that using a specialist behaviour therapy, in addition to standard treatment was more cost effective and provided better outcomes compared to standard treatment alone.

11.2.7 Summary

This review shows that there are a limited number of studies containing cost effectiveness to help inform commissioning and planning and locally. However, there are studies which support the recommendations of *Valuing People Now* including;

- Change from residential care to semi-supported living combined with effective health care and financial support is cost-effective with positive outcomes for people with LD.
- Psychological therapies are cost-effective interventions that can improve health and wellbeing.
- Annual health checks are cost-effective.
- Supporting people with LD into employment are cost-effective and beneficial to society and individuals.

12. Recommendations for needs assessment work

- Need to further quantify projected for supported living and residential care opportunities in the next 5 – 10 years
- Other priorities for needs assessment include:
    - people with LD in offending services, including police custody
    - families with parents with LD
    - people with LD and substance misuse and
    - BME communities

- Needs assessment to inform effective dissemination and sharing of accessible information

- Future needs assessment of osteoporosis and falls prevention should consider the needs of people with learning disabilities.

13. Key contacts

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14. Key Supporting Documents

Local documents

Brighton & Hove Learning Disability partnership board website
The Big Bridge
The Brighton & Hove Learning Disability Commissioning Strategy 09/12

National documents

Valuing People
Valuing People Now
Six lives
Healthcare for all
Health Inequalities and People with Learning Disabilities in the UK: 2010
Health Inequalities and People with Learning Disabilities in the UK: 2010. Implications and actions for commissioners
Planning and Commissioning Housing for People with Learning Disabilities: A toolkit for Local Authorities
South East Public Health Observatory Learning Disabilities and Health
Learning Disability Observatory - Improving Health and Lives
Commissioning specialist adult learning disability health services: a good practice guidance
Transforming the quality of people's life: how it can be done
Planning for Tomorrow
Estimating future need for Adult Social Care Services for Adults with Learning Disabilities in England
Estimating future Numbers of Adults with Profound Multiple Learning Disabilities in England
Down's Syndrome and Dementia – Briefing for Commissioners

Thanks to everyone who helped by submitting invaluable data, information and comments to help inform the JSNA.

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