Learning Disabilities

Summary

- The World Health Organization (WHO) has defined learning disabilities as a state of arrested or incomplete development of mind. Somebody with a general learning disability is said to have a significant impairment of intellectual, adaptive and social functioning.
- There are nearly 5000 people in Greenwich with mild to moderate learning disability and likely to be around 1000 who have a severe or profound learning disability.
- This number is predicted to increase in those aged 34-64, by 2020. However there is predicted to be a slight reduction in learning disabilities between the ages of 18-24 as a result of prevention initiatives over the past two decades.
- There are about 4,000 people with mild/moderate learning disability not recorded on learning disability registers in Greenwich. However Greenwich has higher levels of recognition than similarly deprived boroughs.
- There are about 400 people with severe or profound learning disabilities not recorded on Primary Care service registers.
- It appears as if some of those missing from official recognition are in the black and minority ethnic (BME) community and those over the age of 60.
- Not being on a register reduces the likelihood of appropriate medical care and social support. This means that services such as acute hospitals cannot adapt their care appropriately; this in turn may contribute to the high mortality and morbidity among those with learning disabilities.
- Local mortality data is limited, as learning disabilities are not routinely recorded as an underlying or contributing cause on death certificates. It is estimated that half (50%) of all people who are learning disabled die 15 years younger than people with no learning disabilities.[1] (IHAL, 2010)
- More than half of people with learning disabilities recorded on their death certificates in Greenwich died from respiratory causes, a significant amount due to dysphagia and aspiration, consistent with the national picture.
- Cardio-vascular disease (20%); aspiration (14%) and epilepsy (13%) were also common causes of potentially preventable deaths in those with learning disability in Greenwich
- 70% of people with learning disabilities saw their GP less frequently than the general population. When they did see their GP, many people with learning disabilities found they rarely had enough time to communicate their needs to the doctor (IHAL, 2010)
- Of those known to primary care there are high levels of lifestyle risk factors such as obesity (36%), smoking (19%) and high alcohol intake (8%). There was also 10% who were significantly underweight.

[1] How People With Disabilities Die, IHAL, 2010

Source: Greenwich JSNA 2013/14 “Closing the Gap.” Public Health & Well-Being, Royal Borough of Greenwich.

- Of those known to primary care in Greenwich there are high levels of co-morbidity especially epilepsy (30x times more likely); diabetes (50% higher); coronary heart disease (6 times more likely); asthma (3% more likely)
- Despite the high prevalence of risk factors and chronic diseases, a survey carried out in GP practices in Greenwich showed less than half of those with learning disabilities had an annual health check from 2010-2011.
- Nearly three quarters (73%) had no record of a carer and no carer was recorded as having had a health check themselves.
- Over 40% of people with learning disability on the Greenwich register were not in stable accommodation and there is no residential accommodation in the south of the borough for people with learning disability.
- Greenwich has low levels of employment of people with learning disability compared to deprivation comparison boroughs, although the local employment service has supported more than 20 people to successfully find and maintain work, and the target is to double that figure by March 2014.
- The 'personalisation agenda' appears to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families, and continued progress in widening access to these kinds of services will enable more people to benefit
- Transition support for young people is improving but there is still a gap in transition support.
- The lack of recognition of older adults with learning disability means that a very vulnerable group of people are either managing alone or being supported by older carers. The finding that few carers have health or social care assessments themselves in this group suggests that they may be without adequate support themselves.

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

What do we know about Learning Disability?

Introduction

NHS Greenwich and the Royal Borough of Greenwich have adopted the definition of learning disability offered by *Valuing People*, which is:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence),
- with a reduced ability to cope independently (impaired social functioning),
- which started before adulthood, with a lasting effect on development.

Learning disability is categorised according to severity. IQ score is incorporated into the assessment of a person's degree of disability but it is insufficient to rely on this factor alone to discriminate between people with and without learning disability and those with mild or severe learning disability. The degree of functional impairment and ability to integrate socially is also considered, and therefore will include a person's ability to communicate and interact. All these things may change as a person develops, making regular re-evaluation of each person's disability and support crucial. This functional ability, in combination with the following IQ scores, are used to define a learning disability:

Mild: 50-70 Moderate: 35-50 Severe: 20-35 Profound: <20

The World Health Organization (WHO) has defined learning disabilities as a state of arrested or incomplete development of mind. Somebody with a general learning disability is said to have a significant impairment of intellectual, adaptive and social functioning. A learning disability is not acquired in adulthood and is evident from childhood. People with learning disabilities can suffer with a wide range of physical, psychological and behavioral problems. Many of the causes of learning disability are unknown; some of the known causes are listed below (please see Appendix A for explanation of these terms) and not all people with these disorders have a learning disability. In addition in most people with a learning disability the causes are multifactorial. Below lists the main causes of some of the more common reasons for learning disability:

Pre-determined and antenatal causes

- Genetic : (eg Downs Syndrome, Fragile X Syndrome, Angelman Syndrome)
- Metabolic: (eg phenylketonuria.)
- Cerebral degeneration
- Cerebral malformations
- Structural disorders
- Intrauterine problems:(nutritional deficiency; toxicity such as high levels of alcohol; and congenital infections)
- Spina bifida and hydrocephalus (38% have LD) [main causes are folic acid deficiency but also related to some drugs; diabetes and obesity]

Perinatal:

- Antenatal and intra-partum factors leading to hypoxia.
- Prematurity

Neonatal:

- Intra-ventricular haemorrhage
- Infections such as meningitis

Postnatal:

- Accidental or non- accidental injury
- Infection
- Anoxia
- Metabolic
- Endocrine
- Poisoning
- Malnutrition

Unclear/mixed origins

- Autism
- Cerebral palsy (44% have LD)

National Strategies

Healthcare for people with a learning disability is a particular focus for improvement nationally. In the UK, people with a learning disability suffer greater health inequalities than the general population. They have poorer health outcomes and are less likely to receive appropriate social care provision, and experience younger mortality as a result.

In 2007, *Death by Indifference*[2], a report by Mencap, called attention to gaps in NHS-provided care for people with a learning disability. *Healthcare for all*[3], an independent inquiry into access to healthcare for people with a learning disability followed in 2008. Again it was highlighted that neither primary nor secondary care health services were effectively meeting the needs of people with a learning disability. The report re-emphasised the frequency of poor standards of care for people with a learning disability. A significant level of avoidable suffering and deaths amongst this population was identified.

A set of recommendations were formed with a view to improving healthcare for people with a learning disability by making health services more effective, safe, fair, and personalised. The Department of Health responded in 2009, publishing *Valuing People Now*[4], which

[2] Death by Indifference, Mencap, 2007
[3] Michael J. Healthcare for all, 2008
[4] Valuing People Now, DH, 2009

describes the Government's three-year plan to deliver its ideals and strategies outlined in *Valuing People*[5], the 2001 White Paper. Firstly, the document states the Government's fundamental belief for this community:

> *"All people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens."*

The report also reflects the changing priorities across Government that will have a direct effect on people with a learning disability. The vision for *Valuing People Now* is laid out in the following points:

- all individuals should have personalised, high-quality support and care plans
- to lead fulfilling lives there are many aspects that need to be addressed including health, housing, work and education and relationships.
- there are improvements required in healthcare in communities, in hospitals and in specialist services
- more people will live in their own homes
- more people will have jobs
- more people are able to live in their locality
- the needs of people with the most complex needs are met in creative and personalised ways

The strategy recognises that more needs to be done to ensure the inclusion of those that have previously been excluded such as those with complex needs, people from the BME (Black & Minority ethnic) community, people with autistic spectrum conditions and offenders.

