

Learning Disabilities in Hammersmith and Fulham, Kensington and Chelsea, and Westminster

Tri-Borough Joint Strategic Needs
Assessment (JSNA) Report 2013-14

January 2014

This Report

Purpose of the report

The purpose of this report is to describe the needs of people in the Tri-borough areas of Hammersmith and Fulham, Kensington and Chelsea, and Westminster who have learning disabilities. As part of this, the report identifies the health inequalities experienced by this group compared to the general population.

This report will be used to assess and develop local strategy around support for people with learning disabilities, alongside a range of other information, such as other specific needs assessments, strategies, action plans and routine monitoring.

Some detail has been provided in this report on Tri-borough services and how they are responding to local needs, but it is envisaged that this detail will predominantly be captured in resulting action plans and strategies, which will ensure that issues from this report are addressed.

This report should also be considered in conjunction with the October 2012 report *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)*¹ from the Learning Disabilities Observatory, the Royal College of General Practitioners and the Royal College of Psychiatrists.

Populations under scrutiny

The populations described in this document include those with learning disabilities registered with local GP practices, those known to local adult and child social care or third sector services, those attending local schools, those known to prison or police services, or those in the general population not known to services. The report also captures some information around those with Autistic Spectrum Disorders (ASDs).

Definition of learning disability

The definitions of learning disabilities vary. For the purposes of this report, learning disabilities is understood to refer to a significant general impairment in intellectual functioning that is acquired during childhood. Learning disability is typically defined as being where someone has an IQ of less than 70.

The 2001 White Paper on the health and social care of people with learning disabilities *Valuing People* defines learning disability as including the presence of:

- a significantly reduced ability to understand new or complex information, or 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

People with learning disabilities can often have additional needs such as challenging behaviour or complex physical disabilities.

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CONTENTS

1. POPULATION	7
1.1 Data summary	8
1.2 The number of people with learning disabilities	8
1.3 The number of adults known to services	9
1.4 The number of children known to services	14
1.5 Prison population	16
1.6 Profile of the learning disabilities population	17
1.7 Future changes in the numbers with learning disabilities	22
2. HEALTH STATUS	26
2.1 Background	27
2.2 Mortality and life expectancy	27
2.3 Burden of ill-health and causes of death	28
2.4 Common conditions	29
2.5 Lifestyles	33
2.6 Self-reported health from the Statutory Adult Social Care Survey	34
2.7 Reducing inequalities experienced by those with learning disabilities	35
3. HEALTH SERVICE USE	36
3.1 Primary care use	37
3.2 Health checks and screening	37
3.3 Acute care	42
3.4 Other clinical services	46
4. ACCOMMODATION	47
4.1 Context	48
4.2 Number of adults living in types of accommodation	49
4.3 Living in stable and appropriate accommodation	50
4.4 Adult acute placements (ATUs)	52
4.5 Residential and nursing care	53
4.6 Changing demand for accommodation	57
5. COMMUNITY SOCIAL CARE	58
5.1 Spend per client known to services, aged 18-64	59
5.2 Spend per service type on adults aged 18-64	60
5.3 Summary of clients receiving a service	61
5.4 Personal budgets/ direct payments	61
5.5 Day services	62
5.6 Short breaks	64
5.7 Home care services	65
5.8 Assessment and review	66
5.9 User experience of social care	66
6. TRANSITION INTO ADULT SERVICES	68
6.1 Background	68
6.2 Numbers transitioning into adulthood	69
6.3 Challenges around transition	70

7. EDUCATION AND EMPLOYMENT	72
7.1 Education	72
7.2 Employment rates	74
7.3 Employment support	78
8. SAFEGUARDING, ABUSE AND CRIME	81
8.1 Safeguarding and abuse	81
8.2 Crime	84
9. CITIZENSHIP	86
9.1 Social contact and relationships	86
9.2 Transport issues	87
9.3 Rights	88
10. CARING RESPONSIBILITIES	90
10.1 Number of carers of people with learning disabilities	90
10.2 Experiences of carers	90
10.3 Carers assessments and reviews	92
10.4 Future need for carers of those with learning disabilities	93
10.5 The impact of welfare reform	93
APPENDICES	
Appendix A – Further information on Reasonable Adjustments	94
Appendix B – Detailed profile of children with learning difficulties in schools	96
Appendix C – Detailed numbers of adults with chronic diseases	100

HOW THIS NEEDS ASSESSMENT FITS INTO THE BIG PLAN

Big Plan area	Needs Assessment Chapter
Including everyone	1. Population
Better health	2. Health Status 3. Health Service Use
Having real choice and control in our lives	5. Community social care – personal budgets/ direct payments 8. Abuse and safeguarding and crime 9. Citizenship
Having a home I can call my own	4. Accommodation
What people do during the day	5. Community social care 7. Education and employment
Being part of my community	7. Education and employment 9. Citizenship 5. Community social care
Partnership with families	10. Caring responsibilities
Making transition a positive experience	6. Transition – moving to adult services

1. POPULATION

Key messages

- The proportion of **people with learning disabilities** accessing GP and council services is among the lowest in the country, particularly in Kensington and Chelsea and Hammersmith and Fulham. Council numbers have been static but GP lists have been rising, probably due to out-of-borough patients moving back and better recording.
- The rates of **children** in tri-borough schools with a statement for learning difficulty are lower than London and England, although the nature of Hammersmith and Fulham schools means numbers are higher in that borough, and are much lower in Kensington and Chelsea. Changes have followed national trends to some extent, with big drops in numbers with a moderate learning difficulty and very large rises in numbers diagnosed with autistic spectrum disorders. Numbers with severe learning disability have dropped in Westminster in particular, but those with profound and multiple learning difficulties have been slowly rising.
- The **profile of people with learning disabilities** shows a greater likelihood of living in areas of social housing and deprivation, with a significant proportion living outside the boroughs. The Black ethnic group is twice as high as in the general population, and the Asian group is half the proportion (but higher in the younger age groups). Men are over-represented, accounting for close to 6 out of 10 of the population, as is the case nationally. Numbers drop off sharply with age, but there appear to be a larger than expected number of 45-54 year olds and fewer 35-44 year olds, possibly due to changes in eligibility criteria
- **Predicting changes in the size** of the learning disabilities population is difficult locally, but national trends give some clues. Changes are being driven by factors such as better survival rate into adulthood and old age, changes in the overall birth rate, and a changing ethnic profile.
- National data suggests **numbers transitioning into adulthood** won't rise until later in the decade and will continue to rise thereafter. Local schools data suggests small increases in profound and multiple learning difficulties, a mixed picture around severe learning difficulties, and very large increases in autistic spectrum disorders. However, local calculations are in conflict with national predictions, showing greater numbers transitioning in the next 2-3 years, with a high proportion of autistic spectrum conditions and challenging behaviour.
- Recent national **projections of total numbers of people with learning disabilities** accessing services suggest increasing numbers over time, particularly in areas with lower adult social care (FACS) thresholds. At their lowest, projections suggest growth in total numbers of around 1.5% a year. Critically, national modelling predicts much greater proportionate rises in areas with lower thresholds. Some factors locally – lower than average birth rates, increasingly expensive property prices, relatively low numbers from 'high risk' ethnic groups, movements out from welfare reform – may mean growth could be at the lower end of national predictions.
- Numbers are being driven in particular by **better survival rates**, which are likely to have an impact on resources where carers become elderly and unable to provide continued support, or where service users develop debilitating chronic diseases such as dementia.

Recommendations:

- Ensure that cross-organisational systems are in place to identify those with learning disabilities, in order to tackle potential under-diagnosis in the local population. This is particularly relevant for the child population and identifying those transitioning into adult services
- Ensure that local services plan for expected increases in numbers of complex clients in transition, as well as numbers reaching old age, and the specific requirements that these groups have, such as planning for more and more varied models of accommodation and support. This has been detailed later in this report

1.1 Data summary

The numbers of people with learning disabilities have been discussed in the following sections in more detail. Overall numbers have been summarised below:

Table 1a: Summary of numbers of people with learning disabilities

	H&F	K&C	West	Tri-borough
All				
With LD in population (estimate), 2011	3,500	3,500	5,300	12,300
Adults				
Known to GPs (18+), 2012/13	352	308	504	1,164
Receiving services during year (18+), 2012/13	490	285	520	1,295
Known to NHS and councils (SAF), 2012/13	327	212	509	1,048
Children				
School age resident (moderate - estimate), 2011	449	239	460	1,149
School age resident (severe - estimate), 2012	50	34	45	129
School age resident (PMLD - estimate), 2011	11	6	12	29

1.2 The number of people with learning disabilities**Numbers with learning disabilities in the population**

Recent estimates suggest that there are around 236,000 children and young people under 18 and 908,000 adults with learning disabilities living in England.² This equates to a prevalence of around 2% of the general population. Around one in five of these people are known to learning disabilities services, meaning 0.5% of the total population nationally are known by councils or GPs to have a learning disability.

When national prevalence rates are applied to local population structures, the expected numbers with learning disabilities in the general population are as high as 12,000 people in the tri-borough area, broken down as follows:

- Hammersmith and Fulham – 3,500 people
- Kensington and Chelsea – 3,500 people
- Westminster – 5,300 people

The substantial difference between expected numbers locally and numbers known to services (see below) can probably be explained in part by local factors such as barriers to affordable housing, out-of-area housing, and the nature of the local population, resulting in an over-inflated population estimate. This has been discussed in more depth below.

Numbers with autistic spectrum disorders in the population

‘Autism’ refers to a spectrum of conditions including classic autism, Asperger’s Syndrome and high functioning autism. As the concept of autism has broadened, estimates of prevalence have increased.

Around 1% of the population is likely to have an Autistic Spectrum condition. This *very broadly* equates to the following numbers likely to have the disorder locally (social and demographic factors listed above are also likely to impact on the accuracy of estimated numbers):

- Hammersmith and Fulham – 1,800 people
- Kensington and Chelsea – 1,800 people
- Westminster – 2,700 people

Around a third to a half of these people are also likely to have a learning disability³ (included in the estimates in the previous section). Around four in five of those with autism are male. Identification of autism is often challenging among people with learning disabilities, due to ‘diagnostic overshadowing’, where clinicians may not spot the autism as it is ‘overshadowed’ by the learning disability.

1.3 The number of adults known to services

Numbers of adults known to GPs

There are 1,230 adults aged 18+ on GP learning disabilities registers, with a greater number and proportion in Westminster than in the other two boroughs (see Table 1b)⁴. In 2011/12, practice prevalence of learning disabilities in Kensington and Chelsea and Hammersmith and Fulham were the lowest and second lowest in the country, with Westminster ranked the 7th lowest (see Chart 1a for London rates)⁵.

Within these registers, 73 patients were identified as having Down's syndrome (18 in H&F, 22 in K&C, and 33 in Westminster). This measurement was only introduced in 2012/13 and does not include those also on the hypothyroid register and may therefore be an undercount).

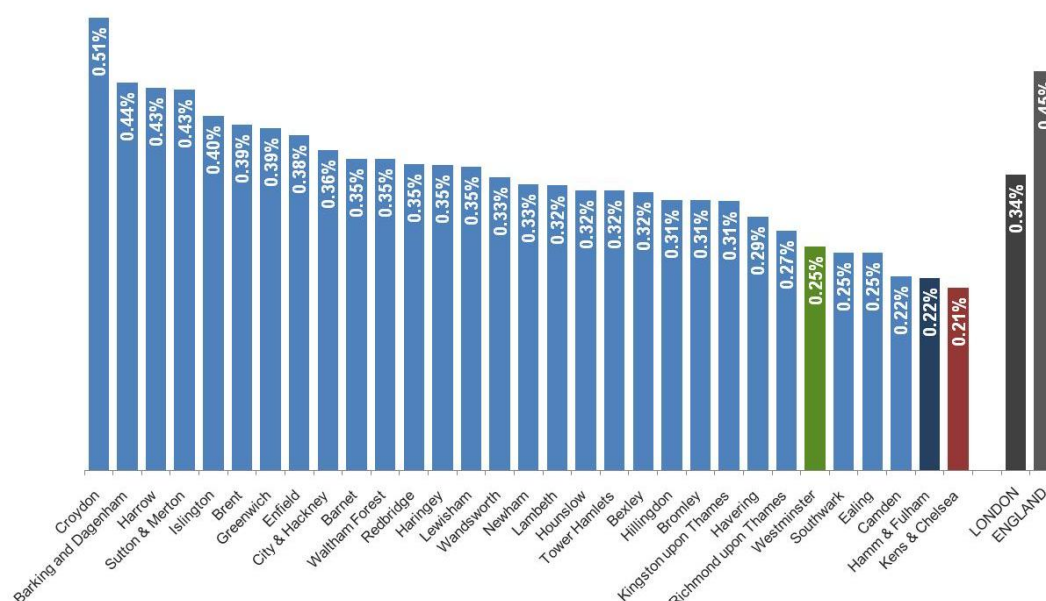
Table 1b: Number and prevalence of learning disabilities in GP practices

Source: QOF 2012/13 (2011/12 for London and England)

		Number with LD aged 18+	Prevalence per 18+ pop (%)
Borough	H&F	385	0.23%
	K&C	316	0.21%
	Westminster	529	0.25%
	Tri-borough	1,230	0.23%
CCG	H&F	385	0.23%
	West London CCG	507	0.27%
	Central London CCG	338	0.20%
Comparison	London 11/12	-	0.34%
	England 11/12	-	0.45%

Chart 1a: Practice prevalence of learning disabilities by PCT

Source: QOF 2011/12 (2012/13 comparator data not yet released)



Number of adults known to council learning disability teams

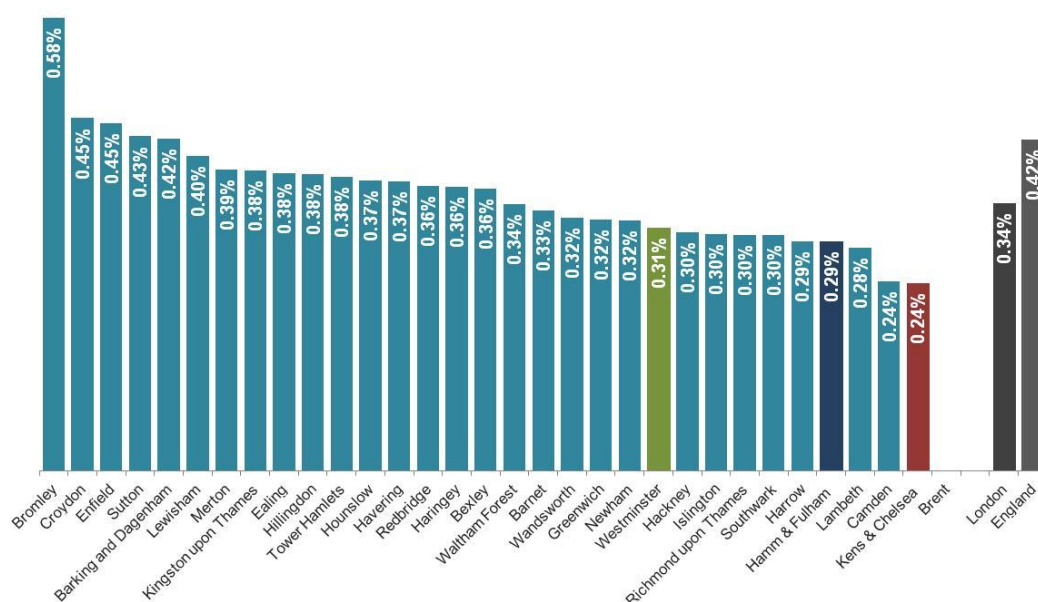
There were just under 1,200 people aged 18-64 with learning disability known to tri-borough local authorities in 2012/13.⁶ Kensington and Chelsea had the second lowest prevalence in London and one of the lowest rates nationally. Hammersmith and Fulham had the fifth lowest prevalence in London. Westminster had the 11th lowest rate in London, just below the London average. Estimates suggest around 20-33% of these people are also likely to have autism.

Table 1c: Number of adults aged 18-64 known to council learning disabilities teams
Source: NASCIS ASC-CAR L2

		Number with LD aged 18-64	Prevalence %
Borough	H&F	389	0.29%
	K&C	270	0.24%
	Westminster	489	0.32%
	Tri-borough	1,148	0.29%
Comparison	London	-	0.34%
	England	-	0.42%

Chart 1b: Prevalence of learning disabilities by London council, 2012/13, aged 18-64

Source: NASCIS L2 2012/13, 2011 Census populations



There were close to 1,300 people aged 18 or more receiving a service during the year in 2012/13. Kensington and Westminster has a lower rate per population than London and England. The rate in Hammersmith and Fulham was higher than London and similar to England.

Table 1d: Number of adults aged 18+ receiving a service during 2012/13

Source: NASCIS RAP P1 . Population denominators from NASCIS

		Number with LD aged 18+	Prevalence %
Borough	H&F	490	0.34%
	K&C	285	0.22%
	Westminster	520	0.28%
	Tri-borough	1,295	0.28%
Comparison	London	-	0.30%
	England	-	0.35%

Numbers known to both NHS and Councils

As part of the health checks programme, the NHS and councils are required to identify the number of adults known to both GPs and Social Services. These numbers have been detailed below.

The lower number than expected in Kensington and Chelsea in particular may relate to the large number of clients living outside the borough area and hence not registered with local practices. There may also be instances where those on GP lists are not considered to be learning disabilities patients (but may have more general mental health issues).

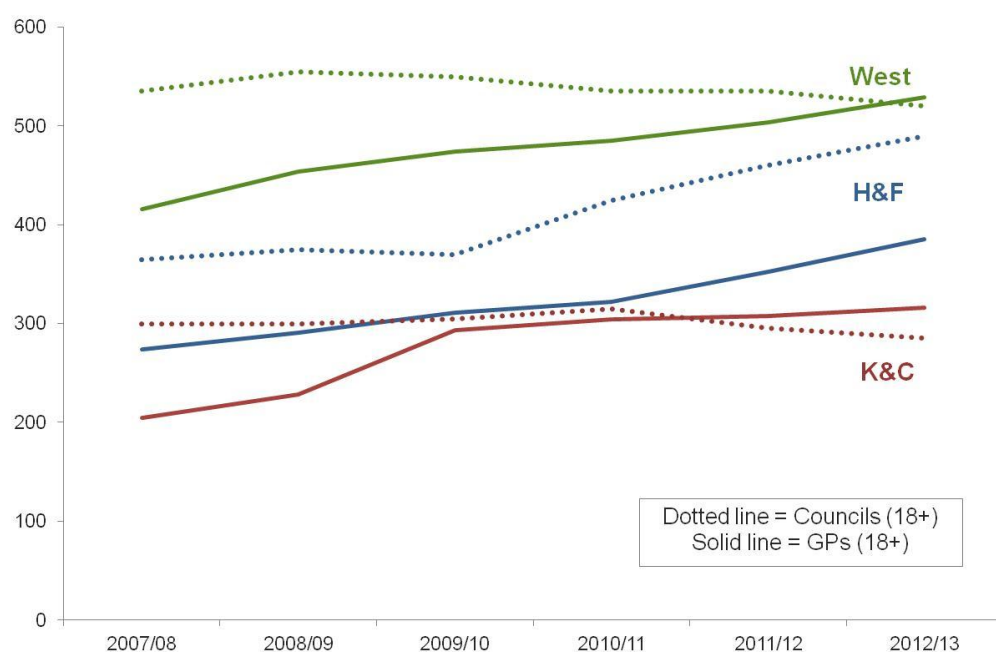
Table 1e: Number of adults known to council learning disabilities teams (used for SAF Health checks) Source: SAF 2011/12 and 2012/13⁷

	Known to both GPs and Social Services, 2012	Known to both GPs and Social Services, 2013
H&F	321	327
K&C	205	212
Westminster	505	509
Tri-borough	1,031	1,048

Numbers known to services over time

All three boroughs have seen substantial increases in size of GP registers of patients with learning disabilities over the last four years, broadly in line with the rise nationally and in London.⁵ The bulk of this rise is likely to be better identification of patients rather than a rise in numbers in the population.

Recent council data on numbers receiving a service in the year suggests stable numbers in Kensington and Chelsea, gradually declining numbers in Westminster, and a large increase in Hammersmith and Fulham between 2009/10 and 2012/13. There are likely to be a combination of factors for council changes, such as better recording of cases, closure of inactive cases, and changes in eligibility.

Chart 1c: Numbers with learning disabilities known to councils and GPs over time**Table 1f: Numbers with learning disabilities known to councils and GPs over time**
NASCIS RAP P1

	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13
GP registers (18+)						
Hammersmith and Fulham	274	291	311	322	352	385
Kensington and Chelsea	205	228	293	304	308	316
Westminster	416	454	474	485	504	529
Tri-borough	895	973	1,078	1,111	1,164	1,230
Councils (18+)						
Hammersmith and Fulham	365	375	370	425	460	490
Kensington and Chelsea	300	300	305	315	295	285
Westminster	535	555	550	535	535	520
Tri-borough	1,200	1,230	1,225	1,275	1,290	1,295

SAF Self-assessment score: LD QOF registers in Primary Care⁷

PCTs assessed themselves against a range of standards in 2012/13, with Level 1 being the lowest rating and level 3 being the highest

All three PCTs reported themselves as 'Level 3' for A1. QOF registers. Three other PCT areas in London reported Level 3, seven reported Level 1, and the remainder Level 2.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A1. Learning disability and Down's syndrome QOF registers reflect local prevalence data and there is evidence of people on the registers with profound/ multiple LD/ BME communities Autism	Level 3	Level 3	Level 3

1.4 The number of children known to services

Numbers of school children with learning difficulties

Among school age children, the national prevalence rate of learning difficulties in schools in 2011/12 was⁸:

- Moderate learning difficulties: 2.4% of the population
- Severe learning difficulties: 0.4% of the population
- Profound and multiple learning difficulties: 0.1% of the population

The numbers with learning difficulties in each borough has been illustrated in the Table 1g below.