Facts and figures

The Department of Health estimated in 2001 that 20 in 1,000 people had mild to moderate learning disabilities, and 3-4 in 1,000 people had severe or profound learning disabilities. This would equate to an estimated 4,912 people in Greenwich with mild to moderate learning disability and 736-982 with severe or profound learning disability (based on the 2011 census population estimates for Greenwich). Since learning disability is more common in deprived areas it is likely that the upper end of the estimate of people with severe learning disability applies in Greenwich.

There are 826 adults known to specialist learning disability services on the Royal Borough of Greenwich register, of whom 571 are known to Greenwich primary care services, suggesting under-recording of mild and moderate learning disability in both health and social services; possibly some under-recording of severe learning disability and definitely some under-

[5] Valuing People, DH, 2001

recognition and recording of severe learning disability in general practice (571 versus an estimate of nearly 1,000).

It appears as if some of those missing from official recognition are in the black and minority ethnic (BME) community. Pro-rata we would expect 66% of those with learning disability to be "white" but 80% are recorded as having white ethnicity, suggesting under-recording of learning disability in BME groups. The literature suggests that Black and Asian and in particular South Asian population groups are likely to be under recognised and not availing of services.

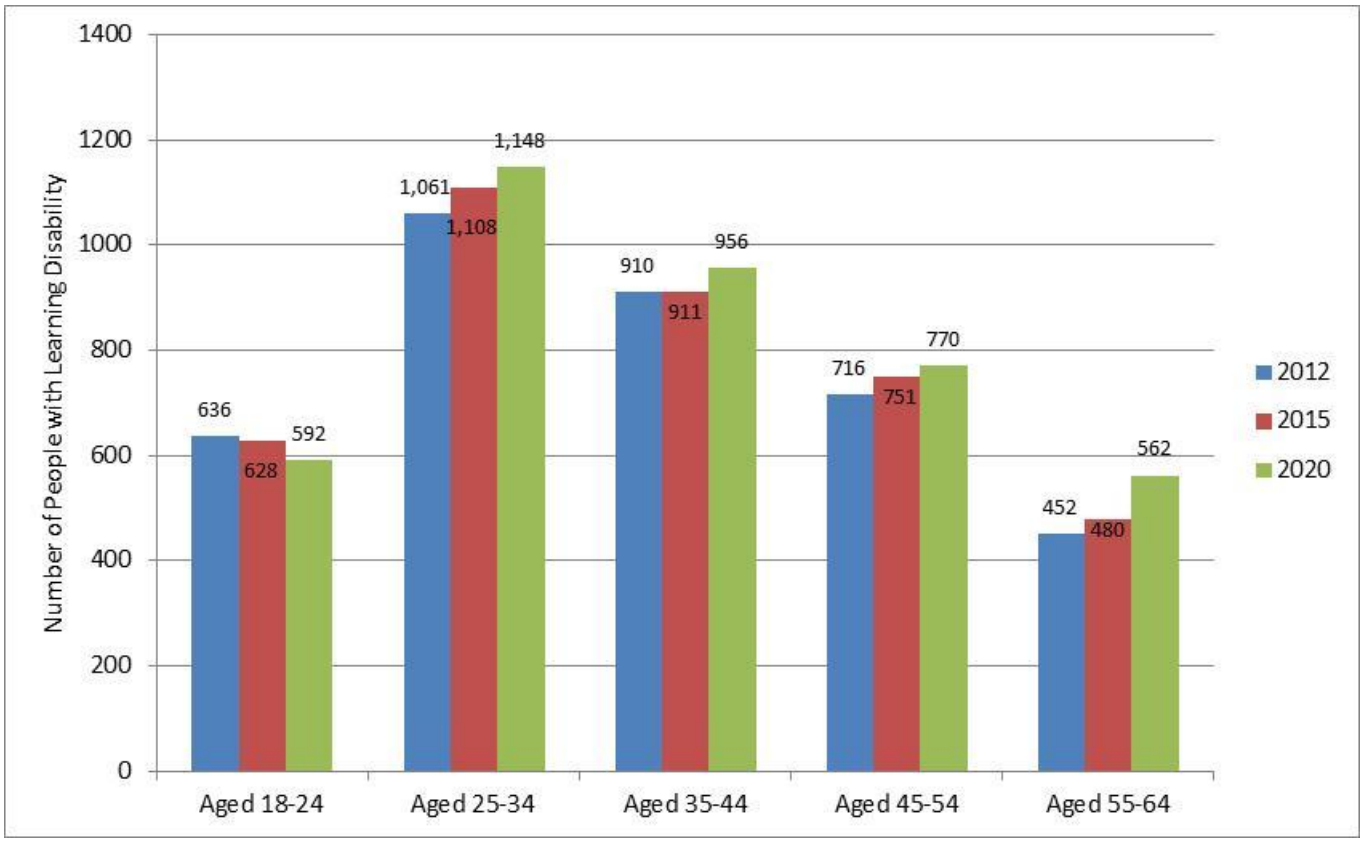
There are 94 people with learning disabilities over the age of 60 known to services and on the Greenwich register. The predicted number of people with learning disabilities in Greenwich over the age of 60 is 601, according to Projecting Adult Needs and Service Information System (PANSI)[6]. People with learning disabilities develop age-related problems at a younger age compared to the general population, with dementia being a major concern. The relatively low number of people known to services within this population is therefore a concern.

PANSI data includes estimates for the prevalence of learning disabilities now and at various points up to 2030. Figure 1 shows the estimated prevalence of learning disabilities amongst adults for Greenwich, up to 2020, broken down by age. It shows that there is estimated to be the highest number of people with learning disability between the ages of 25-34. The numbers are set to rise by 2020 in most age groups, except for those aged 18-24 where there is expected to be a slight decrease, which is likely to be a result of prevention initiatives over the past two decades.