In inner London boroughs, the numbers with learning difficulties attending local schools is not only influenced by pupils travelling across borough borders to their school, but also by the nature and level of provision of specialist education. In some cases, parents may move to be close to specialist schools. It is therefore challenging to capture the 'true' prevalence of learning difficulties among children with accuracy.

This is particularly apparent for Hammersmith and Fulham, which had the 5th highest rate in London of pupils with profound and multiple learning difficulties in 2011, probably due to the presence of two local specialist schools, Jack Tizard and Queensmill schools (Westminster has QE2 and College Park). Kensington and Chelsea was the 2nd lowest in London. Local estimates of learning difficulties by residence shows numbers more balanced between the three boroughs (Table 1g).

Autism affects around 1% of the child population. It has been estimated that between 40% and 67% of children with autism are likely to also have a learning disability, and around a third of children with a learning disability will also have autism.

Table 1g: Numbers of primary, secondary and special school children with learning difficulties known to schools (2012)⁹, and estimated to be resident in the Tri-borough area (2011)¹⁰

	Moderate learning		Severe learning		Profound and multiple		Autistic spectrum	
	In borough's schools	Resident in borough (estimate) ¹	In borough's schools	Resident in borough (estimate)	In borough's schools	Resident in borough (estimate) ²	In borough's schools	Resident in borough (estimate)
H&F	400	90	75	50	39	11	211	137
K&C	174	96	54	34	10	6	58	103
Westminster	559	160	68	45	28	12	154	159
Tri-borough	1,133	346	197	129	77	29	423	399

1. Different definition. IHAL estimates 1,149

2. No local estimates. IHAL estimated used

Changing numbers with learning difficulties and autistic spectrum disorders over time

Learning difficulties

Nationally and in London, the number of school children known to have learning difficulties has dropped over the last four years, largely a result of a drop in numbers of children with moderate learning difficulties. The numbers with severe difficulties has risen by 6%, and the number with profound and multiple learning difficulties has risen by 12%.⁹

In local schools, there has been a drop, due to a drop in moderate and severe learning difficulties. The numbers with profound and multiple learning difficulties has risen by 4% over the period. There have been large variations between boroughs, detailed in Appendix B.

Autistic spectrum disorders

Over the last four years, there has been a 40% rise in the number of children known to have autistic spectrum disorders nationally, and a 50% rise in London⁹. Locally, the rise has been twice as fast, and local data on residents suggests a three to fourfold rise since 2003. However, the rate in Westminster schools is lower than average, and Kensington and Chelsea rate is far lower (the rate in Hammersmith and Fulham is similar). See appendix B for more detail.

There is a general consensus that rises in numbers with autism is a result of better methods of detection of the condition, as well as a broadening of the concept of autism, particularly among those with near-normal non-verbal intelligence.

Table 1h: Change in numbers of tri-borough school children with learning difficulties, and comparison to London, 2012⁹

	Change in numbers 2008-2012		2012 Tri-borough rate compared to London
	London	Triborough	
Severity			
Moderate	-14%	-3%	Slightly lower
Severe	+6%	-22%	Much lower
Profound & multiple	+12%	+4%	Slightly lower
Autistic spectrum	+50%	+91%	Much higher

Numbers of children *in need* with a disability in learning

Nationally and in London, 0.21% of the child population were identified as being 'in need' and with a disability associated with learning in 2012¹¹. Children in need are those who have been referred to the local authority and have been assessed to be in need of services. This is substantially lower than estimates of likely levels in the population.

Locally, the number was higher in Kensington and Chelsea (93 children, 0.35%) and Westminster (86 children, 0.24%) but considerably lower in Hammersmith and Fulham (9 children, 0.03%), which may relate to a data categorisation or quality issue.

Looked after children

Nationally, over 1 in 5 looked after children have a special educational need associated with learning disabilities¹². The risk of a child being looked after continuously for a year or more has been calculated nationally at:

- 0.1% for those with **no** special educational needs
- 2.0% for those with a **moderate** learning disability
- 2.5% for those with a **severe** learning disability
- 3.1% for those with a **profound or multiple** learning disability

Children transitioning into adult services

The Tri-borough area generally sees 20 people transition from Children's into Adult social services each year in total. However, 36 people are likely to transfer in 2013/14, and 52 in 2014/15 across the three boroughs, and numbers appear to be rising.¹³

More detail on transition can be found later in this section and in the Transition Section.

1.5 Prison population

Local data from reception screening at HMP Wormwood Scrubs indicates that 2.4% of prisoners are recorded as having a Learning Disability at their initial health screen (equivalent to 18 prisoners at any one time). The reception data is supported by data on diagnosis provided from Primary Care visits, which suggests prevalence at any one time in HMP Wormwood Scrubs is equal to 3.1%¹⁴.

Both of these rates are higher than the equivalent rate in the population locally, and indicates that the high prevalence of inmates with learning difficulties is a significant challenge for HMP Wormwood Scrubs. There may even be under-diagnosis, as national figures suggest up to 7% of prisoners have an IQ of under 70.¹⁵

Recommendations from the JSNA for the prison population identify a need for better collection on health and disability on induction, improvements in data recording, and actions plans shared with healthcare providers, specialist services and prison services to improve care and reduce DNAs.

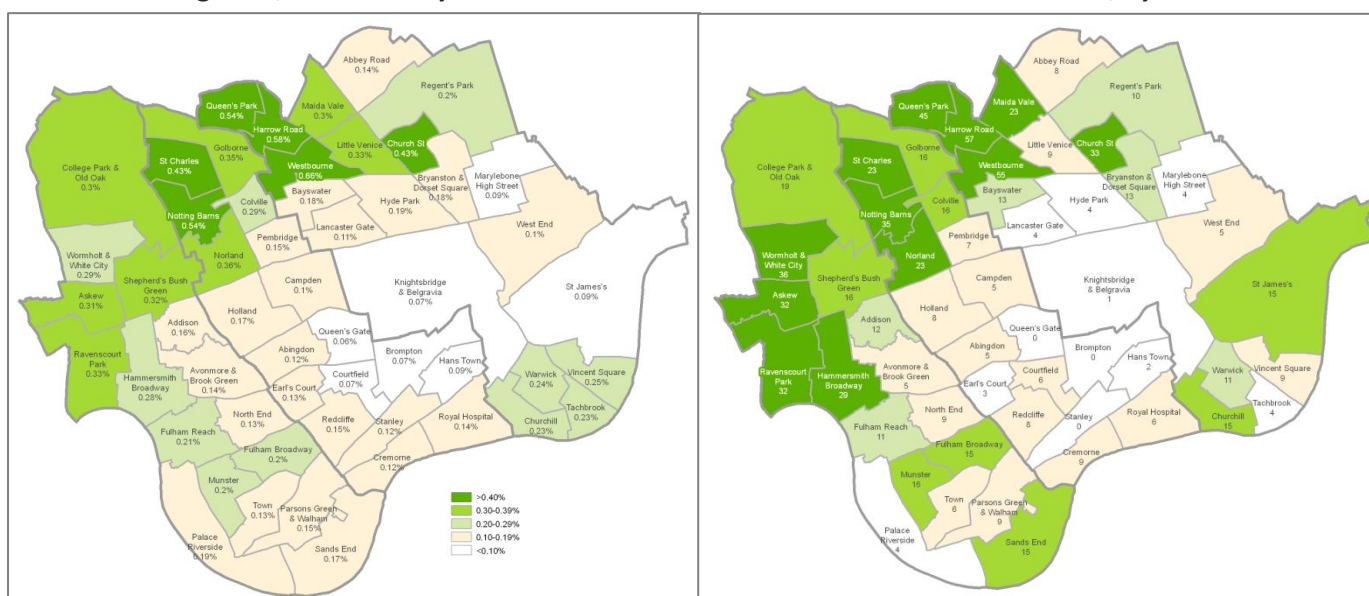
1.6 Profile of the learning disabilities population

Location of adults with learning disabilities within the tri-borough area

Those with learning disabilities are more common in areas of deprivation, which relates in part to the location of supported housing and social housing. The far northwest of Westminster has a high prevalence of people with learning disabilities, particularly in the Queen's Park, Harrow Road and Westbourne area, as well as in Church Street. The far north of Kensington and Chelsea and Hammersmith and Fulham are also high.^{16, 17}

Map 1a: Prevalence of GP learning disabilities registers, estimated by ward

Map 1b: Number of clients known to learning disabilities services, by ward



A number of people with learning disabilities live outside of their home borough (see Table 1i), primarily those in nursing and residential care, where three quarters are outside their home borough. In the case of Kensington and Chelsea, this rises to 9 out of 10.¹⁷

Table 1i: Numbers and percentages of people all ages with learning disabilities living inside and outside borough

Figures are based on a snapshot (31 March 2013 for RBKC but 31 Dec 2012 for LBHF and WCC)

	Numbers						Percents					
	Community		Nursing/residential		Total		Community		Nursing/residential		Total	
	In borough	Out of borough	In borough	Out of borough	In borough	Out of borough	In borough	Out of borough	In borough	Out of borough	In borough	Out of borough
H&F	201	4	65	99	266	103	98%	2%	40%	60%	72%	28%
K&C	163	12	9	87	172	99	93%	7%	9%	91%	63%	37%
West	308	22	30	107	338	129	93%	7%	22%	78%	72%	28%
Tri-borough	672	38	104	293	776	331	95%	5%	26%	74%	70%	30%

Social deprivation and the learning disabilities population

The area of residence of adults with learning disabilities tends to be linked to the areas of social and supported housing, given authorities' responsibilities for accommodation. Those with learning disabilities are therefore often located in areas of deprivation (see map). Nationally, among children and young people, there is a fourfold difference in prevalence of moderate learning difficulties between deprived homes in deprived areas and non-deprived homes in non-deprived areas. For severe learning disabilities it is twofold and for profound and multiple learning disabilities it is slightly less than this.¹⁸

Age and gender profile of adults with learning disabilities

Around 55% of people with learning disabilities known to the council¹⁷ and 58% of those on GP registers¹⁹ are male in the Tri-borough area, which is similar to nationally. Generally, the greatest numbers fall into the under 35 category with reducing numbers over age, due to the effects of mortality and possibly movements out of the area.

The exception to this is the larger than expected number in the 45-54 age group, particularly for men. This age group is likely to have a disproportionate impact on adult social care budgets as this group ages. The number of people in the 35-44 age band is smaller than expected. This may be due to changes in eligibility criteria or natural patterns.

Around 9% of the GP registered population with learning disabilities and 10% of those known to councils are aged 65 or over, compared to 11% in the general tri-borough population and 16% nationally; those with learning disabilities have poorer life expectancy than the general population.

Chart 1d: Age and gender structure of the GP-registered and council learning disabilities population across the tri-borough area

GP registers scaled up due to undercount in Westminster

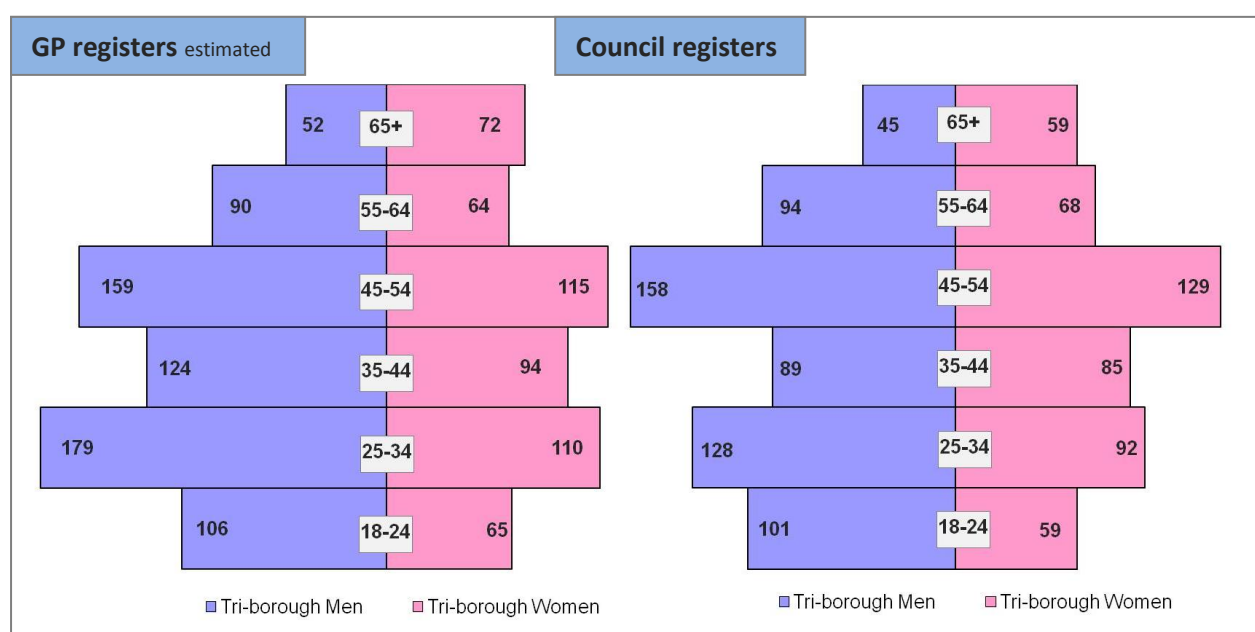


Table 1j: Numbers known to councils by age and gender across the tri-borough

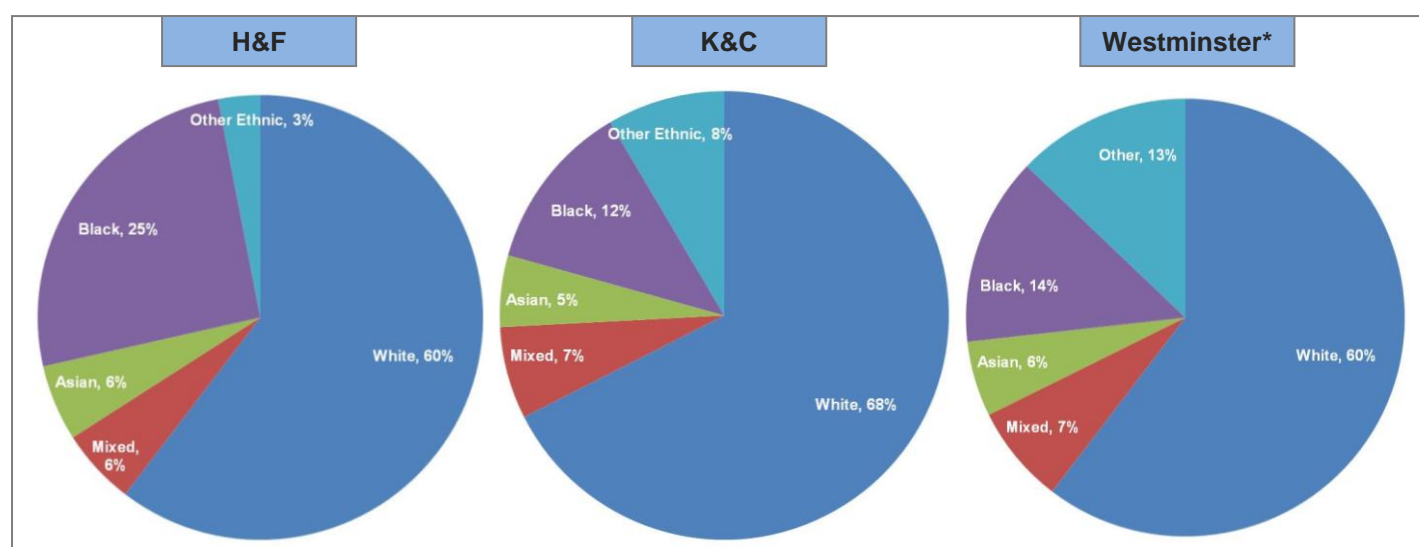
area. Dec 2012/ March 2013. Due to inconsistencies in data, total numbers do not match borough counts in other parts of the report exactly.
Kensington and Chelsea figure for 18-24 year olds may be an over-count – operational managers report 32 with learning disabilities.

	H&F			K&C			Westminster*			Tri-borough		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
18 to 24	24	18	42	35	18	53	42	23	65	101	59	160
25 to 34	55	37	92	33	19	52	40	36	76	128	92	220
35 to 44	31	26	57	25	13	38	33	46	79	89	85	174
45 to 54	54	43	97	28	26	54	76	60	136	158	129	287
55 to 64	38	29	67	27	12	39	29	27	56	94	68	162
65+	6	8	14	19	16	35	20	35	55	45	59	104
Total	208	161	369	167	104	271	240	227	467	615	492	1107

Ethnicity and nationality of the learning disabilities population

Ethnicity and nationality can influence the prevalence of learning disabilities, with certain ethnic groups and nationalities having higher prevalence rates, particularly people from Irish Traveller and Gypsy/Romany groups for moderate to severe learning disabilities, and Pakistani and Bangladeshi groups for profound and multiple learning disabilities. Black ethnic groups also show a considerable difference.²⁰ These high risk ethnic groups do not tend to be common in the tri-borough area, although Westminster has a similar sized Bangladeshi population to the London average.

A breakdown of broad categories has been given below. In all three boroughs, the Black ethnic group is double the proportion compared to the general population and the Asian group is lower, surprising given the higher risk among some Asian sub-groups. The White groups are similar or slightly lower.¹⁷

Chart 1e: Proportion of learning disabilities population by broad ethnic group

In all three boroughs, there are greater proportions from Black and minority ethnic groups in the younger age groups than the older, particularly in Westminster (notably in the Asian and Other ethnic groups).

Table 1k: Proportion of learning disabilities population by broad ethnic group and age

	H&F		K&C		Westminster	
	<35	35+	<35	35+	<35	35+
White	45.9%	67.4%	53.3%	76.5%	32.6%	72.4%
Mixed	9.8%	3.0%	9.5%	4.8%	12.1%	5.2%
Black	31.6%	21.5%	16.2%	9.6%	15.6%	13.2%
Asian	9.0%	5.6%	5.7%	4.8%	11.3%	3.1%
Other	3.8%	2.6%	15.2%	4.2%	28.4%	6.1%

Investigation of detailed ethnicity data highlights the higher than average proportion from the White British and Irish groups and lower proportion from the 'White Other' group. The Black Caribbean group tends to be 3-4 times over-represented.

Table 1l: Number and proportion of learning disabilities population by ethnic group

		Numbers			Percentages			General pop 2011 Census		
		H&F	K&C	West	H&F	K&C	West	H&F	K&C	West
White	British	178	139	229	48.6%	51.3%	49.0%	44.9%	39.3%	35.2%
	Irish	19	9	23	5.2%	3.3%	4.9%	3.5%	2.3%	2.3%
	White Other	21	35	30	5.7%	12.9%	6.4%	19.7%	29.0%	24.2%
Mixed	White and Asian	1	4	5	0.3%	1.5%	1.1%	1.5%	1.9%	1.6%
	White and Black Caribbean	8	4	11	2.2%	1.5%	2.4%	1.5%	1.1%	0.9%
	White and Black African	1	4	5	0.3%	1.5%	1.1%	0.8%	0.7%	0.9%
	Other mixed background	10	6	13	2.7%	2.2%	2.8%	1.7%	2.0%	1.8%
Asian	Indian	8	3	6	2.2%	1.1%	1.3%	1.9%	1.6%	3.3%
	Pakistani	3	2	2	0.8%	0.7%	0.4%	0.9%	0.6%	1.1%
	Bangladeshi	1	3	15	0.3%	1.1%	3.2%	0.6%	0.5%	2.9%
	Other	13	6	3	3.6%	2.2%	0.6%	4.0%	4.8%	4.6%
Black	Caribbean	47	13	39	12.8%	4.8%	8.4%	3.9%	2.1%	2.0%
	African	28	18	14	7.7%	6.6%	3.0%	5.8%	3.5%	4.2%
	Black other	17	2	12	4.6%	0.7%	2.6%	2.1%	1.0%	1.3%
Other	Chinese	0	1	5	0.0%	0.4%	1.1%	1.7%	2.5%	2.7%
	Other ethnic group	11	22	55	3.0%	8.1%	11.8%	5.5%	7.2%	11.1%

GP data identifies a higher proportion of the learning disabilities population (82%) were born in the UK than is typical for the Tri-borough area. Common areas of birthplace matched the general profile of the area: higher than average numbers from the Middle East and Western Europe and relatively low numbers from South Asia (see Table 1m)¹⁹.

Table 1m: Region of birth of GP-registered learning disabilities population

Area of birthplace	% of learning disabilities population	Estimated numbers Tri-borough
UK	82.1%	956
Middle East	5.2%	61
Western Europe	3.7%	43
Central & Southern Africa	1.9%	22
Caribbean Countries	1.5%	18
Eastern Europe	1.4%	17
South Asia	1.1%	12
North & East Africa	0.9%	11
Far East Asia	0.8%	10
North America	0.7%	8
Latin America	0.5%	6
Antipodean	0.1%	1

Levels of severity of the learning disabilities population

- Currently, Westminster has a FACS threshold of Substantial/ Critical need. The decision to change this was made in January 2011 after consultation
- Hammersmith and Fulham currently has a FACS threshold of Greater Moderate
- Kensington and Chelsea currently has a threshold of Moderate need

The adult social care database is not comprehensive regarding the type of learning disability people have across the three boroughs. Approximate information on people aged 18+ who are known to **Hammersmith and Fulham** services gives an indication of how many may be known across the three boroughs. In Hammersmith and Fulham, out of 460 clients identified:

- Around 80 have challenging behaviour
- Around 50 have autistic spectrum disorder
- Around 50 have profound and multiple learning disabilities
- An estimated 70-80 have Down's syndrome
- Around 6 have Down's syndrome and dementia
- Around 20 also receive CPA (Care Programme Approach) with mental health services

Westminster is likely to have a slightly larger burden than Hammersmith and Fulham, and Kensington and Chelsea a smaller burden, given lower numbers known to services and lower threshold.

1.7 Future changes in the numbers with learning disabilities

Factors influencing the numbers with learning disabilities

The numbers of people with learning disabilities in the population is influenced by a range of demographic factors which influence incidence (number of new cases) and prevalence (numbers of people increasing from improved life expectancy). This is generally increasing the level of *need* in the population, although a declining birth rate in the 1990s has had the opposite effect nationally²¹:

Demographic factors influencing need

- ***Survival rates in infancy*** – babies with learning disabilities are increasingly likely to survive due to technological advances in medicine, where previously they would have died
- ***Life expectancy into adulthood*** – better health and care amongst those with learning disabilities will impact on survival rates into adulthood and old age
- ***A changing overall birth rate*** – changes in overall numbers of births in the population will impact on numbers of new births with learning disabilities e.g. more births in post-war period, declining births in the 1990s, and an increase in the 2000s
- ***A changing ethnic profile*** – certain ethnic groups, such as Pakistani and other ethnic groups, have a higher rate of learning disabilities. Recent increases in the number of people from these groups will impact on numbers with learning disabilities
- ***Changing attitudes towards abortion*** – attitude changes towards aborting children found to have disabilities during testing in pregnancy result in some changes in numbers subsequently born with disabilities

Added to these changes are changes to the structure of informal care networks, which mean that *demand* for services is likely to increase as well:

Factors affecting informal care provision and demand

- ***More lone parent families*** – resulting in families being less able to provide informal care for those with learning disabilities
- ***More women in work*** – meaning they have less time to provide informal care
- ***People with learning disabilities living longer*** – an increasing number of people with learning disabilities will outlive their parents, or will have parents who are frail, and therefore require additional support
- ***An increasing expectation of independence of life*** – changing social attitudes among families mean more expect those with learning disabilities to have a fully independent life from carers
- ***Access to local affordable suitable housing*** – the increasingly high cost of housing locally has resulted in movements out of the area to more affordable areas

Expected change in numbers reaching ‘transition’

Local transition data is at odds with national predictions. It appears to be showing increasing numbers transitioning, with greater levels of complexity

National modelling by Emerson et al^{22,21} suggests the number of people with learning disabilities reaching adulthood and requiring adult social care support – the annual *new incidence* - will drop until 2019. This is a result of a declining birth rate in the 1990s in the general population. However, local examination of numbers reaching transition suggests an *increase* in numbers in recent years, and an increasing proportion with autistic spectrum disorders, complex needs and challenging behaviour.

Although the Tri-borough area generally sees 20 people a year transition from Children’s into Adult services, 36 people are likely to transfer in 2013/14, and 42 in 2014/15 across the three boroughs. One third of these people have ASD, one fifth severe learning disabilities, and one fifth challenging behaviour (with overlaps between categories). See Transition chapter for further detail.

Expected change in numbers of adults with learning disabilities

Approaches used to predict total numbers with learning disabilities suggest an **annual growth rate in the region of 1.5%, with a 10-15% growth in numbers by 2020**. Areas with lower FACS thresholds are likely to see two to three times this level of growth

If numbers known to services locally is a reflection of national demographic changes for the population with learning disabilities, then the numbers known to services in the future is likely to grow substantially. In reality, local factors will also greatly influence the numbers, so these projections should be used as a guide only. There have been several approaches to modelling population change.

PANSI estimates of population growth, 18-64

Estimates of growth in the working age population with learning disabilities have been calculated by applying national findings from previous modelling from Emerson et al to local population projections for the general population. These predict annual growth in the number of adults 18-64 with learning disabilities of around 1.5%. This yields an 11% increase by 2020 and 23% increase by 2030.²³ Local authority estimates of growth calculated in this way may not be reliable, as the profile of the learning disabilities population does not always follow the same patterns as changes in the general population (in the general population, the number and ages structure of residents is less influenced by life expectancy and birth rates and much more influenced by movements in and out of the boroughs).

Emerson estimates of population growth, 2011, all ages

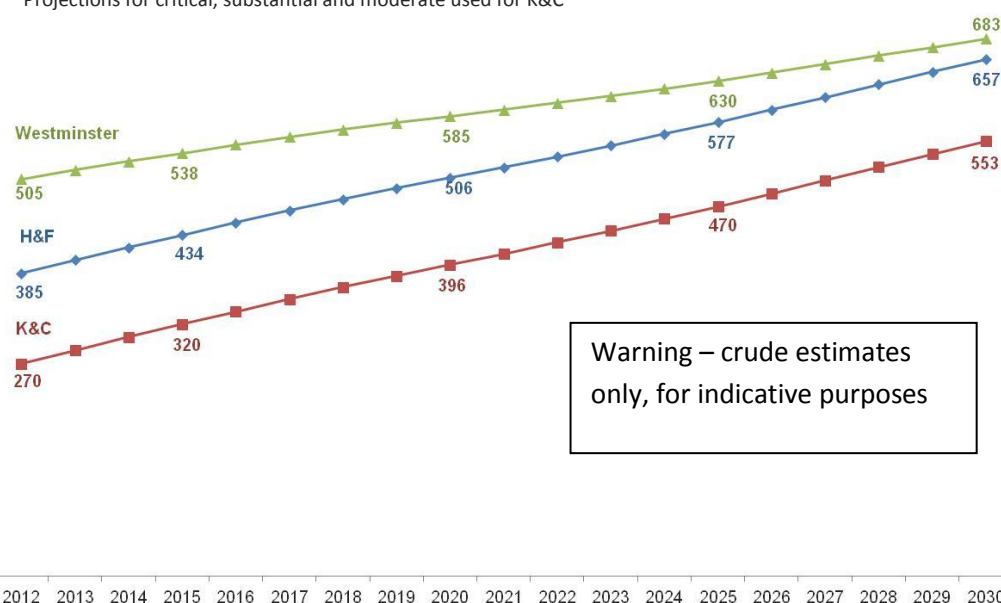
Emerson et al calculated a more robust range of projections for numbers known to social services in the future. Projections are very sensitive to the level of access: areas with a threshold of critical and substantial have a much slower forecasted rate than areas with moderate threshold.²¹

Chart 1f: Predicted change in number of working age adults with learning disabilities known to social services over time, assuming national predictions occur locally

Projections for critical and substantial used for Westminster

Projections for critical, substantial and 50% moderate used for H&F (Greater Moderate)

Projections for critical, substantial and moderate used for K&C



Borough	Threshold	Annual growth	By 2020	By 2030
Westminster	Critical and substantial	1.7%	+16%	+35%
Hammersmith & Fulham	Critical, substantial, 50% moderate (Greater Moderate)	3.1%	+32%	+71%
Kensington & Chelsea	Critical, substantial, moderate	4.2%	+47%	+105%

Expected number of older people using social care services

Recent modelling suggests that for those aged 50+, there will be an **annual growth rate in the region of 0.7%**, with a **5% growth by 2020** and a **13% increase by 2030** – around 20 more by 2020 and 50-60 more by 2030. These figures are approximate

The Emerson modelling²¹ predicts a 14% increase in numbers of older people aged 50+ using social care services from 2011 to 2030, or around 0.7% a year. This broadly equates to a 5% increase from 2013 to 2020, and 13% increase by 2030. Although proportionate growth is much higher in the older age bands, there are fewer numbers in these age groups, and therefore smaller growth in actual numbers of people.

Table 1n: Estimates of rise in numbers of older people (50+) using social care services in the Tri-borough councils over time. *Caution: estimate only*

Age band	Current estimate of numbers known to services (Tri-borough)	Expected numbers 2020	Expected numbers 2030
50+	431 (estimate)	452 (+21)	487 (+56)

The number of older people requiring services is of critical importance for planning housing and care needs: increasing life expectancy for people with learning disabilities means many will outlive their parents, who may be principal carers for them. Diseases such as dementia, which is more than three times as common in the learning disabilities population for those over 65 than the general population, will impact on people's needs, as will some other common health conditions.

2. HEALTH STATUS

Key messages

- **Age at death** of people with learning disabilities is well below the national average. Expected age at death varies enormously by the severity of the condition: those with mild learning disabilities would be expected to live close to the national average, whereas those with profound and multiple learning disability may typically die in their forties, barely half the age of those in the general population.
- The **factors influencing ill-health and mortality** for those with learning disabilities are complex, but involve (1) the higher health impact of the condition itself (2) problems accessing timely and effective healthcare and (3) social impacts on health, like housing, poverty, and education
- **Respiratory disease** accounts for half of all deaths nationally, with cardiovascular disease the second most common. A recent confidential enquiry found half of deaths could be considered 'premature', and another study found around 1 in 5 deaths could have been avoided with good care. Lung problems (from solids or liquids going down the wrong way) and epilepsy/ convulsions alone account for around 13-14% of deaths nationally.
- **Local disease registers** show many of the trends identified nationally, with prevalence of depression, diabetes, hypothyroidism, asthma, chronic kidney disease, severe mental illness and epilepsy are all markedly higher than in the general population (20 times higher in the case of epilepsy).
- **Solutions for tackling health inequalities** experienced by people with learning disabilities focus on: early identification of illness and disease; tackling social determinants which impact on poor health; improving the 'health literacy' of those who support people with learning disabilities; improving the knowledge and skills of health workers; making 'reasonable adjustments' in a range of settings; and improving understanding through further research

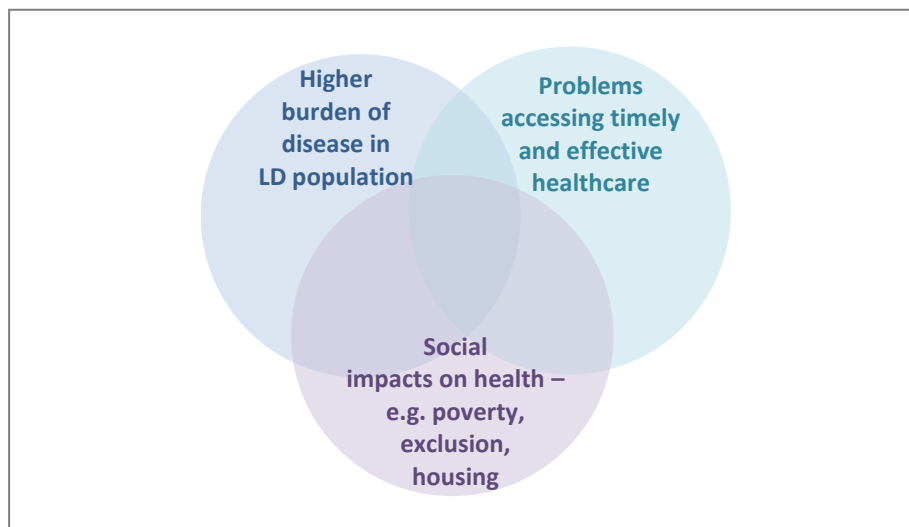
Recommendations:

- To work with housing, leisure services and care providers around issues relating to the promotion of leisure facilities and the tackling of obesity for people with learning disabilities
- Work with GPs around referrals to secondary healthcare, such as ensuring that GP IT systems are able to 'flag' whether reasonable adjustments are needed in secondary care
- Continue working with acute hospitals to ensure reasonable adjustments are made to enable people to access services easily for those with learning disabilities and autistic spectrum disorders. A Tri-borough inpatient audit into service users' experiences is currently being carried out which will help to improve the quality of the service
- To report causes of death of those with learning disabilities, to give indications of possible preventability (e.g. lung problems / epilepsy)

2.1 Background

Those with learning disabilities have significantly poorer health than the general population and experience substantial health inequalities. Whilst many with learning disabilities have complex health needs, a proportion of the inequality relates to conditions common to the general population. These are often left untreated due to challenges around identifying conditions and barriers to accessing services in a timely and effective way. Therefore, effective and joined up commissioning and service provision is likely to result in a narrowing of the inequalities 'gap'.²⁴

Chart 2a: Summary of factors impacting on health of those with learning disabilities



2.2 Mortality and life expectancy

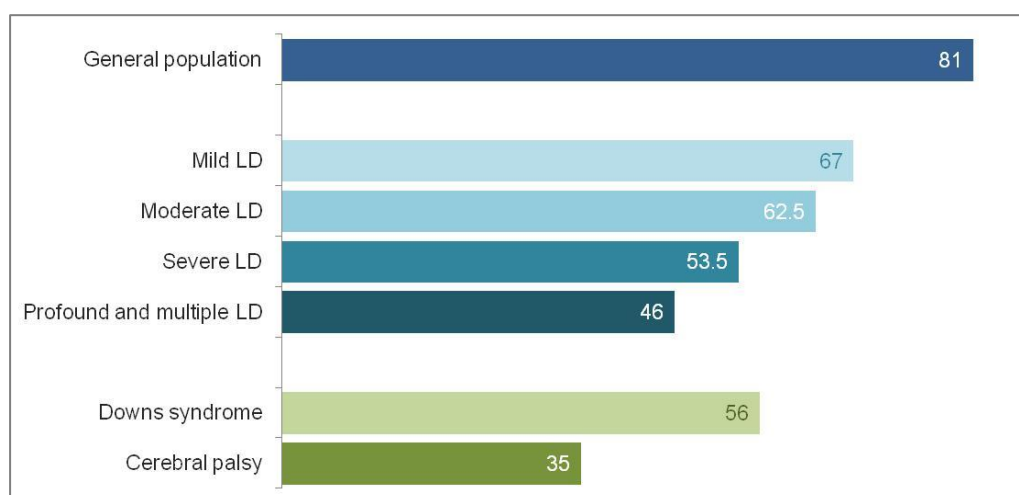
People with learning disabilities experience shorter life expectancy than the general population. Whilst there have been improvements in life expectancy and rates for those with mild learning disability is close to that of the general population, mortality for those with moderate to severe learning disability is around three times higher than in the general population. Although mortality from Down's syndrome has been dropping, it is still low, with a life expectancy of around 56.

In 2011, the average (median) age of death of those with learning disabilities was 57 years of age in England (and around 47 in London)²⁵. This is around 23 years less than the median age in the general population, which is 81. Figures²⁶ suggest median age at death for those with Down's syndrome is around 56, with cerebral palsy around 35. Thorpe (2000) suggests most adults with a learning disability who live past the third decade are likely to live into old age.

A recent confidential enquiry into the deaths of people with learning disabilities in the Southwest²⁷ found that 56% of the deaths were considered by experts to be 'premature', based on the specific circumstances of the death, and half were unexpected. Over half of all deaths were from cardio-respiratory causes.

Chart 2b: Median age at death by severity and type of learning disability

Note difference sources used for chart (Southwest Confidential Enquiry for mild/moderate/severe/ PMLD; Learning disabilities Observatory for remainder)



2.3 Burden of ill-health and causes of death^{253,26}

Main causes of death

Respiratory disease is the most common cause of death among people with learning disabilities (49%, compared to 16% in the general population). Coronary heart disease (CHD) is also one of the main causes of death, accounting for around 17% of deaths. Increasing life expectancy among people with learning disabilities is associated with a lower but growing burden of CHD among the learning disabilities population. The burden of CHD on those with Down's syndrome is also large, with half the population suffering from congenital heart defects.

Avoidable death

National published figures suggest 1 in five (18.8%) of deaths among the learning disability population could have been avoided with good medical care, compared to just over half that (10.4%) among the general population. A recent study identified lung problems (from solids or liquids going down the wrong way) and epilepsy/convulsions as two areas specific to the learning disabilities population that may have been potentially avoidable, each accounting for 13-14% of deaths. These two conditions are not included in the avoidable deaths data detailed above.

It has not been possible to link data locally to understand the burden of mortality in the Tri-borough area, and numbers are likely to be very small and therefore not reliable enough for analysis.

2.4 Common conditions

Summary of common conditions for people with learning disabilities

The main conditions suffered by people with learning disabilities has been summarised below. Table 2a has greater detail on these areas.

Common chronic disease	Physical and sensory impairment
<ul style="list-style-type: none"> Respiratory disease and chest infections Coronary heart disease Endocrine disorders Mental health problems (including dementia) Epilepsy 	<ul style="list-style-type: none"> Physical impairment (e.g. postural distortion and hip dislocation) Sensory impairment (e.g. visual impairment) Eating and swallowing problems Poor oral health Constipation and incontinence

Local disease burden¹⁹

Locally, the learning disabled population are more than twice as likely to have at least one chronic disease compared to the general Tri-borough population, with nearly two thirds doing so (see Chart 2c). Prevalence of depression, diabetes, hypothyroidism, asthma, chronic kidney disease, severe mental illness and epilepsy are all markedly higher than in the general population.

Chart 2c: Number of diagnosed chronic diseases among the GP-registered learning disabilities population in the Tri-borough area

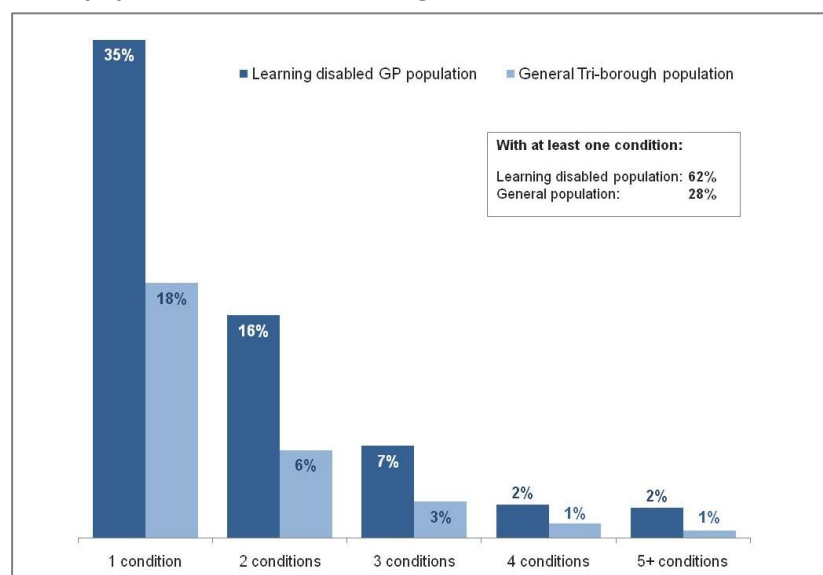
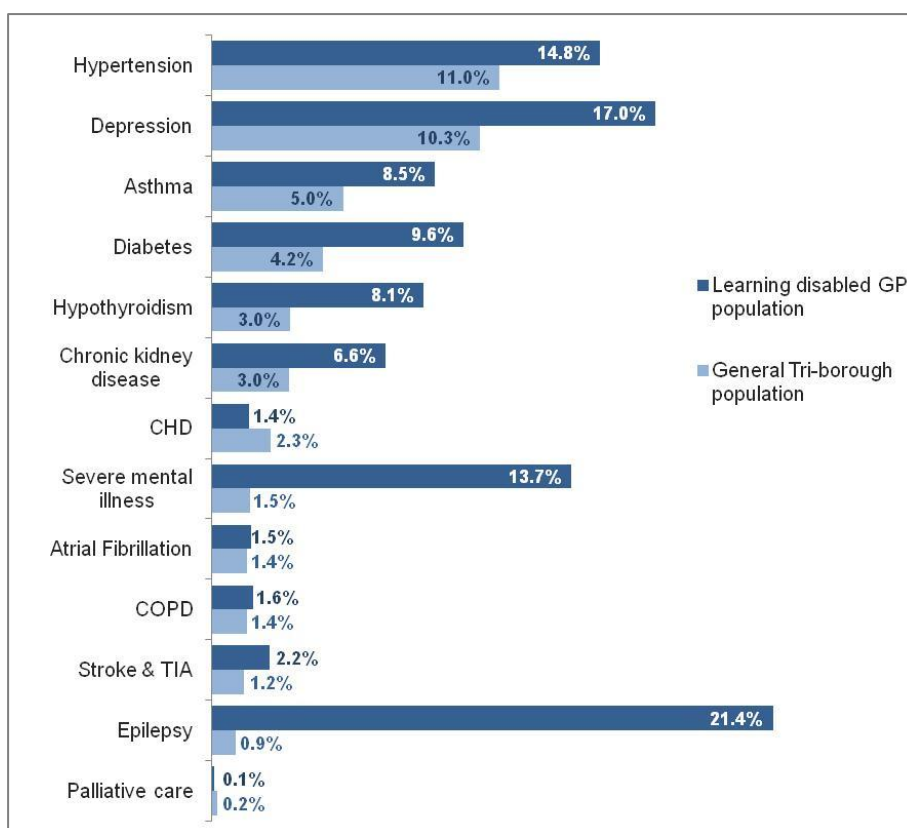


Chart 2d: Type of diagnosed chronic diseases among the GP-registered learning disabilities population in the Tri-borough area



The burden of conditions common to those with learning disabilities has been summarised in Table 2a below.