6 http://www.pansi.org.uk/

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 1: Greenwich estimated prevalence of Learning Disabilities amongst adults by age group (18 – 64) up to 2020

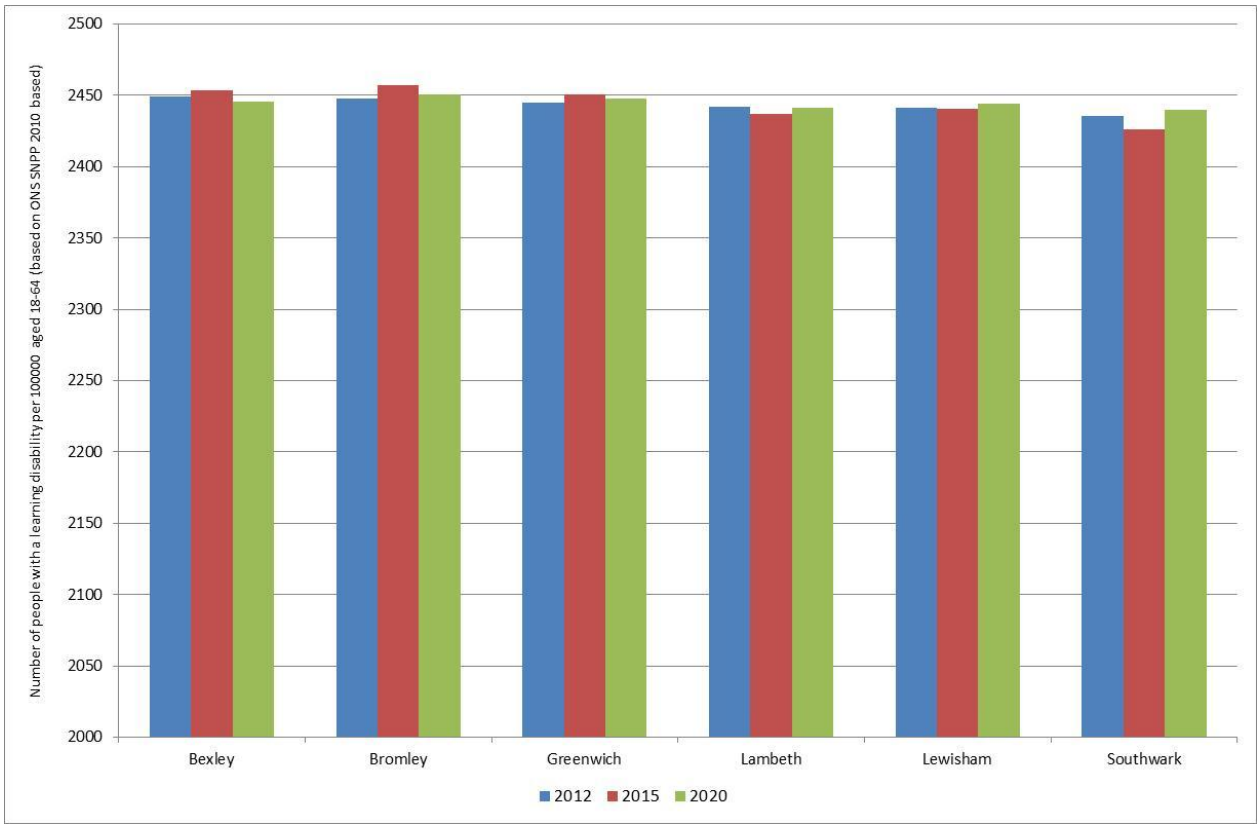


Source: PANSI 2012

The data from Figure 1 suggest that around 90 people per year with a learning disability in Greenwich (636 aged 18-24 years/7) will become adults at aged 18 years; though not all may be eligible for adult social care support as most will not have a severe or profound learning disability. Currently lower numbers enter services and therefore at this early stage those with less severe learning disability are not known to services.

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 2: Population aged 18-64 predicted to have a learning disability (DSR per 100,000 people) in South East London Boroughs 2012-2020



Source: PANSI, 2012

Figure 2 shows only very small differences in predicted DSRs (directly standardised rates) of learning disability within NHS South East London boroughs.

Health inequalities

Health outcomes and health services

Local mortality data are limited, as learning disabilities are frequently not recognised as an underlying cause or risk for many other conditions. It is stated in *How People With Disabilities Die*[7], that the number of people reported as having learning disabilities on their death certificates or the cause of their learning disability recorded is below half the expected figure. Nationally, people with learning disabilities die younger than the general population. Half (50%) of all people who are learning disabled die 15 years younger than people with no learning disabilities.[8]

More than half of people with learning disabilities die from respiratory causes, compared with 26% of the general population. Dysphagia and aspiration pneumonia contribute significantly to this figure. Greenwich mortality data (from 2003-2010) identify that 54% of people with a learning disability died from a respiratory cause, in line with national figures.

[7] How People With Disabilities Die, IHAL, 2010

[8] How People With Disabilities Die, IHAL, 2010

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

In addition to preventable deaths from respiratory causes (principally aspiration pneumonia, aspiration (14%) and epilepsy (13%) were also common causes of preventable deaths.

Prescription for Change[9] identified that 70% of people with learning disabilities saw their GP less frequently than the general population. When they did see their GP, many people with learning disabilities found they rarely had enough time to communicate their needs to the doctor.

Results of Greenwich audit of people with learning disability known to primary care services

In 2011, 571 people were recorded on General Practice databases as having a learning disability across all 46 practices. Of these, only 275 (less than half) had had an Annual Health Check within the last year (2010-2011), and only 48% of those using primary care services had a Personal Health Profile. An audit of 28 Practices in Greenwich took place in May and June 2011. In these 28 Practices, 348 patients with learning disability were identified. The following summary identifies the main health issues in this group and compares where available with national data from the published literature.

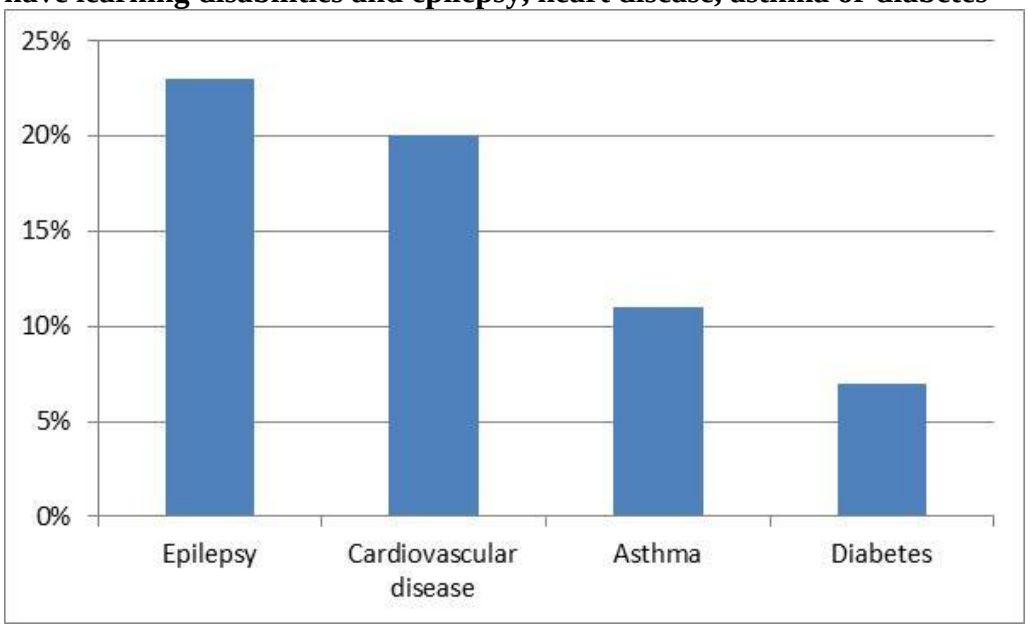
Obesity
Obesity (as defined by Body Mass Index BMI) was not recorded in 28% of cases. Where BMI was recorded obesity (BMI>30) was identified in over one third (36%) of people compared to 16% in the general population in Greenwich. Also of concern was the finding that where BMI was recorded, 10% of those with learning disability were underweight (defined as BMI<20).