Table 2a: Type of diagnosed chronic diseases and conditions among the GP-registered learning disabilities population in the Tri-borough area

Condition	What we know nationally ^{25,26}	Local Tri-borough picture ¹⁹
Respiratory disease	<ul style="list-style-type: none"> Most common cause of death (49% compared to 16% or 26% in general population). Lung problems (from solids or liquids going down the wrong way) account for 13% of all deaths but may be preventable. Particularly common for those with cerebral palsy 	<ul style="list-style-type: none"> Higher rates of asthma (8.5% of adults, or 100 people). Slightly higher rates of COPD (1.6% or 20 people)
Circulatory disease	<ul style="list-style-type: none"> As with the general population, CHD is one of the most common causes of death and ill-health (12% of deaths compared to 29% in general population). Half of those with Down's syndrome have a congenital heart defect 	<ul style="list-style-type: none"> Lower rates of CHD (1.4% or 20 people) compared to 2.3% in Tri-borough population. Much higher rates of hypertension (14.8%, or 170 people). Higher rates of stroke/TIA (2.2%; 30 people). Atrial fibrillation 1.5%; 20 people
Endocrine disorders	<ul style="list-style-type: none"> Diabetes is more common than in the general population, influenced in part by higher rates of obesity. Hypothyroidism is common among those with Down's syndrome 	<ul style="list-style-type: none"> Hypothyroidism more than twice as high as Tri-borough population (8.1% or 90 people). Diabetes twice as high population (9.6% or 110 people). May influence high chronic kidney disease (CKD) rate (6.6%, compared to 3.0%; 80 people)
Epilepsy & convulsions	<ul style="list-style-type: none"> Epilepsy found to be around 20 times more common than in general population. Epilepsy & convulsions account for 14% of deaths, many likely to be preventable. Seizures are often multiple and also resistant to drug treatment 	<ul style="list-style-type: none"> Epilepsy more than 20 times as common as in Tri-borough population (21.4% or 1 in 5 of the learning disabilities population, compared to 0.9% in Tri-borough population; 250 people)
Mental ill-health	<ul style="list-style-type: none"> Prevalence rates for schizophrenia around 3 times higher than general population and high for South Asian adults. Anxiety and depression higher than general population, particularly among those with Down's syndrome 36% of children with learning disabilities have a psychiatric disorder compared to 8% in general population Of all children with a psychiatric disorder, 14% have learning disabilities 	<ul style="list-style-type: none"> Severe and enduring mental illness – common in 13.7% of the learning disabled population (9 times more common than Tri-borough population; 160 people). History of depression is common in 17% of the learning disabled population, or 200 people, 1.7 times the Tri-borough rate 23 patients in Kensington and Chelsea with a mental health problem under review; 21 in Hammersmith and Fulham

Challenging behaviour	<ul style="list-style-type: none"> Aggression, destruction and self-injury common among 10-15% of learning disabilities population, most common among 20-49 year olds Self-injurious behaviour may be common among a quarter of people with learning disabilities Challenging behaviour likely to result in poorer health and is associated with abuse, inappropriate treatment and neglect 	<ul style="list-style-type: none"> Estimated 120-180 people locally with challenging behaviour and 300 with self-injurious behaviour 32 patients in Kensington and Chelsea with challenging behaviour, 7 of whom display severe challenging behaviour and 7 of whom display self-injury Around 80 patients in Hammersmith and Fulham with challenging behaviour
Dementia	<ul style="list-style-type: none"> Dementia more common in learning disabilities population than general population (22% compared to 6% for aged 65+). Those with Down's syndrome develop dementia 30-40 years earlier than general population 	<ul style="list-style-type: none"> Estimated that around 25 people aged 65+ known to local services may have dementia. May also be significant numbers with dementia and below the age of 65 6 people in Hammersmith and Fulham have both Down's syndrome and dementia
Physical impairments	<ul style="list-style-type: none"> Postural distortion and hip dislocation more common among learning disabilities population Being non-mobile associated with sevenfold increase in death and partly mobile with twofold increase 	<ul style="list-style-type: none"> No local data
Visual impairment	<ul style="list-style-type: none"> Evidence^{28 29} suggests that around one in 10 adults with learning disabilities are likely to be blind or partially sighted, which is ten times higher than the general population. Six out of ten people with learning disabilities need glasses 	<ul style="list-style-type: none"> Estimated 120 adults known to services in the Tri-borough area who are blind or partially sighted.
Eating and swallowing problems	<ul style="list-style-type: none"> 8-15% of those with learning disabilities have difficulties and may need mealtime support 4 out of 10 of those having difficulties have recurrent respiratory tract infections 	<ul style="list-style-type: none"> Estimated 100-200 adults may have difficulties and may need support, with 50-100 likely to have recurrent respiratory tract infections
Oral health	<ul style="list-style-type: none"> 1 in 3 adults with learning disabilities and over three quarters of those with Down's syndrome have unhealthy teeth and gums Those living with families have more untreated decay; those in institutional care have more extracted teeth 	<ul style="list-style-type: none"> Estimated 400 adults may have unhealthy teeth and gums, including 60-80 with Down's syndrome
Constipation and incontinence	<ul style="list-style-type: none"> Constipation common in 17-51% of those in institutional care Common side-effect of drugs prescribed, but often missed due to communication problems A third of adults and two thirds of children with profound and multiple learning disabilities have difficulties of urinary incontinence A quarter of those with profound and multiple learning disabilities have difficulties with bowel incontinence 	<ul style="list-style-type: none"> No local data Constipation likely to be common in around 50-150 adults in institutional care Estimated 40-50 adults and 20 children with PMLD likely to have urinary incontinence Estimated 30-40 adults and 8-10 children with PMLD likely to have bowel incontinence

2.5 Lifestyles^{253,26,19}

Smoking, drinking, and drug use

Nationally, levels of smoking and drinking among those known to learning disabilities services are slightly lower than in the general population, which is also the case locally for smoking (see Table 2b below). Local data identifies a slightly higher rate of at-risk drinking (based on Hammersmith and Fulham data only). Males, and those with mild learning disabilities, were most likely to abuse substances. Local services suggest cannabis use is not uncommon among those with mild learning disabilities, and exploitation to sell illicit drugs has also occurred in some instances.

Table 2b: Smoking and at-risk drinking in the Tri-borough area

	Rates		Expected numbers by borough		
	Learning disabled GP population	General Tri-borough population	H&F	K&C	West
Current Smokers	17.6%	19.8%	62	54	89
At-Risk Drinkers (H&F only)	3.0%	2.4%	11	9	15

Diet, exercise and obesity

Less than 10% of adults living in supported accommodation eat a balanced diet, with low levels of fruit and vegetable intake.

Less than a quarter of those with learning disabilities take part in regular exercise at the Department of Health recommended minimum level, compared to around half for the general population. The challenges associated with living in a restricted environment contribute to inactivity.

Obesity is far more prevalent in the learning disabilities population than the general population, with women, people with Down's syndrome, and those living in less restrictive environments such as in their own homes particularly at risk. Underweight is also more common among people with learning disabilities.

One focus of work around tackling lifestyle issues locally is the use of audit tools by learning disabilities teams to monitor the quality of health checks. In particular, those providing supported housing schemes will be regularly checked to see if their residents have had a health check and whether health action plans are delivered on

Sexual health

Research has identified that people with learning disabilities often face barriers to experiencing good sexual health. The sexuality of people with learning disabilities is not routinely acknowledged, and needs are often ignored. People with learning disabilities may feel overprotected by professionals and family carers which can result in them being unable to express their sexuality. People with a learning disability complain about a lack of information and this may have resulted in a poorer knowledge of their bodies and sexuality.

2.6 Self-reported health of people with learning disabilities (from the Statutory Adult Social Care User Experience Survey)³⁰

Despite the considerable health issues for people with learning disabilities, seven out of ten respondents to the Users Survey in the tri-borough area stated they had good or very good health in 2011/12. This is slightly better than nationally, but probably not significantly so.

Chart 2e: Self-reported health, Adult Social Care Survey 2011-12



2.7 Reducing inequalities experienced by those with learning disabilities

A recent report for the national Learning Disabilities Observatory *Health Inequalities & People with Learning Disabilities in the UK, 2012*²⁴ identified a number of solutions for reducing inequalities among those with learning disabilities. These have been summarised below:

Solutions for tackling inequalities among those with learning disabilities

Summarised from Health Inequalities & People with Learning Disabilities in the UK: 2012

- Reduce the exposure of people with learning disabilities to **social determinants**: poverty, poor housing, unemployment, social disconnectedness and discrimination
- Improve the **early identification** of illness through annual health checks and cervical and breast screening
- Enhance the **health literacy** of people who play a critical role in promoting healthy lifestyles: e.g. family and carers
- Enhance healthcare workers' **knowledge and skills** for working with people with learning disabilities
- Make '**reasonable adjustments**' in all areas of health promotion and healthcare, and act within the legal frameworks of the Equality Act 2010 and the Mental Capacity Act 2005 (e.g. by providing more accessible information and longer appointments)
- Build a more robust **evidence-base** of the determinants of health inequalities among people with learning disabilities, and effectiveness of interventions to reduce them. Monitor progress towards the elimination of these health inequalities

3. HEALTH SERVICE USE

Key messages

- People locally with learning disabilities and their carers have suggested that **improvements can be made to General Practice** to accommodate their needs more, around communication and process. In particular, they suggest more training may be needed to aid communication, particularly around avoiding jargon, understanding their condition and, where possible, using pictures and slower speech to get points across more effectively. They also felt shorter waiting times, double appointments, and seeing the same GP each time would help improve quality and access to care.
- GP-initiated **health checks** are effective in highlighting previously unidentified health needs and conditions among the learning disabilities population. 2012/13 has seen substantial drops in health checks achieved in Westminster and Kensington and Chelsea (Westminster was previously the 5th highest in London). Hammersmith remains similar to the London average
- There is limited available evidence around update of **cervical and breast screening** but rates appear to be low compared to the general population.
- Significant challenges still exist around **oral health**, particularly the high number of patients needing treatment under general anaesthetic and the high did not attend rate
- Hospital **emergency admissions** are twice as common in the learning disabilities population compared to the general population. Associated cost locally - £480 a year – was two and a half times as high (overall cost per year across all hospital settings was £1,000 a year). Epilepsy was the most common cause of admission, followed by pain in the throat/ chest and abdomen/ pelvis, as well as urinary infection.
- Local people with learning disabilities and their carers have suggested a number of **changes to hospital care** that might make it more suitable and effective for them. In addition to communication issues common to those for general practice, they mentioned that staff should be willing to learn from parents, and should consider parents/ carers as equal to staff in their knowledge and expertise. They want more signage in hospitals, better waiting areas and less waiting, and a 'flag' system to tell people they have learning disabilities.
- Local service users also requested that secondary health provision takes account of the impact on them in relation to **transport needs**, or the cost of additional support to accompany them to hospital if facilities are further away.

Recommendations:

- To ensure that work with general practice and hospital trusts is addressing issues raised by local families
- To address data quality issues around numbers attending cervical and breast screening and develop actions to improve uptake where necessary
- To improve systems around health checks to address the recent drop in uptake. This could be addressed through monitoring at a small area (GP locality) level
- To work with dentistry services in the community and secondary services to make further adjustments to enable service users with complex and challenging behaviour to access the service e.g. designated slots when there are fewer patients and minimise waiting times

3.1 Primary care use

Consultations with their GP

Studies²⁴ have established that people with learning disabilities visit their GP at a similar frequency to the general population, which does not reflect their greater burden of ill-health. This may in part be explained by collaboration between GPs, primary health care teams and specialist services which, in the past, been reported as poor. **Error! Bookmark not defined.** There is no recent local data to establish this.

What people with learning disabilities and their carers have said in the Tri-borough area about their GP care. Views collected at the Hammersmith and Fulham, Kensington and Chelsea and Westminster Big Health Check days, 2012-13³¹

Communication and staffing

- “Some GPs know the service user has learning disabilities but don’t know how to deal with it. For example, some people with learning disabilities do not like to be touched”
- “Please don’t use medical jargon. Slow down speech”
- “More pictures needed, with big, simple words”
- “Receptionists should be trained about their attitudes towards people with learning disabilities. They are not very understanding”

Processes and systems

- “Appointment times need to be longer – service users need to be given time to talk. Double appointments are given but are sometimes not available”
- “Can it be arranged that people with learning disabilities see the same GP and nurse each time?”
- “I feel frustrated making an appointment – press 1, 2 etc”
- “Can they use texting to remind me of appointments, and big, simple letters so I can read them myself?”
- “GPs are the worst place to go because you have to wait up to two hours to get seen. Can they make waiting times shorter?”

3.2 Health checks and screening

Health checks

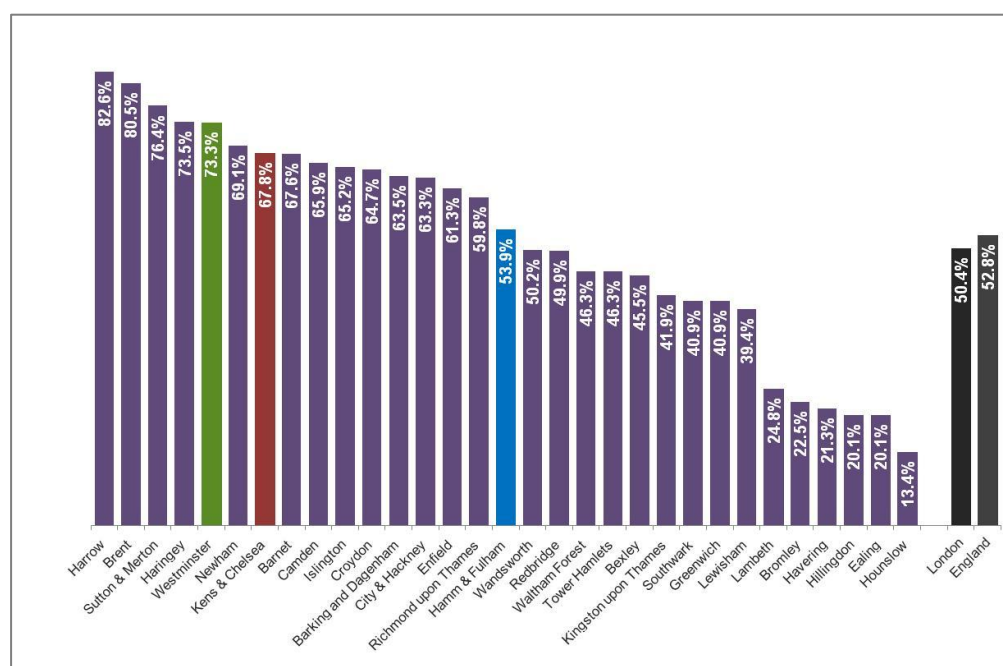
Those with learning disabilities have poorer health than the general population. This is partly due to challenges identifying and diagnosing ill-health and common conditions which may even become life-threatening over time.

There is good evidence to suggest that GP-initiated health checks are effective in highlighting previously unidentified health needs and conditions among the learning disabilities population, which allows for appropriate care and onward referral.^{24, 32}

Since 2009, annual health checks have been provided by GPs to adults with learning disabilities who are known to both their GP and council service, as part of a nationally agreed Directed Enhanced Service scheme. In some parts of the country, PCTs have funded a more comprehensive scheme covering all those on GP registers, regardless of social care crossover.

All three PCTs had a greater uptake of annual health checks among the learning disabilities population in 2011/12 than London and England³³. Rates, which have remained stable over the last few years, were particularly high in Westminster (see Chart 3a).

Chart 3a: Proportion of eligible patients receiving an annual health check, 2011/12



Data for **2012/13** identifies drops in two of the boroughs. No comparator data is available yet³⁴. Figures show:

- A **drop** in Westminster from 73.3% to 66.8%
- A **drop** in Kensington and Chelsea from 67.8% to 55.7%
- A similar figure in Hammersmith and Fulham (53.9% to 54.1%)

A 2012 commissioning guide for CCGs suggested a target rate of 90% uptake of health checks. In order to achieve this rate Westminster would have needed to provide 118 more health checks during the year, Kensington and Chelsea 73 more, and Hammersmith and Fulham 117 more. However, more recent guidance ranks 80% as a target, meaning the increase needed would be considerably less.

SAF Self-assessment scores:⁷

PCTs assessed themselves against a range of standards in 2012/13, with Level 1 being the lowest rating and level 3 being the highest

All three PCTs reported themselves as Level 3 for A3. *Disease prevention data*. Seven other PCT areas in London reported Level 3, six reported Level 1, and the remainder Level 2 (some comparative data but not for all areas).

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A3. Data on access to disease prevention and screening by people with learning disabilities compared to general population is collected, with comparator data	Level 3	Level 3	Level 3

All three PCTs reported themselves as Level 3 for A4. *DES Register Validation*. Fifteen other PCT areas in London reported Level 3, three reported Level 1, and the remainder Level 2.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A4. The Learning Disability DES register is validated at least on a yearly basis, with process for putting people on register	Level 3	Level 3	Level 3

All three PCTs reported themselves as Level 3 for A5. *Annual Health Checks*. Just two PCTs reported Level 3 (90% uptake), six reported Level 1, and the remainder Level 2.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A5. Level 2: 50% of people with LD had an annual health check	Level 2	Level 2	Level 2

Hammersmith and Fulham reported themselves as Level 2 for A6. *Annual Health Action Plans* and the other two reported Level 3. . Just two other PCTs reported Level 3, 11 reported Level 1, and the remainder Level 2.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A6 Level 2: GP annual health check data indicates a Health Action Plan has been completed for 70% of patients	Level 2		
A6 Level 3: Health Action Plans are completed and contain health improvement targets identified during the annual health check for 50% of patients		Level 3	Level 3

Cervical screening

In Hammersmith and Fulham, out of 106 women eligible, 25 have been screened (24%)³⁵. Data is not currently available for the other two boroughs.

Breast Screening

In Hammersmith and Fulham, out of 44 women eligible, 16 have been screened (36%)³⁵. Data is not currently available for the other two boroughs, but systems are being put into place to gather this accurately in the future.

Routine dental care

People with learning disabilities may not always be able to articulate problems they are having with oral health, and in some cases may present pain and discomfort through challenging behaviour. Treatment may also need to be provided in different settings, such as secondary care, if the individual cannot cooperate or has a complex condition. This creates its own challenges around appropriateness of environment.³⁶

Recent analysis³⁷ in Westminster highlighted that at least one quarter of people with learning disabilities were not seen by a dentist within the last year. Of those seen by a dentist 35% were seen within the Community Dental Service and 35% by a local General Dental Practitioner. Reviews of Action Plans locally have identified the following issues:

- Extremely low uptake of care from high street dentists, with the majority of service users making use of the Community Dental Service
- A high number of service users requiring dental treatment under sedation/general anaesthetic
- Very high 'DNA rates' - far greater than in the general population
- A lack of support from services for people with their oral hygiene
- Poor levels of oral hygiene of people in residential care in particular

Assessment for hearing and visual impairments

Evidence^{38 39} suggests that around one in 10 adults with learning disabilities are likely to be blind or partially sighted (ten times higher than the general population) and six out of ten people with learning disabilities need glasses.

In addition, significant barriers to effective screening for visual impairment exist⁴⁰: carers of people with learning disabilities frequently fail to identify sensory impairments, and people living independently or with family are less likely to have had a recent eye examination than people living with paid support staff.

Those with learning disabilities eligible for a health check should be involved in a series of screening questions around difficulties with vision.

Reasonable adjustments⁴¹

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 means commissioners will now have to ensure that those they commission services from regularly assess and monitor the quality of their services. Part 4, paragraph 9 (iv) includes the requirement to make *reasonable adjustments* and avoid unlawful discrimination. A definition of reasonable adjustments has been provided in Appendix A.

Health service organisations will therefore need to consider in advance what adjustments people with learning disabilities need, examples being accessible information and appointment systems, longer appointments and extra support. The annual health check is also an example of this.

SAF Self-assessment score:⁷

PCTs assessed themselves against a range of standards in 2012/13, with Level 1 being the lowest rating and level 3 being the highest

All three PCTs reported themselves as Level 2 for A7. *Screening - comparative data*. Two PCTs in London reported Level 1, 7 level 3, and the remainder Level 2

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A7. Data is collected on numbers completing health screening (cervical, breast, bowel, attended, refused, exempt)	Level 2	Level 2	Level 2

Westminster reported themselves as 'Level 3' for A2. *Primary care communication of LD status to other healthcare providers*, as did five other PCTs in London. The other two PCTs reported Level 2. Three PCTs in London reported Level 1.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A2. Level 2: A CCG wide system exists for noting that the person has learning disabilities and any <i>reasonable adjustments</i> required on onward referrals.	Level 2	Level 2	
A2. Level 3: Secondary care/ other providers can evidence a system for identifying LD status for referrals and reasonable adjustments			Level 3

Hammersmith and Fulham reported themselves as Level 2 for A8. *NHS Commissioned wider primary and community care* and the other two reported Level 3. Three other PCTs reported Level 3, just one reported Level 1, and the remainder Level 2.

SAF Indicator	Reported outcome 2011/12		
	H&F	K&C	Westminster
A8 Level 2: Some NHS Commissioned wider primary and community care services can provide evidence of reasonable adjustments and plans for service improvements	Level 2		
A8 Level 3: All services can provide evidence of reasonable adjustments and plans for service improvements. All service users are known and patient experience is captured		Level 3	Level 3

3.3 Acute care

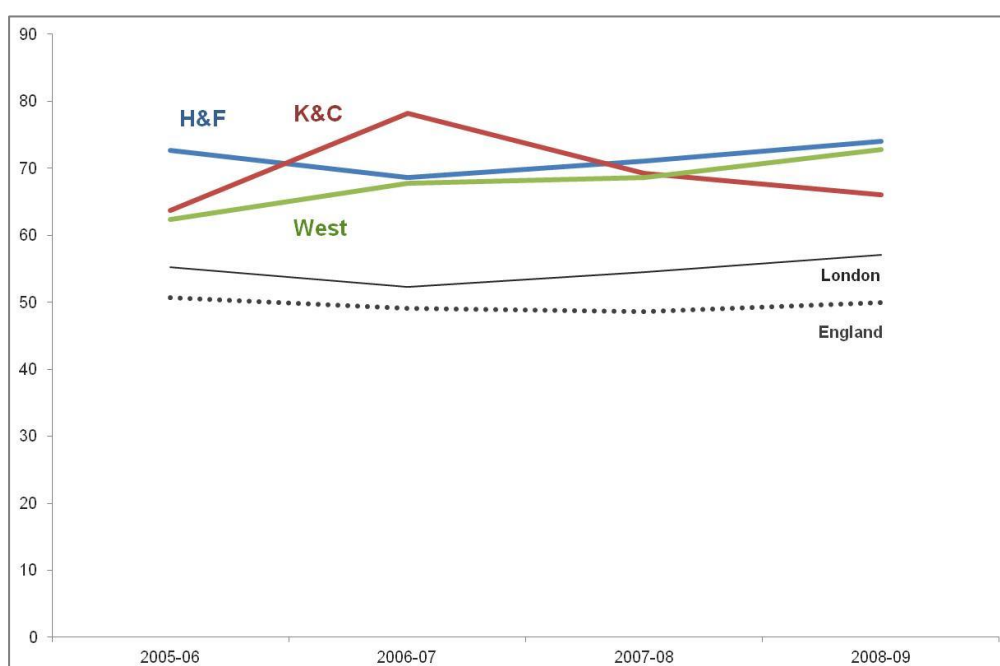
Studies have found that people with learning disabilities have an increased uptake of medical and dental hospital care but a reduced uptake of surgical specialities compared to the general population.