Smoking and alcohol
From the audit, 58% were identified as never having smoked, 19% were current smokers, and 4% were ex-smokers. It should be noted that this data includes children, and represents only the people who have accessed services. In addition, 19% of patients had no data recorded for smoking status, meaning that these data are limited in their accuracy. It is thought that smoking amongst people with mild learning disabilities is more common than these data suggest. Data recording for alcohol consumption was again poor. There was no documentation for 37% of patients, 54% were recorded as drinking within recommended limits, and 8% were exceeding weekly allowances.

Long term conditions
Of the 348 patients audited, 241 had a long-term condition (70%).

[9] Prescription for change, Mencap, 2007
Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 3: Percentage of patients from the 2011 Greenwich audit of primary care who have learning disabilities and epilepsy, heart disease, asthma or diabetes



Source: Greenwich Public Health and Well-being Directorate
*Cardiovascular disease does not include structural heart defects

Epilepsy

From the audit 23% (81/348) had a diagnosis of epilepsy. The prevalence of epilepsy in the general population is 0.8% (1/ 131),[10] therefore in Greenwich people with learning disability are nearly 30 times more likely to have epilepsy than the general population. The proportion of people with learning disabilities and epilepsy is estimated to be one third from national surveys. The more severe the learning disability, the more likely it is the person will have epilepsy. The link is unclear but thought to be related to brain trauma at birth or due to an abnormality in the formation of the brain during foetal development. People with learning disabilities are more likely to die from epilepsy than people with epilepsy who do not have a learning disability. In Greenwich 13% of deaths in people with a recorded learning disability were due to epilepsy. Epilepsy is often harder to control in people with learning disabilities, requiring multiple drugs or atypical regimes. People with learning disabilities commonly have longer seizures, which carry higher mortality. For this reason, the Annual Health Check includes a review of seizure frequency and medication

Cardio-vascular disease
People with learning disabilities frequently have structural heart defects, especially those with Down's syndrome and other congenital syndromes. Cardiovascular disease such as ischaemic heart disease and hypertension are also common. Environmental factors such as smoking, diet, and exercise contribute substantially to this figure. 20% of people with learning disabilities will die from cardiovascular disease. In the local audit 71 (20%) had documented cardiovascular disease, but of these only 8 had a record of being reviewed by a doctor for this within the preceding 15 months.

Asthma
38 in the local survey had asthma (11%).

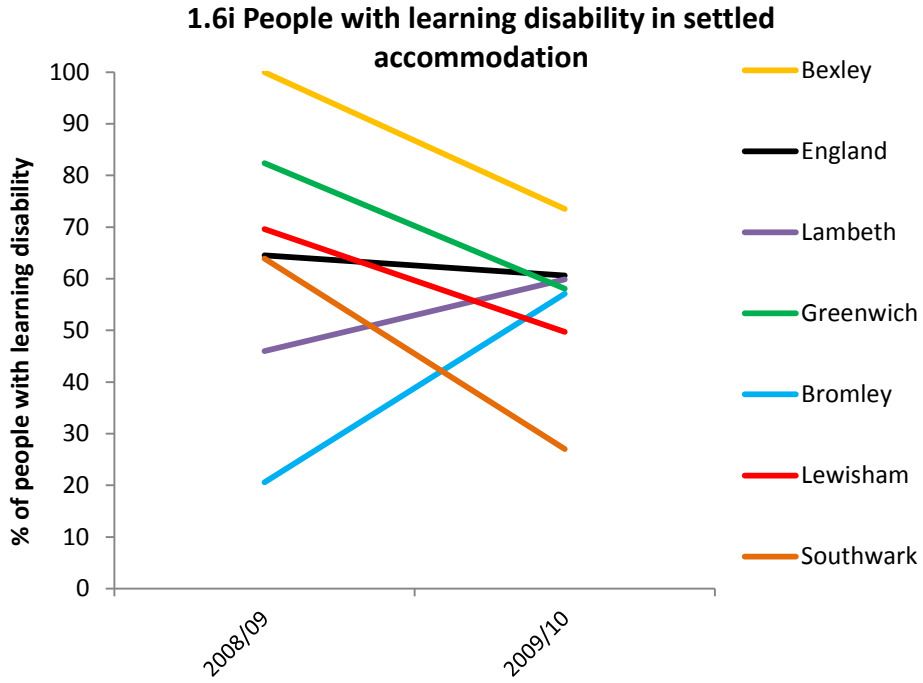
[10] Epilepsy Prevalence, Incidence and Other Statistics, JEC, 2005
Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Diabetes
26 had diabetes, (7%) which may be an underestimate given that over 1/3 were obese. Only 6 of those with recorded diabetes had a record of having attended a diabetic check within the preceding 15 months.

Carer details
Not all people with learning disabilities have a carer as they will be living independently with or without formal support from services, however many will have a carer. Some practices made note of this during the Annual Health Check. However, the review of 348 patients' notes found only 94 (27%) had documentation of a carer's name and address. Carer's ethnicity was not recorded in any of the notes, and no carer was recorded to have had their own health check. Two people with learning disabilities were identified as being carers themselves. Social Care data shows that 117 carers of people with LD received a carer's assessment in 11/12. Many people with mild learning disability may of course be living independently without the need for a carer.

Housing
Improving housing capacity and choice is a key target for the Government. A national survey by Professor Emerson found that 1 in 3 people with learning disabilities wanted to move home. *Valuing People Now* reported that 50-55% of people with learning disabilities live in the family home, 30% live in residential care and 15% rent their own home. In Greenwich, 57.7% in 2009/10 with learning disabilities were reported to be living in 'stable' accommodation when last reviewed by a social worker (see Figure 5). Stable accommodation is defined as being of satisfactory standard, where people can stay indefinitely. The housing arrangement for 7.2% of this population is unknown.

Figure 5: Outlines the people with learning disabilities in settled accommodation in Greenwich and surrounding boroughs. Public Health Outcomes Framework Indicator 1.6i)