Proportion of admissions which are emergency

Analysis of hospital admission data for learning disabilities identifies a higher proportion of admissions which are emergencies compared what is typical in the general population.⁸ Local data from 2012/13 identifies around 57% of admissions for adults with learning disabilities which are emergencies, compared to 30% in the general population, twice as common.⁴²

Historical data also shows the tri-borough area as having a much higher proportion of admissions which are emergency than is typical for London and England, although recent data (see above) suggests it may have dropped down to a more comparable rate.

Chart 3b: Proportion of all hospital admissions for learning disabilities which are emergencies, 2005/6 to 2008/9



Cost of hospital admissions⁴²

The average hospital cost for adults with learning disabilities in the Tri-borough area in 2012/13 was just under £1,000 per person per year, twice that of the general adult population. For emergency admissions, it was over two and a half times higher.

Table 3a: Average cost of hospital care for adults in the general population, and for adults with learning disabilities, 2012/13

	Elective	Emergency	A&E	Outpatient*	TOTAL
Adult – Tri-borough pop	£125	£170	£45	£130	£470
Adult – with LD	£220	£480	£105	£155	£960
Tri-borough estimate	£265,000	£580,000	£130,000	£190,000	£1,165,000

*9 months of data scaled up

Common reason for emergency hospital admissions⁴²

Emergency hospital admissions were for a range of different diagnoses. The most common were for epilepsy, pains, and urinary disorders:

Table 3b: Proportion of all hospital admissions for learning disabilities which are emergencies, 2005/6 to 2008/9

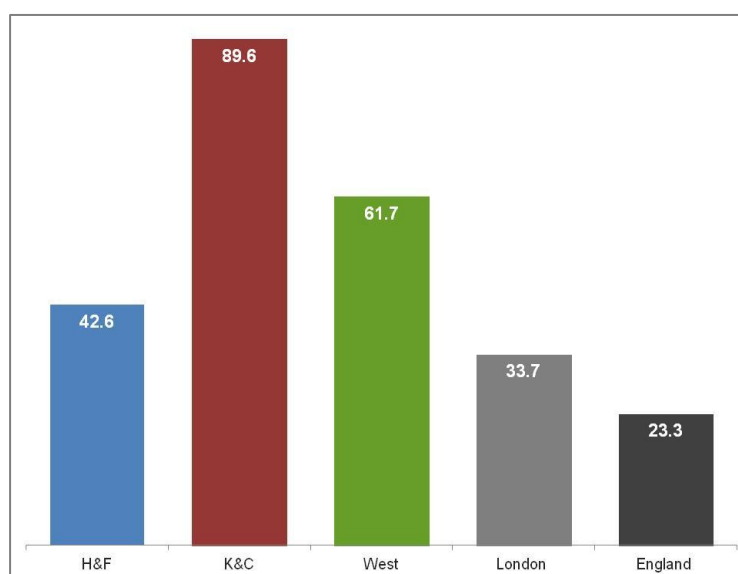
Diagnosis (3 digit ICD10)	Estimated emergency admissions Tri-borough 2012/13	Percent of total emergency admissions
Epilepsy	33	10.1%
Pain in throat and chest	18	5.5%
Abdominal and pelvic pain	15	4.6%
Other disorders of urinary system	15	4.6%
Pneumonia, organism unspecified	11	3.4%
Dizziness and giddiness	8	2.5%
Cellulitis	7	2.1%
Insulin-dependent diabetes mellitus	7	2.1%
Other functional intestinal disorders	7	2.1%
Syncope and collapse	7	2.1%
Asthma	6	1.7%
Open wound of head	6	1.7%
Other chronic obstructive pulmonary disease	6	1.7%
Other diseases of digestive system	6	1.7%
Schizophrenia	6	1.7%
Unspecified nonorganic psychosis	6	1.7%
<i>Other</i>	167	50.8%
TOTAL	329	100%

Ambulatory care sensitive conditions

Nationally, around 8% of all learning disabilities admissions were emergency admissions for ambulatory care sensitive (ACS) conditions, compared to 5% in the general population. The emergency admission rate for ACS conditions in the learning disabilities population is estimated to be at least 5 times higher than in the general population, partly because the emergency admission rate generally is much higher. ACS conditions are conditions which, given effective management at the primary care level, should not normally result in an admission to hospital.⁴³

The study, which used data from 2004-08, found the Tri-borough area to have among the highest ACS rates per learning disabilities population, in common with other urban areas. This may be partly explained by better access and better recording. Similar analysis from 2005/6 to 2007/8 identified high rates of non-psychiatric admissions, statistically so in Kensington and Chelsea (annual average: 18 admissions in H&F, 35 in K&C, 39 in Westminster). Psychiatric admissions over the same period were also high, although still relatively rare (annual average: 4 admissions in H&F, 2 in K&C, 5 in Westminster).⁴⁴

Chart 3c: Admission rates for non-psychiatric ambulatory care sensitive conditions for people with learning disabilities, 2005/6 to 2007/8



Patient feedback on hospital services

The *Death by indifference*⁴⁵ report highlighted a number of issues that required attention:

- Lack of basic care
- Poor communication
- Delays in diagnosis and treatment
- Failure to recognise pain
- Inappropriate use of Do Not Resuscitate orders (DNAR) and failure to fully implement the Mental Capacity Act 2005
- Poor handling of complaints

What people with learning disabilities and their carers have said in the Tri-borough area about hospitals Views collected at the Hammersmith and Fulham, Kensington and Chelsea and Westminster Big Health Check days, 2012-13³¹

Communication and staffing

- “People with learning disabilities can get frustrated and stressed out if they are not listened to”
- “Staff should be willing to learn from parents”
- “Staff should consider parents/ carers as equal to staff”
- “People with complex needs should have 1:1 staff in hospital”
- “Hospital staff need more training about those with learning disabilities”
- “It’s difficult to understand what doctors say – they use long words and don’t explain what they mean. Doctors speak to the carers and not the individual”
- “When services change and people have to go for appointments in lots of places, it becomes confusing”
- “Surgeons need to take the time to explain surgery”
- “When the liaison nurse is in hospital, you can feel confident and safe”

Physical environment

- “Waiting areas are inadequate – people feel unsafe, scared and start screaming. Very distressing and unsafe”
- “Better signs are needed in hospital”
- “Things should be made easier for parents to stay in hospital with their son/ daughter (useful when there are delays)”

Processes and systems

- “More preparation is needed to plan for hospital appointments”
- “More help needed once discharged home from hospital”
- “It’s boring to say the same thing over and over again”
- “Can there be a ‘flag’ process?”
- “Need more advocacy in hospital – trained LD advocates”
- “We should promote communication passports”

Local service users also requested that secondary health provision takes account of the impact on them in relation to transport needs, or the cost of additional support to accompany them to hospital if facilities are further away.

3.3 Other Clinical Services

Tri-borough clinical psychology services for adults with a learning disability⁴⁶

Psychologists from across the adults with learning disability services meet regularly to share best practice and review the implementation of local and national directives, including NICE guidance and policies from the BPS Faculty for Learning Disabilities. Recent developments include agreement around the consistent use of specific outcome measures for psychology across the three boroughs and additionally there are moves to develop of a Tri Borough diagnostic service for adults with Autism.

Psychiatry⁴⁶

Psychiatry services in Westminster identify around 100 service users a year open to psychiatry, with data showing a high number of service users going into crisis and a sharp increase in admission in 2011/12 compared to previous years (5 in 2009/10, 3 in 2010/11 and 9 in 2011/12). There has also been an increase in the psychiatry case load over this period.

Of the 9 admissions, 5 required a specialist learning disability bed due to having more severe learning disability and having complex challenging behaviour related needs often in the context of having autism. This has the potential to create pressures on available residential facilities, day time activities, and other suitable spaces for this group of service users .

Occupational Therapy⁴⁶

Occupational Therapy provide a number of assessments of the functional skills of new service users, including supporting Psychology with eligibility assessments.

Services for people with 'complex' needs⁴⁶

Representatives from psychiatry and psychology across the three boroughs have worked together on agreement of criteria for needs being described as the most complex, enabling a scoping exercise to be carried out identifying individuals and their families presenting with the highest level of challenge.

4. ACCOMMODATION

Key messages

- Within tri-borough Westminster (75%) has the highest proportion of adults aged 18 to 64 who live in accommodation with a secure tenancy (known as **'settled' accommodation**), followed by RBKC (63%), then LBHF (61%). This compares with 68% for London as a whole.
- The increase in the proportion of people living in settled accommodation in Westminster is due to a combination of initiatives, including the remodelling of registered care homes and provision of newly developed units of supported housing
- The numbers in **residential care** of all ages in Hammersmith and Fulham have been steadily rising over time, with around 50-60 more 18-65 year olds in residential care than is typical for London and England. Kensington and Chelsea had experienced falls in numbers in residential care but this has risen sharply in recent years, and has 15-25 more than expected in residential care
- Published figures on the **spend on residential care** suggest it was very high in Hammersmith and Fulham and high in Kensington and Chelsea by virtue of the higher proportion of clients in this type of accommodation. Cost in Westminster appeared low. Actual cost per client in residential care per week was lower than average in Hammersmith and Fulham, but higher in the other two boroughs
- Likely increases in **numbers transitioning** into adulthood with specialist needs, and increases in numbers of older people will lead to increased demand and, in some cases, require bespoke housing solutions

Recommendations:

- To examine residential care placement costs in Kensington and Chelsea and Westminster, which routine data suggests are high
- To plan for long term growth of accessible, local, appropriate accommodation across tri-borough, to minimise the need to move people out of borough and into residential care: the Hammersmith and Fulham housing strategy suggests more Extra Care Sheltered (ECS) placements, and more accessible accommodation is likely to be needed across all the boroughs. Planning should account for pressures created by an increasing and more complex number through transition and greater numbers living into old age.

4.1 Context

People with a learning disability are less likely to live on their own or with friends or partners, and are less likely to own their home than the general population. Nationally only about 15% of people with learning disabilities own their own home or live in accommodation with a secure long-term tenancy, compared to around 70% of the general population. Over half of adults continue to live with their families into middle and older age, with many of the remainder living in housing that they may not have chosen themselves, such as residential care.³⁶

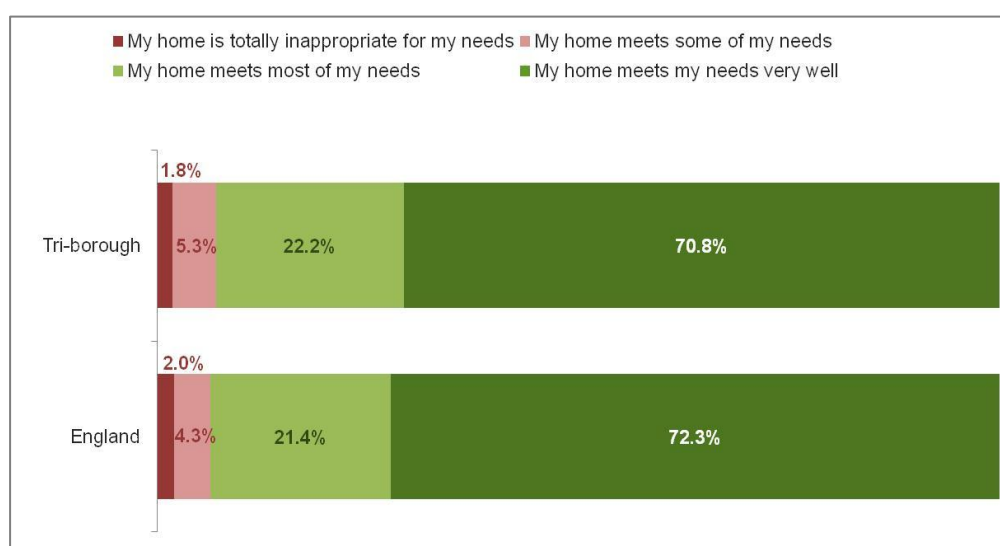
The imbalance in the past has sometimes been a result of an insufficient supply of housing and support providers in order to meet the needs of people with complex needs, affected in inner London by the high cost of property. This meant that many people with learning disabilities and complex needs have been placed out of borough, often in high cost residential care placements.

Research by the Joseph Rowntree Foundation found that living in supported accommodation schemes as opposed to more institutional settings has a positive impact for people with learning disabilities.⁴⁷

As a result, there has been a drive in recent years both nationally and locally to shift from an over-reliance on residential (registered) care models towards the provision more housing options, including more supported housing, so that more people are able to have a home of their own.

Local survey data³⁰ suggests that 7 out of 10 people with learning disabilities feel their home meets their needs very well, similar to national feedback. Around 7% feel their home meets either some of their needs or is inappropriate.

Chart 4a. How well respondents thought their home met their needs, Adult Social Care Survey 2011-12



4.2 Number of adults living in types of accommodation⁴⁸

The proportion of people in different types of accommodation has been detailed below. Non-settled accommodation is predominantly care homes and settled accommodation tends to be supported accommodation/ social housing or living with family or friends. These have been discussed below.

Table 4a: Proportion of people with learning disabilities in settled and non-settled accommodation, 2012/13 Data differences are due to 'unknown' status in some instances. Source NASCIS ASCAR L2

	H&F	K&C	West	London	England
Rough sleeper/Squatting	0%	0%	0%	0%	0%
Night shelter/emergency hostel/direct access hostel (temporary accommodation accepting self referrals)	0%	0%	0%	0%	0%
Refuge	0%	0%	0%	0%	0%
Placed in temporary accommodation by Local Authority (including Homelessness resettlement) - e.g., Bed and Breakfast	1%	0%	0%	0%	0%
Staying with family/friends as a short term guest	1%	0%	0%	1%	1%
Acute/long stay healthcare residential facility or hospital (e.g. NHS or Independent general hospitals/clinics, long stay hospitals, specialist rehabilitation/recovery hospitals)	0%	0%	1%	1%	1%
Registered Care Home	37%	33%	23%	21%	19%
Registered Nursing Home	0%	0%	0%	1%	1%
Prison/Young Offenders Institution/Detention Centre	0%	0%	0%	0%	0%
Other temporary accommodation	0%	3%	0%	0%	0%
Total non-settled accommodation	39%	37%	25%	24%	22%
Owner Occupier/Shared ownership scheme (where tenant purchases percentage of home value from landlord)	2%	0%	0%	2%	2%
Tenant - Local Authority/Arms Length Management Organisation/Registered Social Landlord/Housing Association	15%	12%	27%	11%	11%
Tenant - Private Landlord	2%	0%	1%	2%	4%
Settled mainstream housing with family/friends (including flat-sharing)	41%	25%	35%	34%	36%
Supported accommodation/Supported lodgings/Supported group home (accommodation supported by staff or resident caretaker)	1%	24%	9%	17%	18%
Adult placement scheme	0%	2%	0%	2%	2%
Approved premises for offenders released from prison or under probation supervision (e.g., Probation Hostel)	0%	0%	0%	0%	0%
Sheltered Housing/Extra care sheltered housing/Other sheltered housing	0%	0%	2%	0%	1%
Mobile accommodation for Gypsy/Roma and Traveller community	0%	0%	0%	0%	0%
Total settled accommodation	61%	63%	75%	68%	73%
Total	100%	100%	100%	100%	100%

Much lower than London and England	
Much higher than London and England	

4.3 Living in stable and appropriate accommodation

One of the national indicators in the adult social care outcomes framework looks specifically at the accommodation status of adults with learning disability aged 18 to 64. The indicator focuses on the proportion of people who are 'living on their own or with their family' to give an indication of the extent to which people have security of tenure in their usual accommodation, for example because they own it or are part of a household whose head holds such security. In previous years this type of accommodation (which may include, for example, owner occupier, a tenant in supported housing, a tenant in an extra care housing scheme, or an adult placement scheme) was referred to as 'settled' accommodation, while other types, with less security of tenure, were referred to as 'non-settled' accommodation.

This definition of 'settled' accommodation, is regarded as equivalent to 'Living independently, with or without support', as defined in a corresponding national indicator for adults in contact with secondary mental health services.

Number of adults living in their own home or with their family ('Settled' accommodation)

Provisional data for 2012/13 shows a wide variation in proportions in settled accommodation, with Westminster ranked 11th highest in London (above London and England), Hammersmith and Fulham 7th lowest, and Kensington and Chelsea 10th lowest.⁴⁹

Chart 4b: Proportion of people with learning disabilities aged 18-64 and living in settled accommodation, by London borough, 2012/13

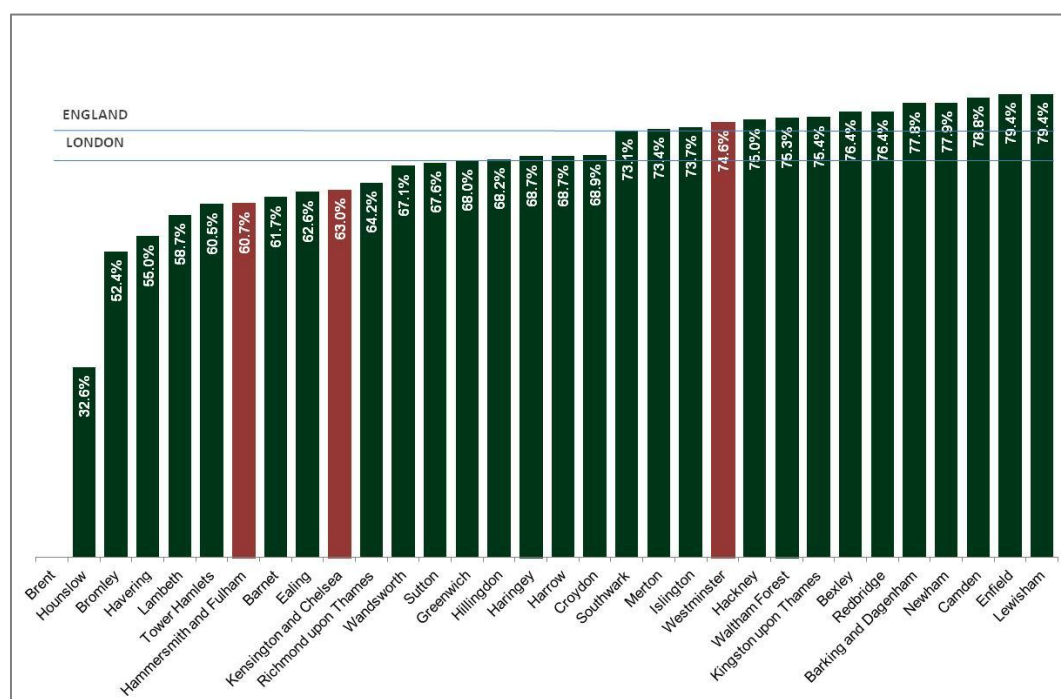
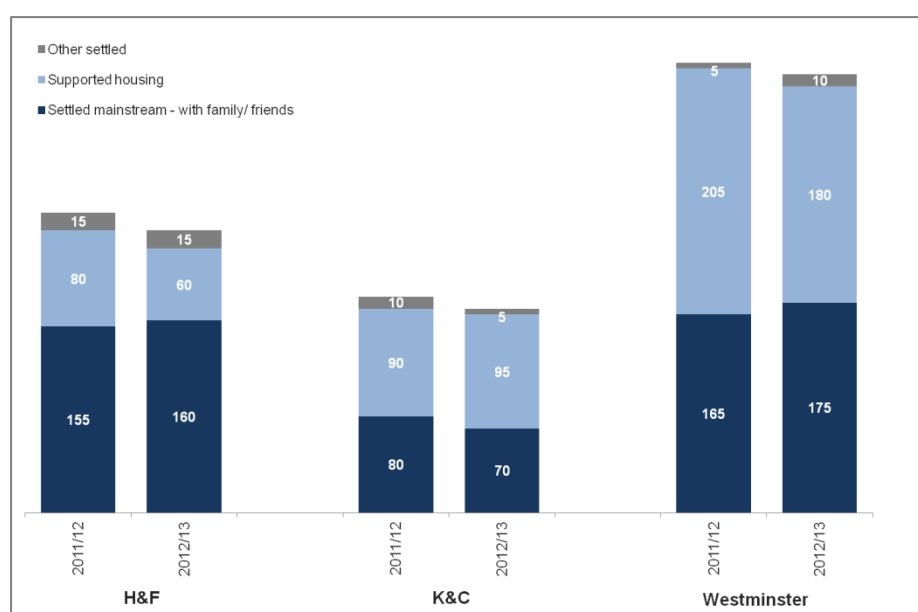


Chart 4d: Number of people in settled accommodation types, 11/12 and 12/13⁵⁰

The increase in the proportion of people living in **settled accommodation in Westminster** is due to the achievement of a number of targets, as set out in the Westminster Housing Strategy for People with Learning Disabilities 2007-11. Over the four year period of the strategy:

- 26 people moved into independent flats via Westminster learning disability quota
- Johnson Place in Pimlico was remodelled to provide five self contained flats which have enabled people with complex needs to return to Westminster from expensive out of borough placements
- Leonora House was developed to provide 21 units of extra care supported flats, 7 of which are for people aged 50+ years with a learning disability
- Five two-bed houses were provided by the Dolphin Square Foundation for people with complex needs; these now provide a hub model of support in the Queen's Park area
- 69 units of registered care were re-modelled by providers, working in partnership with Westminster, to provide supported living models
- one person moved from campus defined accommodation to a two-bed, shared-ownership flat in Westminster

Number of adults living in 'non-settled' accommodation

The vast majority of *non-settled* accommodation in the three boroughs in 2012/13 was registered care homes, accounting for 37% of the 39% in Hammersmith and Fulham, 33% of the 37% in Kensington and Chelsea, and 23% of the 25% in Westminster. The number of people in residential care home and nursing care home is explored in more detail below.

4.4 Adult acute placements - Assessment and Treatment Units (ATUs)

As at May 2013, there were 17 patients in ATUs in the Tri-borough area:⁵¹

- Hammersmith and Fulham has 7 patients in hospital placements
- West London CCG (covering Kensington and Chelsea and NW Westminster) has 7 patients in placements
- Central London CCG (covering the remainder of Westminster) has 3 patients

All patients have been reviewed and all NHS Clinical Commissioning Groups (CCGs) have a register in place that is regularly maintained.

4.5 Residential and nursing care

Residential and nursing care provision

According to recently produced data, the *Market Position Statement for London*,²³ there are a number of residential care home beds locally, which can be used for those with learning disabilities or autistic spectrum disorder:

- 13 care homes and 67 beds in Hammersmith and Fulham
- 2 care homes and 10 beds in Kensington and Chelsea
- 3 care homes and 17 beds in Westminster

There are also a number of beds for those requiring care homes with nursing, which can be used for those with learning disabilities:

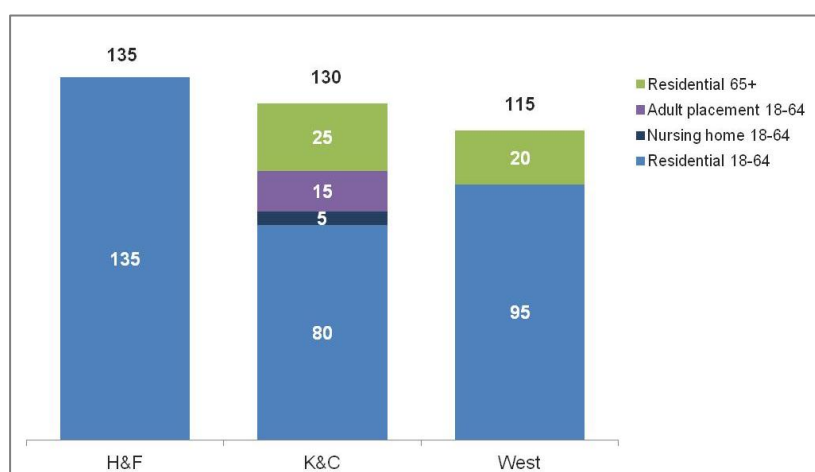
- 3 care homes and 164 beds in Hammersmith and Fulham (St Vincents, Farm Lane, and Coverdale Road)
- 1 care home and 60 beds in Kensington and Chelsea (Ellesmere)
- 3 care homes and 153 beds in Westminster (Forrester Court, Garside, and Alison House)

As is the case in London as a whole, the vast majority of residential care provision in 2011/12 was for local authority-*purchased* residential care, with just 6% of all weeks a year in local authority-*provided* care in Hammersmith and Fulham, 1% in Kensington and Chelsea, and none in Westminster.

Numbers in residential and nursing care

In 2012/13, there were 355 people living in residential care and 5 (rounded) living in nursing care in the Tri-borough area.⁵² There were also 15 in adult placements. Numbers have been broken down by borough in Chart 4e below. *Numbers differ due to rounding.*

Chart 4e: Number of people in residential, nursing care and adult placements in the Tri-borough area, 2012/13 Extracted from NASCIS ASC-CAR S1. Age group not broken down for H&F

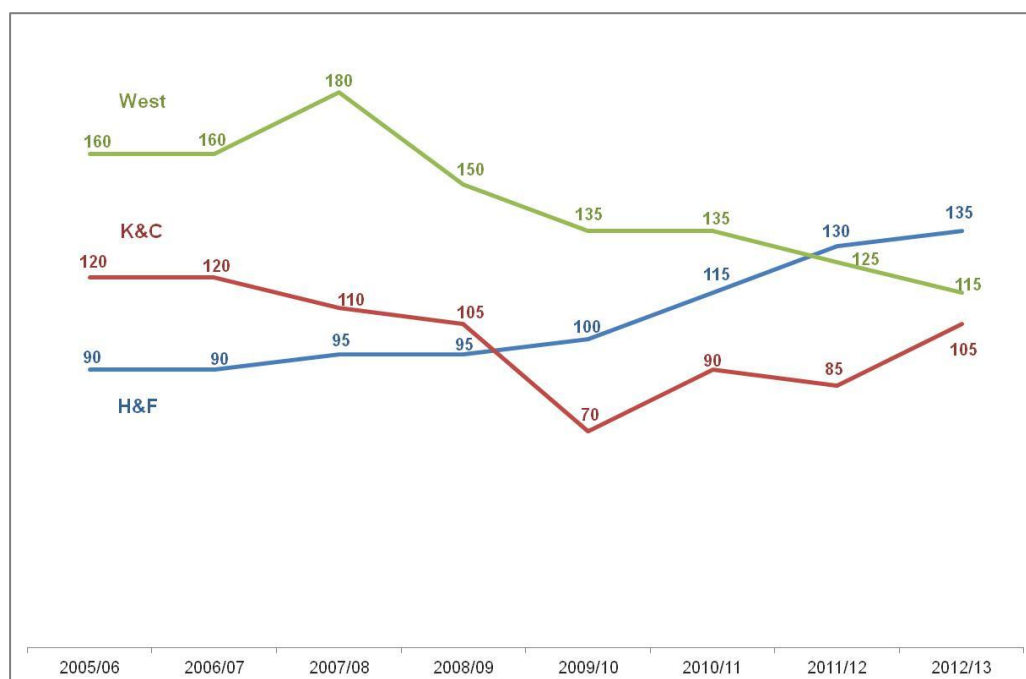


Although the numbers of older people (aged 65+) in residential care in Westminster has grown slightly, the number of 18-64 year olds has dropped dramatically, from 150 in 2005/06 to 95 in 2012/13, a drop of over a third (37%). In the same time period, the number of 18-64 year olds in residential care in London dropped by a fifth (21%).

Hammersmith and Fulham has experienced a 50% rise in numbers aged 18-64 in residential care since 2005/06. If the proportion of clients aged 18-64 in residential care in Hammersmith and Fulham was typical of London, it would have approximately 75-85 clients in residential care, rather than 135.

Kensington and Chelsea has had a relatively consistent number of older people in residential care over time, and has experienced a 16% drop in 18-64s in residential care since 2005/06. However, the trajectory has been sharply upwards since a low point in 2009/10. If the borough was typical of London, it would have around 55-65 clients aged 18-64 in residential care, rather than 80.

Chart 4f: Number of people all ages in residential care in the Tri-borough area over time Extracted from NASCIS ASC-CAR S1



Out of area residential care

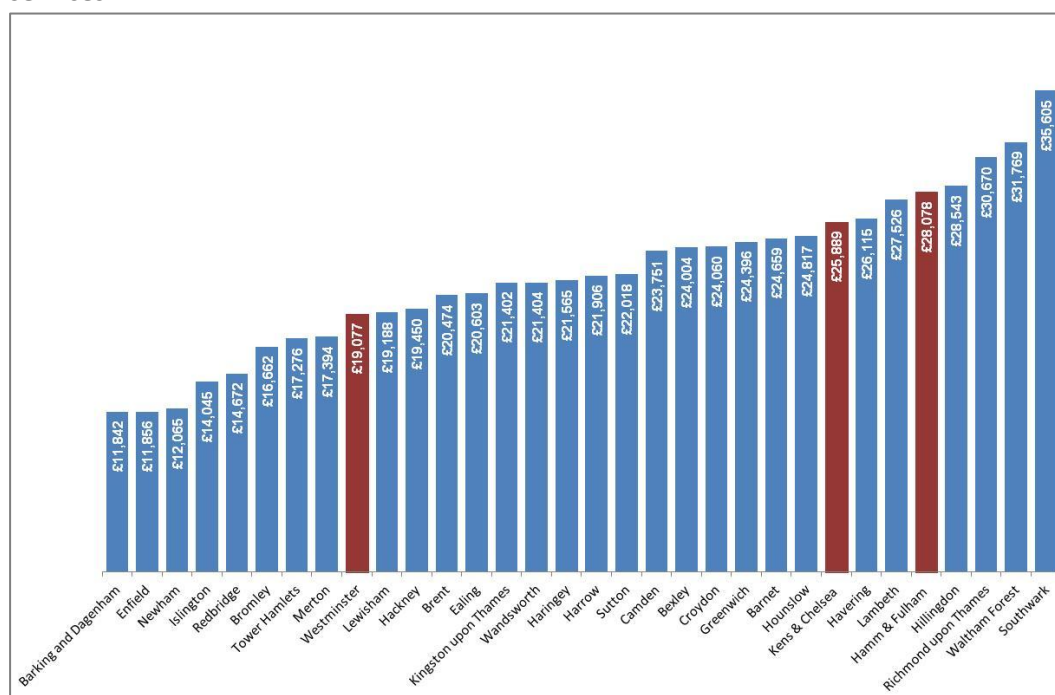
Kensington and Chelsea has the largest proportion of those in residential care living outside the borough (90%), followed by Westminster (77%) and Hammersmith and Fulham (61%).¹⁷ *Note: there may be some discrepancies in data due to technical issues and time periods of extraction*

Expenditure on residential care^{53,23}

As described previously, Hammersmith and Fulham had the 4th highest proportion of clients aged 18-64 in residential care, which accounted for over two thirds of the budget. The spend per learning disabilities population was therefore high – the 5th highest in London. However, the average weekly spend of a client in residential care was slightly less than the London average.

Kensington and Chelsea also had a greater proportion of clients in residential care – the 8th highest in London, accounting for close to half the budget (similar to London) and the 8th highest spend. Weekly spend was 9% more than the London average.

A smaller proportion of the total budget was spent on residential care in Westminster than average and the number in residential care was similar. However, weekly spend per client was the 6th highest in London, 10% higher than average. This is likely to be because the smaller number remaining in residential care have higher needs than average.

Chart 4g: Spend on residential care, per person 18-64 known to learning disabilities services**Table 4b: Number of people aged 18-64 in residential care and associated cost per person in care and ranking in London, 2011/12**

	Number people in residential care 18-64*	As a percentage of those known to LD services	Rank in London	Total annual spend on residential care	As a proportion of total spend	Spend per person per week receiving it	Rank in London
H&F	120	31%	4th highest	£10,810,000	69%	£1,327	12th lowest spend
K&C	75	28%	8th highest	£6,990,000	45%	£1,515	10th highest spend
Westminster	115	23%	16th highest	£9,634,000	39%	£1,536	6th highest spend
Tri-borough	310	27%	-	£27,434,000	49%	£1,442	-
London	-	21%	-	-	46%	£1,396	-

Future changes in numbers in residential care

Straight line projections into the future of past numbers in residential care at a London level suggest a decrease in numbers of 12% over the next three years.²³ This crude indicative approach suggests a predicted drop of around 5 clients a year in each of the three boroughs. However, the upward trend in Hammersmith and Fulham, a result of lack of suitable accommodation and a culture of residential care, suggests a drop in the near future may be unlikely.

Improved survival rates among the learning disabilities population is likely to create an upward pressure in the years to come: London modelling by age group found a gradual rise in the number of over 65s in residential care over time.

Hammersmith and Fulham Accommodation and Support Strategy 2013-16

Hammersmith and Fulham recognise the over reliance on residential care and the insufficient supply and range of other types of housing and support to meet the needs of people with learning disabilities in the borough, particularly those with challenging needs and autistic spectrum disorders.

A key objective of the strategy is therefore to replace out of borough high cost residential care services with local supported housing models that deliver better outcomes for people with learning disabilities in terms of promoting independence, increased choice and control, and value for money.

There is a shortage of supply of high quality specialist housing provision in the borough to meet current and future complex health, social care and physical needs. New housing developments will be needed, as well as a programme of remodelling existing accommodation services.

It has been identified that over the next 3 years, approximately 86 people will need to be found alternative specialist housing in the borough. This analysis is based on local demographic and needs information, and includes people both inside and outside of the borough who need to be re provided into alternative housing that better meets their needs, and the increasing demand from numbers of people in transition from Children's to Adult services and people living with older carers. To meet this housing need the Council will work with existing housing providers to re provide and re model some existing provision and re invest capital from current Council housing stock that does not meet the future needs into 24 specially designed housing units for people with autism, challenging needs and physical disabilities.

4.6 Changing demand for accommodation

New clients in transition

Analysis in Section 1 of this report highlights the increasing number of young people in transition locally with complex and challenging needs. There is also a significant increase in those presenting to the service with Autistic Spectrum Disorders (ASD). Those people surviving into adulthood with multiple disabilities will require accessible accommodation and services that can accommodate specialist equipment, in order to meet complex physical and health care needs.

An ageing population

National modelling detailed in Section 1 highlights a likely trend towards a growing number of people with learning disabilities, fuelled by better survival rates into adulthood and old age. These people will require models of housing and support to meet their needs in regards to accessibility and specialist services, particularly dementia for older service users.

Housing strategies for people with learning disabilities

The trends identified in this section are being addressed in borough-specific housing strategies for people with learning disabilities. The refreshed housing strategy for Westminster, for the period 2012-2015, identifies three main challenges: an increase in the number of young adults with complex needs; an increase in the number of older people with learning disabilities; and an increase in the number of people with autism who require a highly specialised service. It also sets out a number of milestones, including the provision of new specialist autism services and new extra care housing units.

A comparable strategy is being developed for people with learning disabilities in Hammersmith and Fulham. In response to similar challenges, the strategy will involve working with providers to remodel registered care homes to supported living models of support, expanding the use of the private sector, and investing in new and refurbished local housing developments to meet the longer term housing needs of people with challenging behaviour, autism and physical disabilities.

5. COMMUNITY SOCIAL CARE

Key messages

- **Some caution must be exercised around the routine reporting of activity and costs, given variations in approaches in to categorising the data**
- Data from 2011/12 appears to suggest that Hammersmith and Fulham had a lower **total spend** (per 18-64 learning disabilities population) than London. Although a far higher proportion of the total budget is spent on residential care, the money spend on community services is half the rate of London, and the numbers accessing community services are relatively high
- Conversely, spend per head of 18-64 population in Kensington and Chelsea appears to be higher than London, with a greater spend in community and residential than would be expected, given numbers known to services. Spend in Westminster is broadly typical, but biased towards community spend rather than residential
- The proportion of the 18-64 population receiving a **personal budget** is lower than London across all three boroughs, but particularly Hammersmith and Fulham. The uptake of **direct payments** was lower than London in Westminster, similar in Hammersmith and Fulham, and higher in Kensington and Chelsea
- Data suggests a small proportion of people using **day care** in Hammersmith and Fulham and Kensington and Chelsea compared to London, with financial data suggesting Kensington and Chelsea having a high cost per head. A local review of day care services for those with complex needs suggested lower uptake among Kensington and Chelsea residents than in the other two boroughs. There will be a review of lower need clients later in the year
- **Short breaks** are provided in the Tri-borough area. Services in Kensington and Chelsea and Westminster have recently been re-tendered and it has therefore not been possible to get accurate data on usage currently
- Routine data suggests that Westminster had the highest use of **home care** in London, although there may be some issues around accuracy of the data
- There has been a gradual drop over the last few years in the number of clients **receiving a review** in Westminster over time, and a dramatic drop in Hammersmith and Fulham in the last year. Kensington and Chelsea has remained static over the last few years, and is the highest per total clients in London; Hammersmith and Fulham is the lowest
- A greater proportion of respondents to the **Adult Social Care Survey** said they accessed information and advice and almost half found it easy to find, considerably higher than nationally
- Local **advocacy services**, which support service users to 'speak up' for themselves, offer a range of services and facilitate service users to help inform future commissioning of services, via the Tri-borough Learning Disability Partnership Board and local consultation events. Tri-borough commissioners are reviewing how to best involve service users across all client groups in the future. A procurement process is taking place around professional 1:1 advocacy

Recommendations

- Tri-borough commissioning needs to continue to improve their commissioning arrangements in order to maximise value for money, whilst at the same time extending choice and control within their contracted services
- There needs to be access to high quality care and support services and suitable accessible housing in order to ensure that tri-borough Adult Social Care departments keep people in the community rather than placing them in residential care
- The recent drop in existing clients receiving a review needs to be examined and addressed

5.1 Spend per client known to services, age 18-64

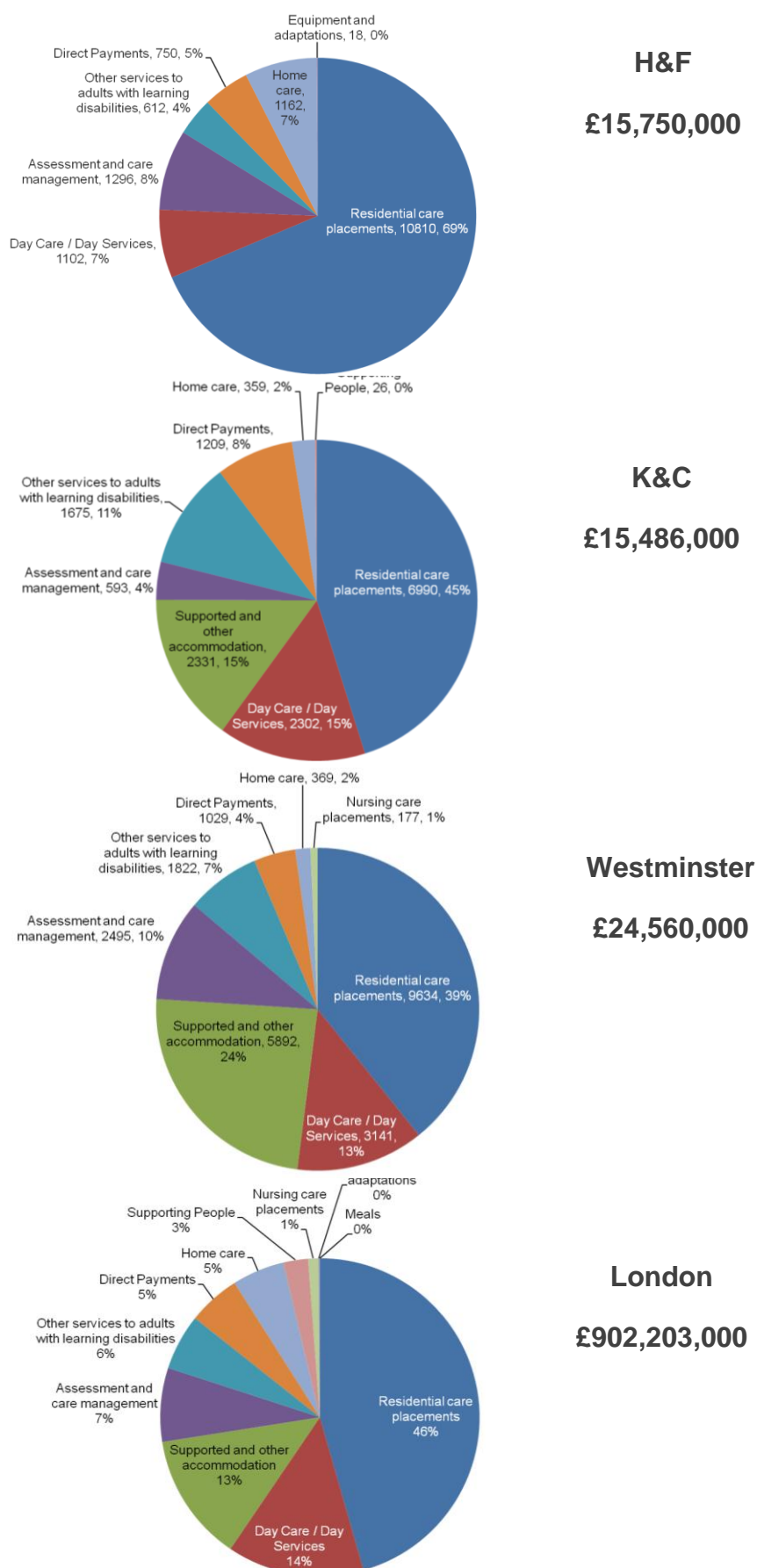
Based on unit cost data (see above), spend per client aged 18-64 known to services was lower than London in Hammersmith and Fulham, with a particular focus on residential care (as discussed in the previous chapter). Spend on community services was less than half the average for London. Based on the numbers accessing community care in the borough, this appears to represent good value for money, although the routine finance data must be treated with some caution.

The spend per head in Kensington and Chelsea among 18-64 year olds was higher than London for both community and residential care. Spend in Westminster was broadly typical overall, but with a slightly larger spend in community and smaller in residential, fitting the smaller reliance on residential care in the borough.

Chart 5a: Average total spend as a proportion of clients known to learning disabilities services, aged 18-64 Based on costs in following section



5.2 Spend by service type on adults aged 18-64 (£000s) , 2011/12⁵³



5.3 Summary of number of learning disabilities clients receiving a service

Table 5a: Summary of numbers of people receiving council services during the period, aged 18-64 (rounded) Extracted from NASCIS PSSEX UCS

	H&F		K&C		West	
	11/12	12/13	11/12	12/13	11/12	12/13
All community services	250	205	165	160	305	315
Percent of total known	65%	53%	61%	59%	60%	64%
Day services	60	45	25	20	130	205
Home care	80	70	30	20	200	135
Professional support	0	0	90	90	80	95
Direct payments	70	75	15	20	60	65
Equipment	45	30	10	5	5	5
Short term residential	5	0	20	15	5	35
Other	85	70	125	130	5	5

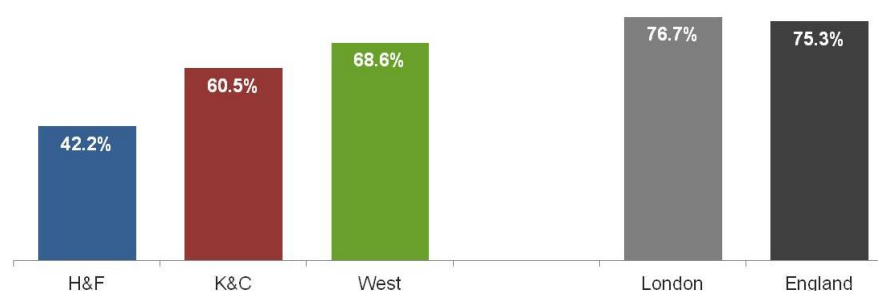
Cautionary note: Some differences in numbers in the table above (and subsequent cost differences) relate to the way services have been categorised. For example, Westminster home care figures include people in supported housing (although expenditure figures only include home care spend). Also, some employment support schemes for learning disabilities clients are counted as professional support rather than day care, although the cost is still charged to the day care budget, resulting in an artificially high unit cost.