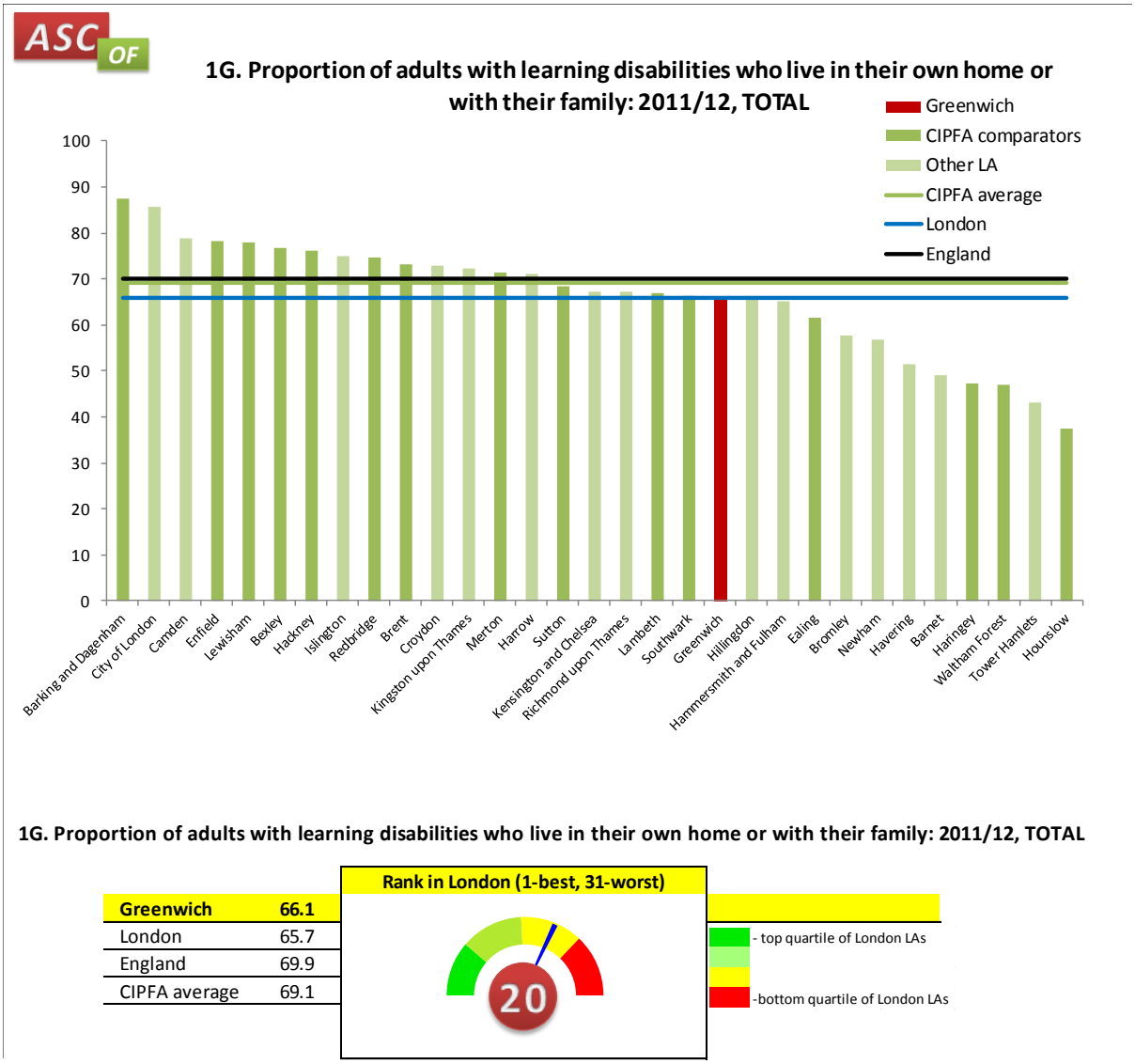


Source: NHS Information Centre (NHS IC) MHMDS. Greenwich Public Health Outcomes Framework

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 6 shows a related measure from the Adult Social Care Outcomes Framework which shows the proportion of people living at home.

Figure 6. Benchmark position of Greenwich within London for the proportion of people with a learning disability living at home, 2011/12



Source: Greenwich ASCOF: https://indicators.ic.nhs.uk.

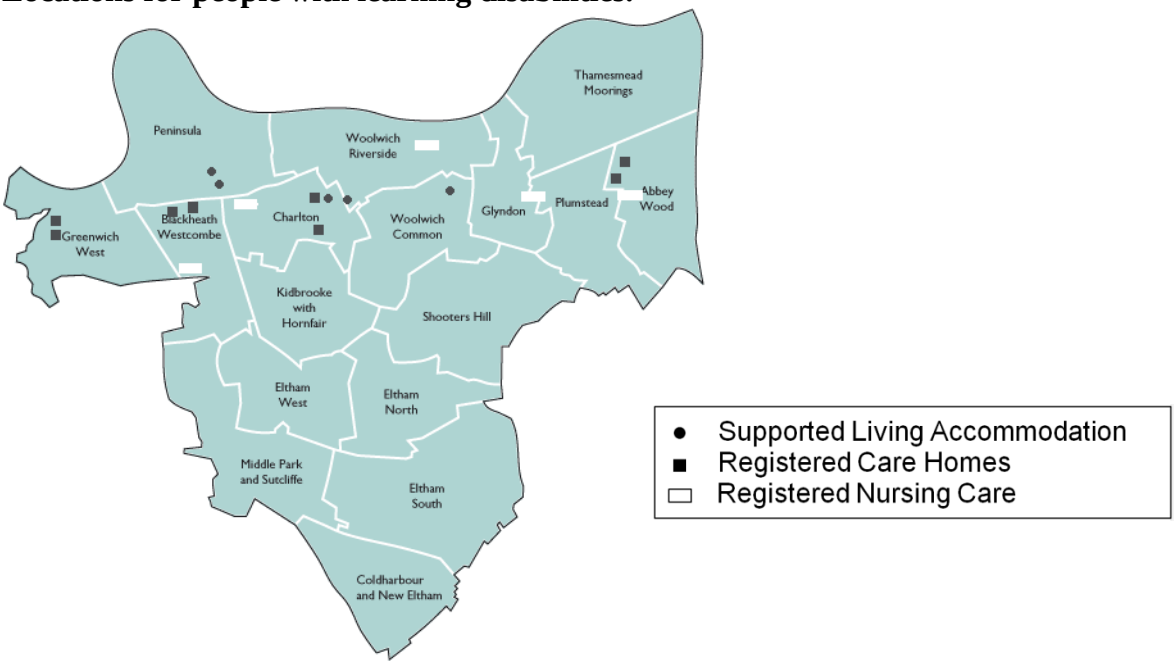
Map 4 shows the areas in Greenwich where supported housing or residential care is offered. There is reasonable provision in the north of the borough, but no placements in the central or southern regions.

Doing the Right Things, a Royal Borough of Greenwich review of community based residential support for people with learning disabilities in Greenwich, has reviewed the housing needs of people with learning disability within the borough and sets out long term plans for future provision. The Royal Borough of Greenwich predicts 25 people per annum

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

will progress from children's services, which will affect housing requirements. Data from PANSI[11] estimates suggest up to 90 people per year will graduate into adult services (see Figure 2 and associated text). The number of people with learning disabilities over the age of 50 known to service providers was 290 in 2007. This is expected to rise to 307 in 2012, and reach 338 by 2017.

Map 4: Registered Care Homes, Registered Nursing Care and Supported living Locations for people with learning disabilities.