5.4 Personal budgets/ Direct Payments

The concept of personal budgets is that recipients know how much money is available to spend on care. They can choose to either have services set up by the local authority (managed budget), or receive a direct payment, or a mixture of both. By 2014, the government expects everyone to have information about their personal budget, regardless of whether they choose to have a direct payment or continue with managed services.

In 2012/13, 4 in 10 Hammersmith and Fulham clients, 6 out of 10 Kensington and Chelsea clients, and 7 out of 10 Westminster clients aged 18-64 had received a personal budget, lower than the three quarters in London and England. The proportion in Hammersmith and Fulham stayed the same as the previous year.⁵⁴

Chart 5b: Proportion of clients aged 18-64 receiving a personal budget, 2012/13



The proportion of clients receiving direct payments in 2012/13 was lower than the London and England averages in Westminster, similar in Hammersmith and Fulham, but higher in Kensington and Chelsea.⁵⁴

5.5 Day services

Day services are split into:

- Services for people with complex needs (challenging behaviour, PMLD, additional complex physical health needs, autism) often requiring a safe accessible building environments and one to one or two to one support with personal care
- Preventive learning disability day services are for people who are more able to get out and about in the community, may live in their own flat with support and generally have lower support needs.

The distinction is necessary because the needs and types of service are quite different.

Statutory data returns for all day services suggest that Hammersmith and Fulham spent half the proportion of the total budget on local authority-funded day services compared to the London average in 2011/12. It reached a smaller proportion of clients with learning disabilities than was typical for London (but still greater than half the London level), resulting in a cost per client attending well below the London average.⁵⁵

Kensington and Chelsea appeared to spend a slightly smaller proportion of the total budget on day services. Figures reported suggest the proportion of people using services was the lowest in London, resulting in the highest spend per client in the capital. However, this may be a **categorisation issue** (see cautionary note above).

Westminster had a broadly similar proportion of money spent on day care services to London, similar take-up, and similar cost per client.

Table 5b: Number of people aged 18-64 receiving day care and associated cost per person in care and ranking in London, 2011/12

	Number people receiving day care 18-64	As a percentage of those known to LD services	Rank in London	Total annual spend on day care	As a proportion of total spend	Spend per person per week receiving it	Rank in London
H&F	62	16%	5th lowest	£1,102,000	7%	£342	8th lowest spend
K&C	24	9%	Lowest	£1,927,000	12%	£1,544	Highest spend
Westminster	132	26%	Similar	£3,112,000	13%	£453	Similar spend
Tri-borough	218	19%	-	£6,141,000	11%	£542	-
London	-	27%	-	-	14%	£461	-

Day services for clients with complex needs⁵⁶

A recent tri-borough review of day services people with complex disabilities identified 118 clients with complex needs using day services in the area, with highest take-up in Westminster and lowest in Kensington and Chelsea:

- **Westminster - Droop Street and Lisson Grove Hub/ Flexible Response Service (Community Access Westminster)** 67 using services (33 Droop St and 34 Community Access), and 2 not using them
- **Hammersmith and Fulham – Options** 32 using services, and 10 not using them
- **Kensington and Chelsea – Resource Centre Ladbroke Grove** 19 using services, (others using *Full of Life*), and 16 not using services

Managing very challenging behaviour and very complex health issues were the two main issues for not accessing in-house services. Health issues included people who had severe seizures, those who required oxygen at various times of the day, and dual diagnosis with mental health needs.

Various services are also commissioned on a spot purchase basis including the National Autistic Society (NAS) basis by H&F and K&C, home care and a new Tri-borough transitions focused framework of day service support comprising of five providers that can be purchased by the Council or by direct payment users from the autumn of 2013.

Vision for day services for clients with complex needs

A Tri-borough ASC internal review of Council managed services commenced in 2012. At the same time, a small focus group of carers were engaged to seek initial ideas about complex need day services, and local groups who represent people with learning disabilities were also asked for their views and ideas. From this, a draft vision for complex day need services was developed and the services are now investigating how they deliver this vision in the future.

DAY OPPORTUNITIES for People with Complex Learning Disabilities

1. A more flexible use of safe and supportive building facilities to be used as resources and touchdown spaces, maximising usage and supporting activities and personal care for people with complex needs if required. This will also link to developing changing places agenda.
2. Quality flexible staffing to support people in the community and buildings as required and to have specialist skills where needed
3. More engagement with the local community and its opportunities, promoting citizenship and social inclusion where possible
4. Personal and individualised support through Personal budgets (with a range of options how to pay for services) will be used to buy day services in the future with support planning and advice, enabling people with learning disabilities and their carers to look at the range of services and opportunities available
5. Real opportunities and experiences like support to work, learn, volunteer and meaningful leisure activities that raise aspirations

6. That day services improve partnerships with Adult Learning, leisure and other departments/organisations to link into and create better opportunities
7. Day services are also preventative, i.e. they will help people with learning disabilities to stay in their local communities and support their families and carers' to continue in their caring role, for example managing behaviour etc
8. Flexible approaches to Travel Support
9. That support is safe, dignified and compassionate
10. Better for less, meaning providing all the above within current funding and in some cases more efficiently

Once the service ideas and options have been developed, further engagement will take place with users of the service and their carers' and parents.

Prevention day services

These services provide much less intense support and may be used on a more ad-hoc basis or a couple times a week. Services include drop-in, one to one 'buddying' mentoring and groups of people with learning disabilities going to somewhere like the cinema by pooling personal budgets. Numbers using these services are more fluid.

Borough	Services	Numbers	Cost per year
H&F	Bishop Creighton House and Mencap	Currently working with 92 clients	Approximately £100,000 in contracts. Further spend in personal budgets/direct payments
K&C	Equal People, Westminster Society, UP2US, Pursuing Independence Paths, Dalgarno community centre	130-150 known to service. About 100 active clients	Contracts are valued at £127,000 per year. Further spend in personal budgets/direct payments
WCC	Pursuing Independence Paths, Westminster Society, UP2US	About 130 active clients	£191,000 including contracts and personal budgets/direct payments

A **Tri-borough strategic review** of prevention day services will commence in the autumn of 2013, including mapping, service review, needs analysis, stakeholder engagement, benchmarking and service redesign (if required) and service procurement were appropriate.

5.6 Short breaks

Service Review

A strategic review of short break services for adults with a learning disability across the tri-borough area is due to commence in September 2013. As part of this review, systems for consistent monitoring and data collection will be addressed - currently, there is a lack of reliable information at this stage due to the retendering of the service in Kensington and Chelsea.

Commissioned services

Kensington and Chelsea and Westminster offer a short break service to adults assessed as eligible for adult social care funded services that are 18+ and living in the family home. The Service operates across two sites, Alison House in Westminster and Kingsbridge Road in Kensington and Chelsea. Short breaks are offered in the form of a bed based night or a session of outreach from the person's home. Kingsbridge Road provides planned bed based short breaks to adults with a learning disability and complex challenging needs. Kingsbridge Road also provides for unplanned (crisis) admissions. Alison House provides planned bed based short breaks to adults with a learning disability and complex physical health needs.

In-house services

Hammersmith and Fulham offer short breaks from its in-house service, Rivercourt Road. The service is available to adults who are 18+ and who are living in the family home, or living on their own with a carer, or a carer themselves, and who are eligible for social care funded services. Rivercourt Road provides a planned bed based short breaks to adults with a learning disability. The Service also provides for unplanned (crisis) admissions.

As part of the short breaks review, a specific work stream is looking at the respite needs of young people in transition 16-25 across the three boroughs to ensure the needs of this specific group are met.

5.7 Home care services

Data returns on home care appear to vary dramatically across boroughs, probably due to differences in reporting (see **cautionary note** above). Data identifies a smaller proportion of the total budget spent on home care services in Westminster but 50% more clients receiving home care. This results in the lowest spend per client receiving it of anywhere in London - £35, compared to £328 in London.⁵⁵ Home care numbers include those in supported housing but the expenditure does not.

Figures suggest Hammersmith and Fulham spent twice the proportion of the total budget on home care compared to London in 2011/12. The proportion seen was considerably higher, but spend per people receiving home care was still 10th highest in London.

Kensington and Chelsea spend a smaller proportion of the budget on home care compared to London and reached a proportionately smaller proportion of clients. Spend per client was a lower than London, but ranked within the middle of boroughs.

Table 5c: Number of people aged 18-64 receiving home care and associated cost per person in care and ranking in London, 2011/12

	Number people receiving home care 18-64	As a percentage of those known to LD services	Rank in London	Total annual spend on home care	As a proportion of total spend	Spend per person per week receiving it	Rank in London
H&F	80	21%	9th highest	£1,162,000	7%	£279	10th highest spend
K&C	29	11%	16th highest	£359,000	2%	£238	15th highest spend
Westminster	201	40%	Highest	£369,000	2%	£35	Lowest spend
Tri-borough	310	27%	-	£1,890,000	3%	£117	-
London	-	15%	-	-	5%	£328	-

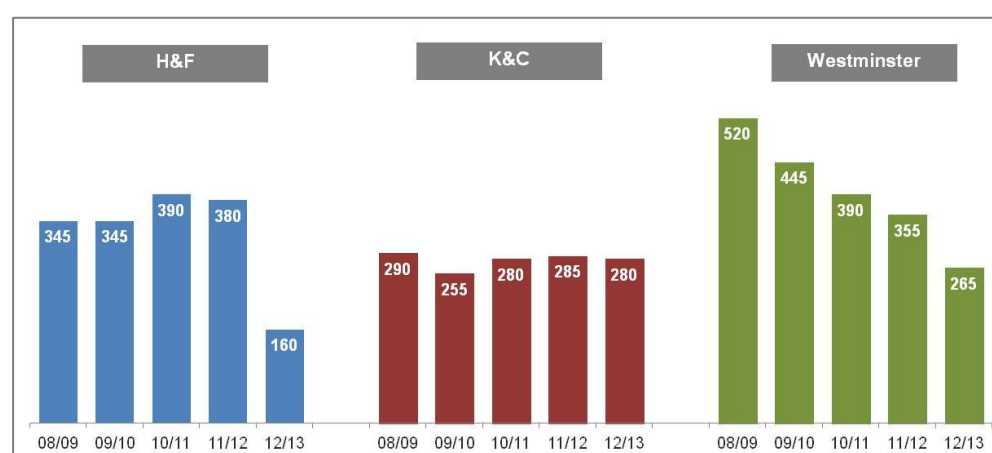
5.8 Assessment and Review

Existing clients receiving a review

Over time, the number of existing clients receiving a review in the year has been maintained in Kensington and Chelsea, and is the highest in London, when expressed as a rate per number of people receiving a service during the year.⁵⁷

Number have more than halved in 2012/13 in Hammersmith and Fulham since the previous year and the rate is now the lowest in London. Westminster has been experiencing a gradual drop in numbers receiving a review over time, and the number in 2012/13 was roughly half the number from 2008/09. The rate is the 8th lowest in London.

Chart 5c: Number of existing learning disability clients receiving a review over time



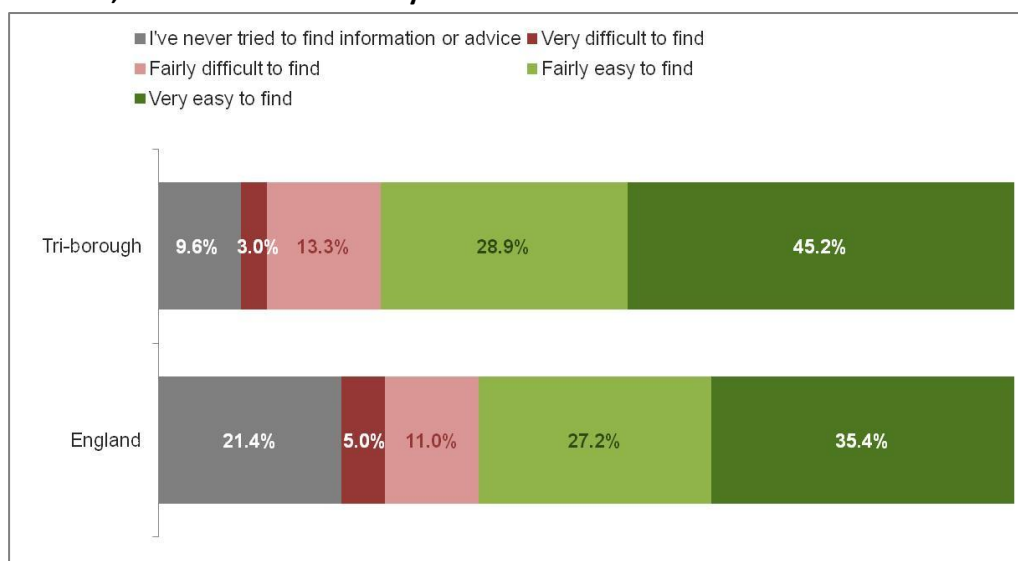
New clients receiving an assessment

There were 50 new clients of all ages receiving an assessment in 2011/12 in Hammersmith and Fulham, 25 in Kensington and Chelsea, and 20 in Westminster. Numbers tend to have risen in Kensington and Chelsea but dropped in the other two boroughs.⁵⁸

5.9 User experience of social care

In 2011/12, a greater proportion of respondents with learning disabilities said they accessed information and advice, and a greater proportion found it very easy to find, compared to nationally. Less than 1 in 30 respondents locally found it very difficult to find.⁵⁹

Chart 5d: 2011/12: Finding information and advice about support, services or benefits, Adult Social Care Survey 2011-12



5.10 Service user involvement and advocacy

Service user involvement and group advocacy

Local advocacy services - Advocacy Project in Westminster and RBKC; Mencap in H&F - support service users to 'speak up' for themselves. Advocacy services offer group sessions to discuss relevant topics and run 'pop up' meetings to make sure the service is widely available.

Local advocacy services also support service users to comment on the design and quality of current services and to help inform future commissioning of services through the Tri-borough Learning Disability Partnership Board and via local consultation events on health and social care topics. Service users and carers contribute to the Health Self Assessment Framework (SAF) and the Partnership Board Report on an annual basis. Tri-borough commissioners will be reviewing (in autumn 2013) how to best involve service users across all client groups in the future.

Professional 1:1 Advocacy

Professional 1:1 advocacy provides individuals with a personal advocate to help them obtain the best outcome in relation to a specific issue, such as dealing with a housing or benefits issue. Advocates provide this support on a short term basis.

The current arrangements have been reviewed and service users involved in a consultation regarding future commissioning intentions. A procurement process will be undertaken in 2013/14.

6. TRANSITION INTO ADULT SERVICES

Key messages

- Although the tri-borough area generally has around 20 young people transitioning into adult services each year, forecasts for this year and the next two years highlight **significant rises in numbers**: 36 in 2013/14, rising to 42 in 2014/15, and 30 across two boroughs in 2015/16, with highest numbers in Westminster
- A third of these people have autistic spectrum disorders, one in five have challenging behaviour, and one in five have a severe learning disability (overlaps will exist between categories). These people are likely to need **ongoing support** and, in some cases, **specialist equipment or care settings**, in order to meet their needs.
- Feedback from **experiences of people going through the transition process** and their parents and carers suggests they would like to be seen as unique, with individual concerns and characteristics. They also want to be able to discuss the transition process on a regular basis
- Feedback from those **planning and running services** identifies a range of complex issues to tackle to improve experiences for families. These issues generally relate to differences in both the eligibility criteria and the design of services between children and adult services, and the timeliness and effectiveness of co-ordination of a wide range of services which all input into the process.

Recommendations

- Explore ways to identify earlier identification and assessment of those with learning disabilities likely to be transitioning into adult services, to ensure that referrals are received in a timely fashion and not 'late in the day'. This will also support professionals to better plan for the young people who are assessed as not eligible and therefore will not receive a service.
- Ensure the care management model supports working with young people in transition, with both a learning disability and/or physical disability.
- The successful implementation of the Education, Health and Care (EHC) plan for 0-25 year olds requires education, health and social care to work in a more joined up way. Planning across the departments has already begun and this needs to progress in 2014 for roll out in September.
- Ensure that current processes involve children and families at all stages
- Plan for likely rises in numbers of more complex children transitioning into adult services, who may have specific requirements around housing and care

6.1 Background

The transition period (between 14-25 years) represents a time during adolescence and early adulthood when young people have to make choices about their future, which relate to employment, education, healthcare and housing. For young people with learning disabilities, the transition is made more difficult by concerns about whether, how and where their health and social care needs will be met.

Transition also means services transfer responsibility of care for young people: Children's Services want to know that the young people in their care have somewhere to transition to; Adults Services need to know the numbers and needs of young people likely to transition so that they can plan adequately for their support.

Transition for young people with learning disabilities, many of whom have complex health needs, is complicated by the number of services who may be providing support at any one time. Children's and Adults' Services in many ways work along different service models and have different entitlement criteria but it is important that they work together to ensure a smooth transition for young people.

6.2 Numbers transitioning into adulthood

Numbers transitioning⁶⁰

Around 20 people transition from Children's into Adult services each year, becoming eligible for adult services. Most of these will have complex needs. The tri-borough area has seen a steady rise in recent years in the number of young people becoming eligible for adult social care at the age of 18. 36 people are likely to transfer in 2013/14, and 42 in 2014/15 across the three boroughs, with 30 across two of the boroughs in 2016/17, with greatest numbers forecast in Westminster, broken down as follows:

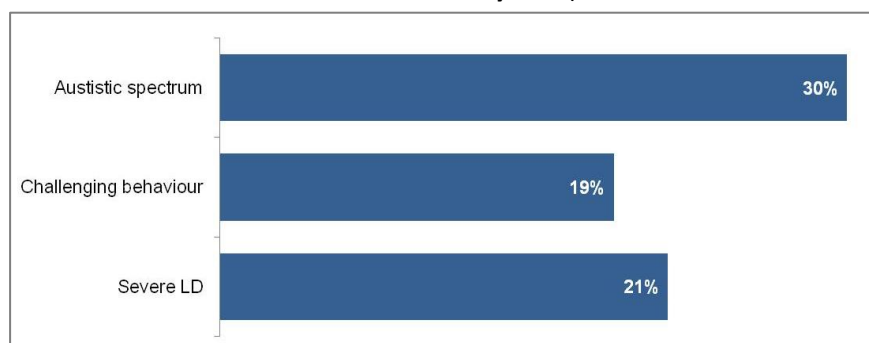
Chart 6a: Numbers with learning disabilities likely to transition from Children's to Adults Services – 2013/14 to 2016/17 (From local data collection. Data for H&F 15/16 currently not available)



Changing numbers and complexity

In addition to the steady rise in recent years in the number of young people becoming eligible for adult social care, there appears to be increasing numbers of people with very complex needs, including physical disabilities and autistic spectrum disorder, entering adulthood. Over the last four years in London, there has been a rise of a third in the number of school-age children with diagnosed autistic spectrum disorders. These people are likely to be in need of ongoing support and specialist equipment.

Chart 6b: Complexity of those with learning disabilities likely to transition from Children's to Adults Services in next 2-3 years (From local data collection)



6.3 Challenges around transition

Information has been collected locally in the past to establish what local people with learning disabilities and their carers feel are the main challenges in the transition process.

Views collected at the consultation events for The Big Plan, 2009-2012³⁶

Consultation workshops were conducted in 2008 when drafting The Big Plan, Westminster's strategy for people with learning disabilities. Transition was among many topics that were covered.

Family carers stressed the need for good quality information about what opportunities were available and for good quality communication with staff. There was a strong view that there needed to be better joint working between agencies, particularly between Children's and Adults Services and that transition planning should start from an earlier age – at 14 years of age (year 10).

Family carers also identified a number of things that they felt would help make transition to Adult Services a more positive experience, including:

- Being seen by staff and services as unique, with unique concerns and unique aspirations
- Being able to discuss all aspects of transition (such as college courses, daytime activities, housing and health) at an earlier stage
- Being able to discuss and share information with staff and other family carers on a regular basis; this could be facilitated, possibly, by a family link having support and advocacy
- Being able to go to open evenings run by services
- Higher expectations among everyone – especially in schools and at transition that people with learning disabilities can work in paid jobs
- Hearing more about people's positive experiences of transition

A number of **challenges** to the seamless transfer between Children's and Adult's services have been highlighted by those providing these services locally:

- Differing criteria from Children to Adult Social Care Services requires transition planning from age 14 to ensure young people, their families /carers can plan realistically for the future: this aids a seamless transfer from children to adult services or referral to third sector services if more appropriate.
- The care management model needs to support working with young people in transition, with both a learning disability and/or physical disability: different models operate across the three boroughs and therefore facilitate transition to a greater or lesser degree
- There also needs to be increased planning across Children's Services and Adult Social Care to plan for young people coming through transition with more complex needs. A review is being undertaken on the respite needs of young people as these can differ to an older LD population.
- The successful implementation of the Education, Health and Care (EHC) plan for 0-25 year olds requires education, health and social care to work in a more joined up way. Planning across the departments has already begun and this needs to progress in 2014 for roll out in September.
- Better planning with education could minimise children being placed in out-of-borough schools.
- Involving young people and parents in the implementation of the EHC is crucial and getting the voice of young people, their parents and carers is critical in the development of adult services for young people in transition planning for young people who are 'Looked After Children' is complex and can be difficult. This is primarily because young people may not fit the criteria for adult services, but remain vulnerable. There are work streams looking at 'early help' for young people who do not fit the criteria for adult services and there is a review across H&F and WCC to ensure there is sufficient advice and information for young people.
- The shift from direct service provision/direct payments to personal budgets can cause anxiety for young people and carers. This is an area in which requires on-going support over a longer period to a majority of young people/carers. Increased use of personal budgets and direct payments in Children's services may minimise this anxiety. Work needs to support young people, parents and carers in understanding the implications of the Mental Capacity Act: whilst parents/carers make decisions for children, from 16, young people have the right to make decisions with appropriate support (provided they have capacity to do so). This can be a challenge for all involved.