Source: Royal Borough of Greenwich Adults and Older People's Services, 2011

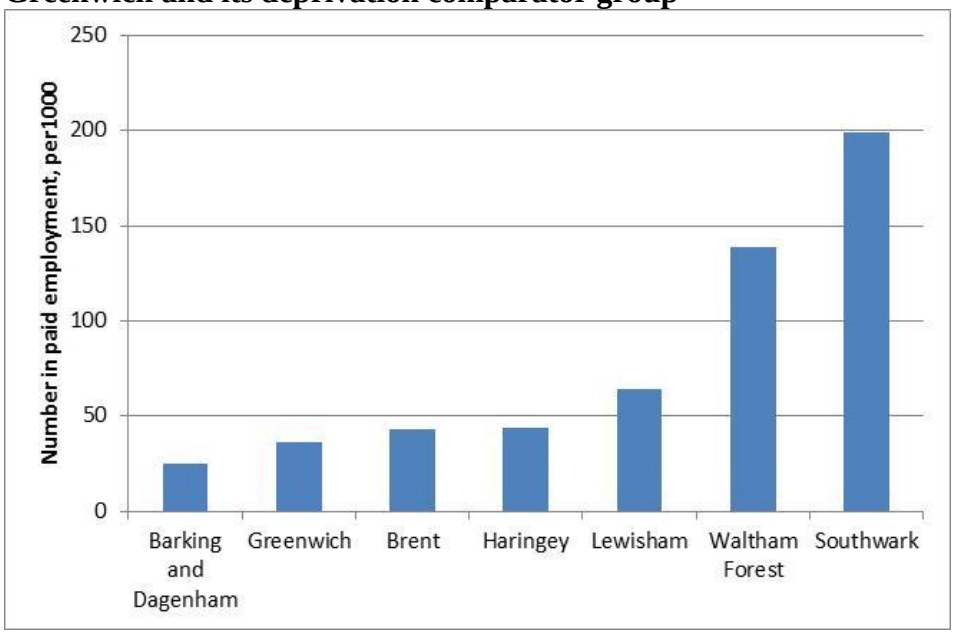
Employment opportunities

The Government identified employment opportunities for people with learning disabilities as a priority in *Valuing Employment Now*[12]. This laid out a cross-Government strategy to increase the rate of employment in people with learning disabilities, aiming to bring the figure in line with that of people with disabilities generally (48%).

In 2009 only 10% of people with learning disabilities known to adult services were working, whilst 65% of people with learning disabilities wanted to be in paid employment. In Greenwich there were 36 people with learning disabilities per thousand in paid employment, who were known to adult services. There are no figures for those who are not working, and there may be a significant number who are not known to adult services who are in fact employed. Figure 7 shows Greenwich against its IMD comparator group and Figure 8 compared to London Boroughs; both give concern as they indicate relatively low levels of employment amongst this group in Greenwich.

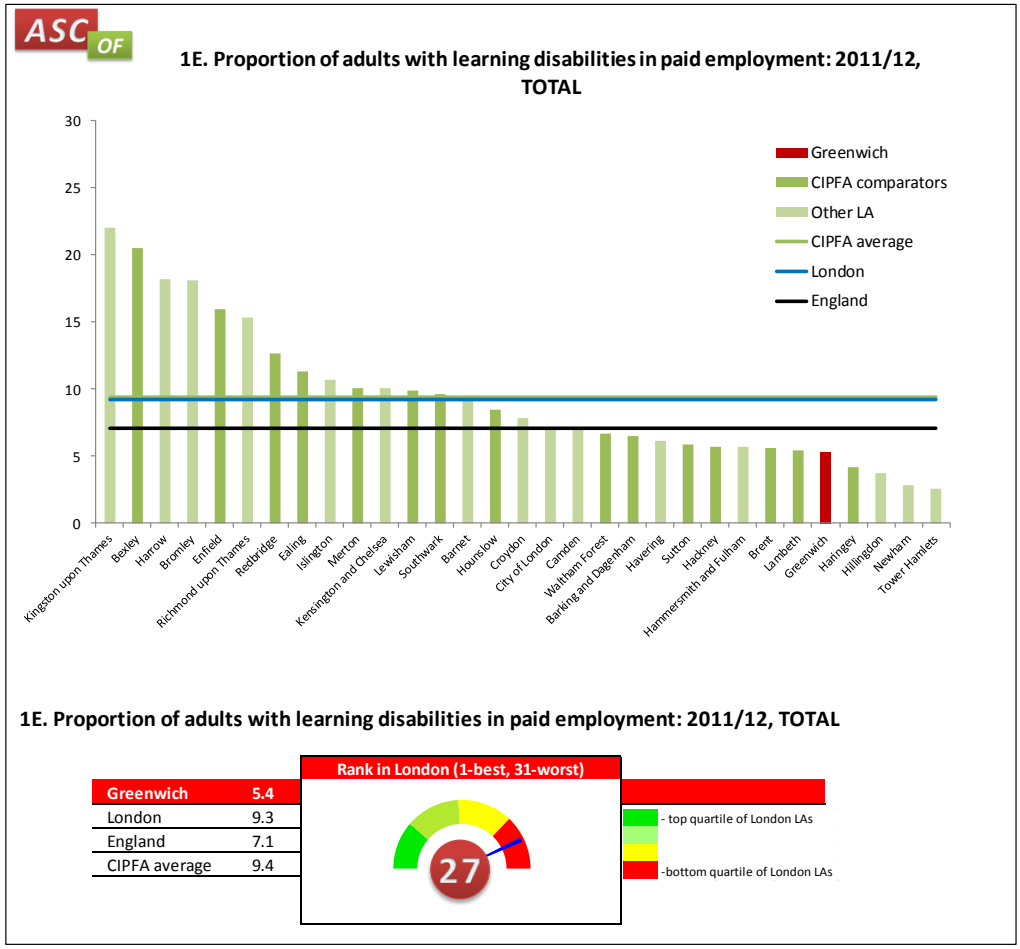
[11] PANSI Projecting Adult Needs and Service Information System
[12] Valuing Employment Now, DH, 2009
Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 7: Number of people with learning disabilities in paid employment per 1000, for Greenwich and its deprivation comparator group



Source: Learning Disability Observatory, 2009/10. Note: This chart uses Greenwich's previous deprivation comparator group which is based on 2007 deprivation ranking.

Figure 8. People with learning disability in employment in London



Source: Greenwich ASCOF: https://indicators.ic.nhs.uk.

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

What works?

Prevention

There has been much improvement with the advancements in modern medicine and with screening programmes in the preventable causes for learning disabilities.

Prevention strategies target the following areas;

- Pre-conception

Advice on smoking cessation, alcohol consumption and the use of folic acid (to prevent spina bifida) prior to conception are important in preventing complications. The importance of maintaining a healthy lifestyle and education about gestational diabetes is extremely important at this point and throughout the pregnancy.

- Antenatal

Blood tests can be done within the first few weeks to detect sickle cell disease and thalassemia. Early detection of these blood disorders can mean more effective early management preventing complications. At 12 weeks mothers have blood tests to detect their haemoglobin, blood group and Rhesus factor. They are also tested for syphilis, hepatitis B, rubella susceptibility and HIV status. Again early detection can ensure appropriate management.

Ultra sound scans are offered around 12 weeks and again a more detailed anomaly scan at 18-21 weeks can pick up abnormalities in the foetus. These can give a variety of detailed information and help guide further management. Downs syndrome screening is offered to all pregnant women.

- Perinatal

Good antenatal, obstetric and paediatric care is important in minimising any complications associated with deliveries.

- Neonatal

Neonatal examinations are carried out in all new-borns and again at 6-12 weeks to detect any abnormalities. All babies are offered screening for phenylketonuria, congenital hypothyroidism, cystic fibrosis, sickle cell diseases and medium-chain acyl-CoA dehydrogenase deficiency (MCADD), as early detection of these abnormalities can mean effective management. Vaccination programmes are implemented to prevent serious infections and their complications.

Source: Greenwich JSNA 2013/14 “Closing the Gap.” Public Health & Well-Being, Royal Borough of Greenwich.

Treatment

Secondary care

There are concerns on a national scale over the widespread lack of understanding amongst health professionals of how to provide safe and comprehensive care for people with learning disabilities in hospital. Patient safety incidents in hospital are more common in patients with learning disabilities, and the types of incidents tend to be different. In all patients in England, accidents were the most common cause of incidents. For people with learning disabilities, behavioural issues and self-harm were the next most common causes of harm, compared with treatment and procedural incidents and medication errors for the general population.

Of the General Practices audited in Greenwich, none had a system to automatically include a flag about learning disabilities when a referral was being written. The Personal Health Profile is supposed to be used as a 'hospital passport' on admission, providing invaluable information to the healthcare professionals in secondary care, however no data is kept on how well this system is operating.

Consent is consistently a problem in healthcare and further training for those who take consent is required. Letters and appointments sent to people with learning disabilities are not in easy read format and Greenwich patients reported finding written information sent to them difficult to understand. This is likely to be linked to gaps in information about learning disabilities on referrals; specialist services should be made aware when they are being asked to see a patient with learning disabilities.

People with learning disabilities did not know where or how to make complaints about the care they received. This information was not being offered or made accessible during admission but systems are now in place in SLHT to improve this. The Learning Disability Executive Group is monitoring how well this works.

Care services

The 'personalisation agenda' expressed in government policy does appear to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families. Continued progress in widening access to these kinds of services will enable more people to benefit.[13]

[13] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

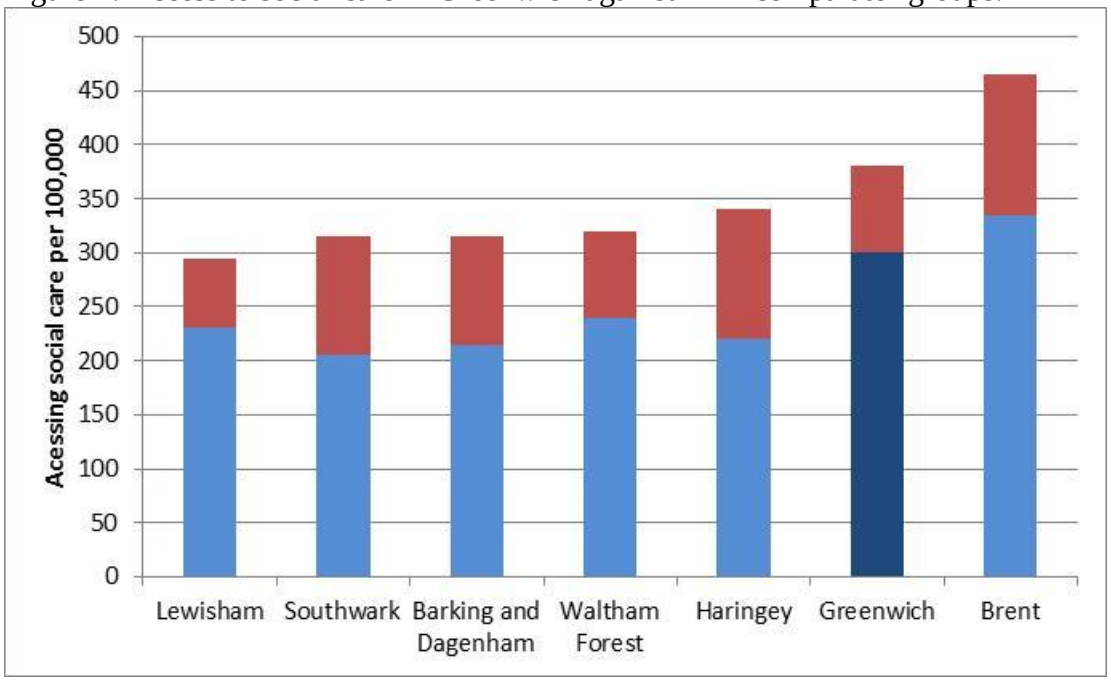
Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

What do we know about the services?

Social care services

Nationally averages of 350 people per 100,000 receive some sort of social care for learning disabilities. In Greenwich, 380 adults with learning disabilities access social or residential care per 100,000 of the general population. Of those, 300 per 100,000 use community based services in their own home. Figure 7 shows access to social care in Greenwich against its IMD comparator group, with the blue section representing the proportion of care that is community based and provided in the individual's home.

Figure 7: Access to social care in Greenwich against IMD comparator groups.

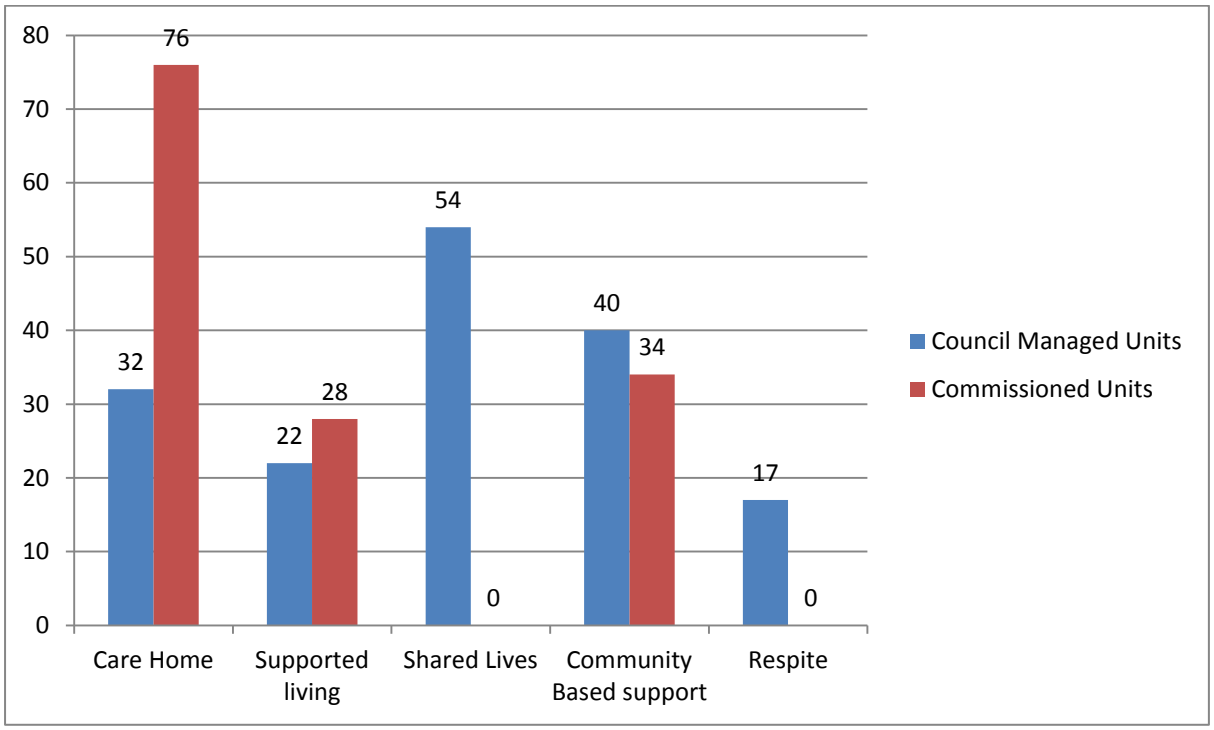


Source: Learning Disability Observatory, 2008/09
Note: This chart uses Greenwich's previous deprivation comparator group which is based on 2007 deprivation rankings. Red = institutional care; Blue= care in own home.

The Council itself is a significant provider of accommodation-based and community-based care and support services. In addition the Council block purchases a number of other services. The chart below shows the range of provision managed or commissioned by the Council. In total these services provide support for 303 people.

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Figure 8: Council Managed and Block Purchased Care and Support Services



Source: Royal Borough Greenwich Directorate Adult and Older People's Services.
These figures assume that Vanbrugh Hill will be deregistered in Jan 13. The chart also includes services commissioned through the Supporting People programme.

Approximately 200 other people with learning disabilities are supported by services that are purchased on a spot basis or through personal budgets. Roughly half of these are outside the borough boundaries.

The local policy is to ensure that no more than 40% of residential services are registered and to offer more people the opportunity to live in supported living services or to receive support in their own home. There are a number of reasons for this, but principally this approach is consistent with the vision of Valuing People Now, in that people with learning disabilities have the same rights and responsibilities as everyone else. Consequently, the Council has been working in partnership with providers to remodel services and deregister them. By April 2013, 20 units of accommodation will have been deregistered. This will mean that people with learning disability can be supported financially to stay in a wider range of accommodation that is more likely to be homely.

Royal Greenwich is committed to giving all its clients greater choice and control over the services they receive. Service users have the opportunity to take up a personal budget and to manage their own care packages. The range of provision is increasing in Greenwich, with more supported living opportunities, more options to be supported in their own homes and reducing the number of people placed in care homes. Furthermore, the number of people that are placed out of borough away from families and friends is being reduced. Where people are already in an out of borough placement, the council will be working with them and their families/carers to give them options to move back to Greenwich so that they are closer to the people that are important to them.

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

For young people in transition to adult social care services, Royal Greenwich is doing more to help them develop the necessary skills to live independently or independently with support. A Transitions Register has been developed that will allow adult social care services to better plan for the needs of people that will become adults in the next five years. A Transitions Board has been established to oversee Greenwich's strategic approach and a Transitions Panel now sits monthly to consider individual cases. A supported living scheme for young people in transition has already been developed.

Healthcare services

Although there are examples of good practice within the health service the audits outlined above show convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective health care treatment than the general population. Disappointingly it is evident that these vulnerable individuals have not been getting the emotional and physical support needed within the current NHS services. This occurs despite the fact the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment.

The evidence has shown that general healthcare staff have limited knowledge about learning disability and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. Communication between different agencies providing care can be poor in relation to services for adults with learning disabilities.[14]

A Big Health Check Day designed to engage with services attracted more than 120 participants in June 2012 at Charlton Athletic Football Club. This was part of the annual Learning Disability Health Self-Assessment (LD SAF) process. Participants were invited to talk about health services and look after their own health needs, and to assess how much progress has been made in improving health care over the past year.

Highlights from the feedback were as follows;

Dental services: people complained that their treatment was not explained to them which made them feel more anxious, and wanted better information on how to look after their teeth. There was agreement that the specialist dentist at Lakeside was providing an excellent service.

Pharmacy services: people wanted an explanation of what is written on the prescription and what medication will do to them, including side effects. They were also not clear about how long medication should taken or what to do if they run out of medicines.

GP Services: there were a variety of concerns about GP services including opening hours, difficulty making appointments and practical use of Personal Health Plans.

---

14 *http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf*

Source: Greenwich JSNA 2013/14 "Closing the Gap." Public Health & Well-Being, Royal Borough of Greenwich.

Hospital services: there were a variety of concerns about these services including access, quality of services and communication.

The Health Sub Group of the Learning Disability Health Partnership Board has included actions based on the findings and the results of the LD SAF in an Improvement Plan.

Employment Support

In Royal Greenwich there is a service to support people with learning disabilities to prepare for employment and to find jobs. The service includes the development of individual work plans, C.V. writing, various training opportunities, volunteering and work experience placements, supported job searches and one-to-one support at work. In addition the service will provide training to employers on making their workplaces accessible. To date, more than 20 people have been supported to find and maintain work. The target is to double that figure by March 2014.

Evidence based improvement

As outlined above one of the main focuses for improvement of services is in health care; employment and housing. A multidisciplinary approach to management of the individuals and their families is essential. The Valuing People Now document highlights some of the steps that need to be taken to improve the current health care services:

- Screening and early identification
- Fair personalised health care
- Regular medical checks
- The need for education for health care professionals

In addition good practice has been identified in the Mansel report[15](DH 2007) written in the wake of the Valuing People Now report. The key recommendations for good practice are;

- Commitment
- Individualisation
- Effective service characteristics
- Good management
- Investment in relationships and networking

[15] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

Appendix A

Glossary

Angelman syndrome is a neuro-genetic disorder characterized by severe intellectual and developmental disability, sleep disturbance, seizures, jerky movements, frequent laughter or smiling, and usually a happy demeanor.

Congenital hypothyroidism; is a condition of thyroid hormone deficiency present at birth. If untreated for several months after birth, severe congenital hypothyroidism can lead to growth failure and permanent mental retardation.

Cystic fibrosis; is a genetic condition in which the lungs and digestive system become clogged with thick sticky mucus

Down's syndrome also known as **trisomy 21**, is a chromosomal condition caused by the presence of all or part of a third copy of chromosome 21. Down's syndrome is the most common chromosome abnormality in humans. It is typically associated with a delay in cognitive ability and physical growth, and a particular set of facial characteristics

Fragile X syndrome is a genetic syndrome that is the most widespread single-gene cause of autism and inherited cause of mental retardation among boys. It results in a spectrum of intellectual disabilities ranging from mild to severe as well as physical characteristics and behavioral characteristics.

Medium-chain acyl-CoA dehydrogenase deficiency; is a disorder of. The disorder is characterized by hypoglycemia and sudden death without timely intervention, most often brought on by periods of fasting or vomiting.

Phenylketonuria (**PKU**) is an autosomal recessive metabolic genetic disorder characterized by a mutation in the gene for the hepatic enzyme phenylalanine hydroxylase (PAH). The body is unable to break down a substance called phenylalanine, which builds up in the blood and brain. High levels of phenylalanine can damage the brain. Untreated PKU can lead to mental retardation, seizures, and other serious medical problems.

Thalassemia and sickle cell disease are serious inherited blood disorders that require specialist care and can cause several complications.

References

1. DH 2007, Mansell report
2. DH,2009, Valuing Employment Now.
3. DH, 2007, Valuing People Now,
4. DH, 2001, Valuing People
5. IHAL, 2010, How People With Disabilities Die
6. JEC, 2005, Epilepsy Prevalence, Incidence and Other Statistics.
7. Mencap, 2007, Death by Indifference.
8. Mencap, 2007, Prescription for change.

9. Michael J. Healthcare for all, 2008
10. Projecting Adult Needs and Service Information System

Source: Greenwich JSNA 2013/14 “Closing the Gap.” Public Health & Well-Being, Royal Borough of Greenwich.