7. EDUCATION AND EMPLOYMENT

Key messages

- Westminster has a very high proportion of school children with moderate learning disabilities educated in **mainstream schools** (as opposed to special schools), whereas Kensington and Chelsea has a very low proportion.
- **Educational attainment** for people with learning disabilities tends to be poor. Nationally, a third of those who had a statement due to a learning difficulty in schools have no formal qualifications, compared to 10% among the general population. School absence, which is predominantly authorised, is predominantly a result of illness.
- For people with learning disabilities, employment has been shown to have a number of positive effects, such as improving quality of life, as well as financial benefits. Within the three boroughs, **levels of paid employment** are highest in Kensington and Chelsea (higher than London and England rates), lower in Westminster, and among the lowest in London in Hammersmith and Fulham; to some extent this reflects differences between the boroughs in the way they capture information on employment status. Westminster has also been working with complex need, meaning lower numbers but more intensive support.
- Nationally, half of those out of work cited a lack of job opportunities as being the **limiting barrier to employment**, although a lack of skills and qualifications and healthiness were also cited as barriers.
- Spend per head of learning disabilities population on **employment support services** was broadly comparable across the three boroughs, and was more per head than for physical disabilities, but considerably less than for mental health clients. Employment support services are currently being retendered in the tri-borough area.

Recommendations

- The recent need to provide an Education, Health and Care (EHC) plan in 2014 for 0-25 year olds with complex needs will require a co-ordinated approach by local authority departments and local health and services, working in conjunction with local families, carers and young people in transition.
- Action is required to implement the legislation around the Children and Families Bill 2013 Part 3
- To allow valid comparisons to be made within tri-borough, all three boroughs should collect information on employment status in the same way and according to the same interpretation of the guidance (for example about what constitutes paid work).
- To develop specific targets for increasing the numbers of people with learning disabilities achieving employment and work with local employers to ensure more people with learning disabilities can access employment opportunities

7.1 Education

Numbers of children with learning disabilities in schools

Details of the number of school children in schools locally have been presented in Section 1 of this report and the Appendix.

Education in mainstream schools

In 2011/12, the percentage of children with moderate learning disabilities (School Action Plus or statements) educated in mainstream schools varied considerably across the Tri-borough area, with Westminster having among the highest in the country (>96.5%), Kensington and Chelsea having among the lowest (<80%) and Hammersmith and Fulham having below average (80-86%).

All three boroughs had a higher than average proportion of children with severe learning disabilities or profound or multiple learning disabilities in mainstream schools.

The Children and Families Bill 2013 Part 3

The Children and Families Bill, which is currently 'work in progress' pending the completion of the Pathfinder pilots, contains clauses on Special Educational Needs and the indicative Code of Practice. The bill gives rights and protections to 16-25 year olds with complex needs in further education, similar to those in schools, with a clear focus on outcomes. In particular:

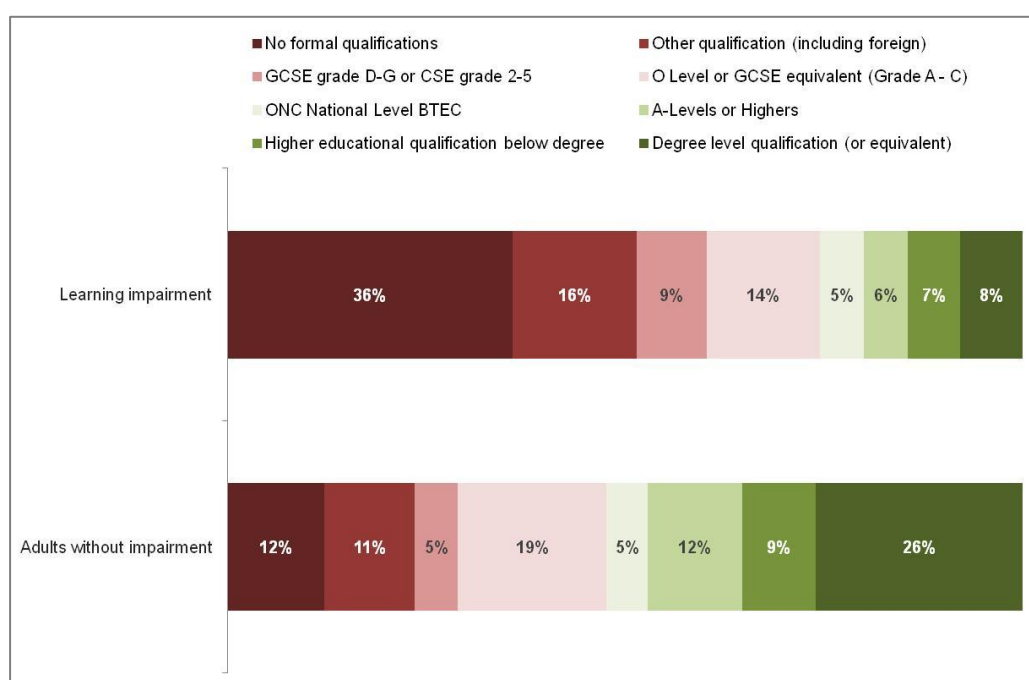
- There will need to be easy identification of children and young people with Special educational needs
- Children and young people with complex needs have the right to a co-ordinated assessment of needs and a new 0-25 education, health and care (EHC) plan. This will require the agencies to work closely together
- There will be increased choice and control, with young people and their carers at the heart of the process, with the option of a personal budget for those with an EHC plan
- Local authorities have to make clear a local offer, outlining options for education, health and care

This legislation covers a very wide range of organisations, including schools, colleges, NHS clinical commissioning groups, academies, people referral units as well as all local authority provision. Local authorities will have to collate information across departments, and streamline processes to enable implementation of the legislation in a meaningful and effective way.

Educational attainment

Nationally, those with a special educational need associated with learning disabilities have much poorer attainment than those without an impairment, with over a third with no formal qualifications, compared to 1 in 10 overall (see Chart 7a). Over the period from 2007 to 2011 there have been improvements in the percentage of pupils achieving expected level of attainment in English and Maths, although this is just 15% of those with a moderate, 3% of those with a severe, and 2% of those with profound and multiple learning difficulty, compared to 74% for all pupils.

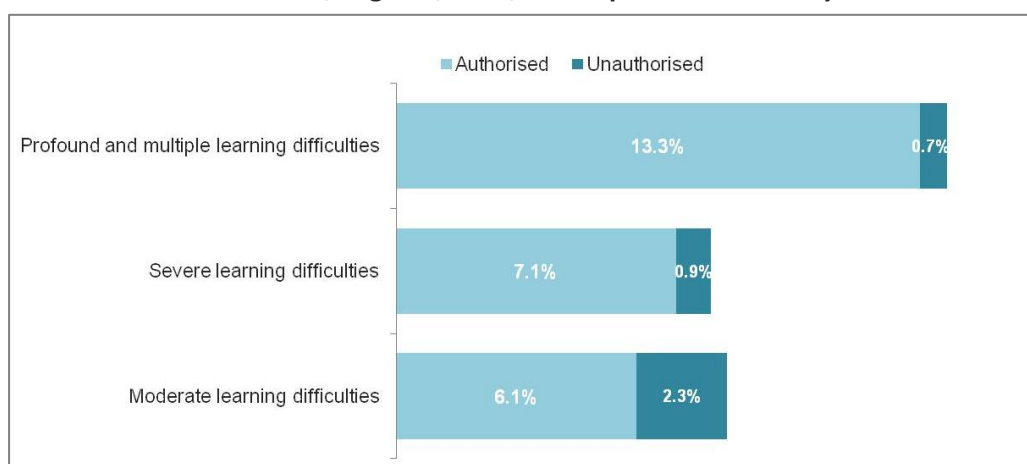
Chart 7a: Educational attainment for those with a learning impairment, Great Britain, 2009/11



Absence from school

Nationally, those with learning disabilities are absent from school for significant periods of time, mostly for authorised absence. Illness accounts for nearly two thirds (62%) of absence from school, with medical and dental appointments accounting for an additional 6%.

Chart 7b: School absence, England, 2010/11. Proportion of half days missed



School exclusion

Nationally, 5.8% of children with moderate learning disabilities are on a fixed term exclusion from school, compared to 1.5% for those without a statement. Proportions are much lower for severe learning difficulties (1.8%) and profound and multiple learning difficulties (0.6%). Verbal assault and physical and verbal abuse are the primary causes of the exclusion.

7.2 Employment rates

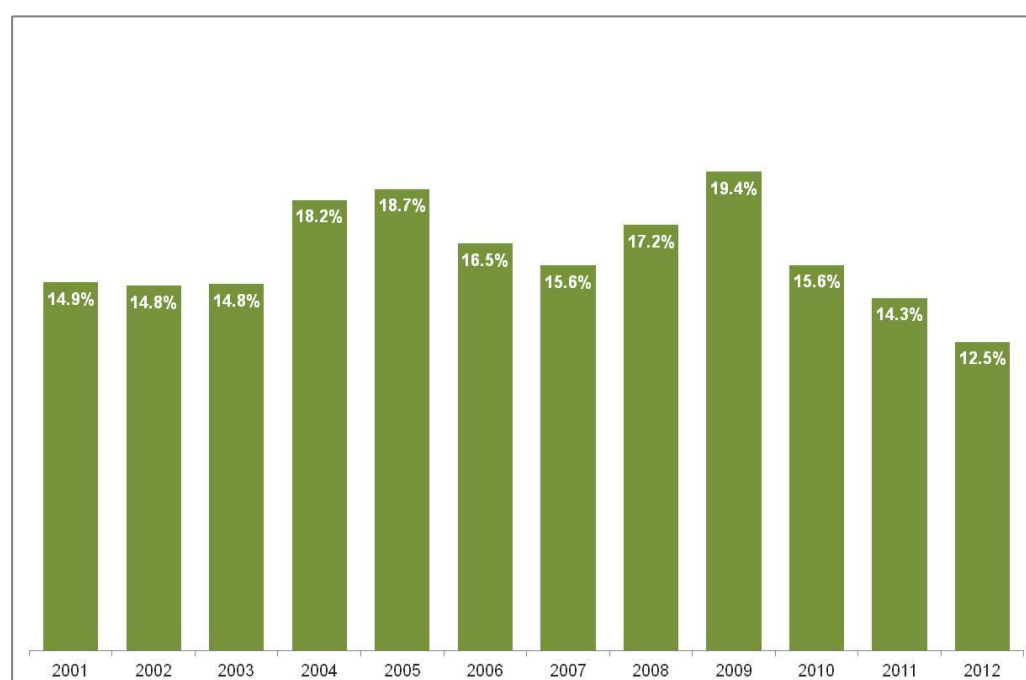
Background

Nationally, there has been a focus on improving employment rates of people with learning disabilities. Employment has been shown to have a number of positive effects, such as improving quality of life, as well as health and wellbeing, reducing the risk of social exclusion. Paid employment also provides financial benefits.

National employment rates

Nationally, employment rates among those with learning disabilities have been around 15% over the last decade, with peaks in 2004-05 and 2008-09. Since 2009, the rate has consistently dropped and now stands at 12.5%, the lowest for over a decade (see Chart 7c below). This may be explained in part by the recession.

Chart 7c: Employment rate for people with learning disabilities in Great Britain over time Labour Force Survey



Local paid employment rates

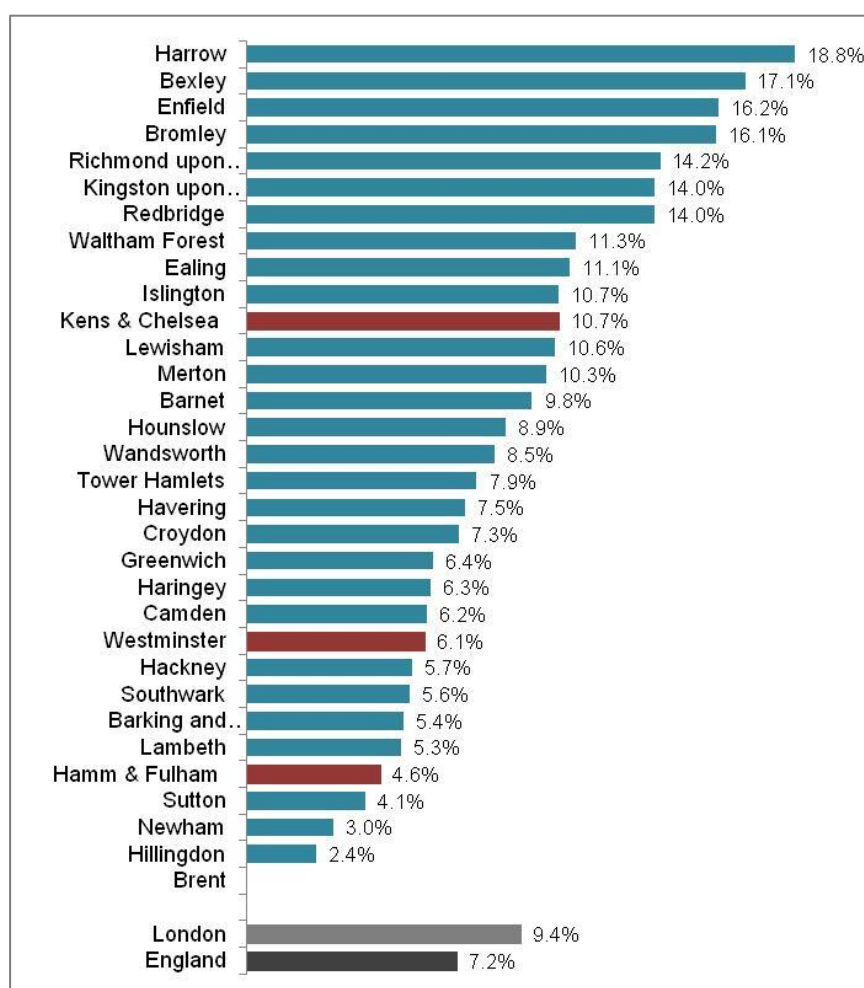
Note: the Adult Social Care Framework indicator for adults with learning disabilities in paid employment is calculated differently to the Labour Force Survey (see above)

One of the national indicators in the adult social care outcomes framework focuses specifically on the employment status of adults with learning disabilities aged 18 to 64 who are 'known to the council'. It is likely that councils across the country collect this information and interpret the guidance in different ways. In tri-borough, for example, Hammersmith and Fulham and Westminster have tended to count only the number of people who have been supported by their respective employment support services, who will account for only a proportion of those who have been in paid work in the year. In Kensington and Chelsea, care managers are asked to identify those people who they know have been in paid work in the year, out of everyone 'known to the council'. This approach is likely to generate a larger number of people who have been in paid work.

This may partly explain why Hammersmith and Fulham and Westminster reported a smaller proportion of adults aged 18 to 64 being in paid work, when compared to London and England. Neighbouring boroughs also had lower than average rates. Kensington and Chelsea had a higher rate of paid work than the other two boroughs and both London and England in 2012/13.

This may partly explain why, in 2012-13, Hammersmith and Fulham and Westminster reported a smaller proportion of adults aged 18 to 64 being in paid work (4.6% and 6.1% respectively) compared to Kensington and Chelsea (10.7%) and also London (9.4%) and England (7.2%). Conversely, Kensington and Chelsea reported a higher employment rate than a number of other neighbouring boroughs and also both London and England.

Chart 7d: Proportion of adults with learning disabilities in any paid employment, 2012/13 (Includes <16 hours/wk). *Figures rounded to nearest 5* Extracted from NASCIS ACCOF 1E



Comparisons over time

There was a change to the way the employment indicator was calculated in 2011/12 and this impacted on results. Therefore, results are not directly comparable with previous years.

Unpaid employment

Around 30 people with learning disabilities in Kensington and Chelsea were also in unpaid employment (voluntary work), or 11% of the total in 2011/12.⁶¹ This was the third highest in London after Redbridge and Lambeth. 40 people were in unpaid employment in Westminster (higher than the London average), with just 5 in unpaid employment in Hammersmith and Fulham.

Barriers to employment

A recent national survey⁶² found that half of those with learning disabilities who were unemployed and looking for work felt there was a lack of job opportunities and 4 out of 10 cited a lack of qualifications/experience/ skills, difficulties with transport and disability related reasons. For those economically inactive, their disability and related health conditions were the main barrier, although a third also cited anxiety or a lack of confidence.

Table 7a: Five most common barriers to employment, Great Britain, 2009/11

Barriers for the unemployed	Barriers for the economically inactive (not seeking work)
<ul style="list-style-type: none"> ▪ Lack of job opportunities (50%) ▪ Lack of qualifications/ experience/ skills (43%) ▪ Difficulty with transport (42%) ▪ Disability related reasons (38%) ▪ A health condition, illness or impairment (24%) 	<ul style="list-style-type: none"> ▪ A health condition, illness or impairment (73%) ▪ Disability related reasons (53%) ▪ Anxiety/Lack of confidence (34%) ▪ Difficulty with transport (19%) ▪ Family responsibilities (18%)

7.3 Employment support

Employment Support Joint Strategic Needs Assessment⁶³

In 2012/13, a very comprehensive review of supported employment services was completed by a small project team of Adult Social Care commissioners, Public Health analysts and care assessment staff across the Tri-borough area, which was coupled with piece of co-production work engaging local residents who use services and local, regional and national providers.

The outcome of this was a JSNA on supported employment for adults, which has led to a new service model that will be procured in 2013/14, with a new service commencing in June 2014. Key themes for the model include

- A strategic board that oversees all supported employment for adult social care including performance
- A vocational pathway function to assess and support people on their pathway to work maximising the offer from DWP funded services like work choices
- Continues the Supported Employment and IPS function that evidence says is the best way to support people with disabilities, social and health care needs into employment
- Emphasises better employer engagement
- Seeks to develop local social enterprises to support people with complex needs to gain work experience or paid work initially in a supportive environment until they move on to supported or long term employment

Hammersmith Fulham are exploring how they maximise the offer from Economic regeneration and the DWP funded services as a strategic priority.

Employment support services offered locally

There are three providers in Hammersmith and Fulham and two providers in each of the two other boroughs currently providing employment support and volunteering opportunities (see Table 7b below).

Table 7b: Five most common barriers to employment, Great Britain, 2009/11

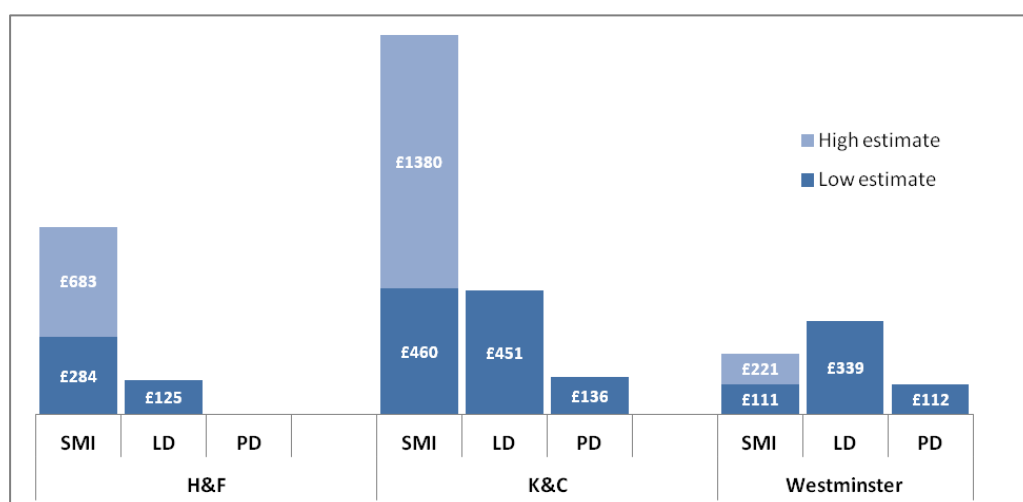
Service	Description	Outcomes
Hammersmith and Fulham		
HAFAD – Travel Works	Gives people with learning disabilities the technical training, qualifications and support needed to find paid work/ work experience in the community transport industry	<ul style="list-style-type: none"> • Five clients received service in year • Two clients completed training programme
Volunteer Centre H&F	Offer placements within their own organisation. Also run and offer MH mentoring and MH programmes: Creative Minds (funded by H+F MIND): a youth project (for 16-25 year olds) which encourages young people to achieve their goals, and receive mentoring AIM - all emotion run with H+F Mind	<ul style="list-style-type: none"> • Not known (access and outcome data not broken down by disability group)
Bishop Creighton House	Provides mentoring, volunteering, supported employment opportunities	<ul style="list-style-type: none"> • Data not available
Kensington and Chelsea		
Stepping Stones	A project led by the Kensington and Chelsea Volunteer Centre which encourages and supports people living with learning disabilities, to volunteer	<ul style="list-style-type: none"> • 26 LD clients received service in year • 15 LD clients supported into volunteering in year
Pure Innovations	Support for people with learning disabilities, physical disabilities, and people with mental health needs to get paid work, or a placement (where this is seen as a step to paid work)	<ul style="list-style-type: none"> • 32 received service in year • 6 into paid work • 9 into work experience
Westminster		
Westminster Employment	Specialist employment services for those with learning disabilities, physical disabilities and mental ill-health (as well as substance misuse clients and young offenders)	<ul style="list-style-type: none"> • 159 with LD or PD received service in year • 30 with LD or PD into paid work • 42 with LD or PD into volunteering
Volunteer Centre WCC	Supported volunteering project targeted to a range of groups, including learning disability clients. Also, specialist projects including mentoring and befriending scheme for clients with learning disabilities, aiming to build employability skills	<ul style="list-style-type: none"> • 69 with LD received service in year • 56 with LD into volunteering

Spend per head of population on employment services

Spend per head of relevant population on employment support services is low for those with learning disabilities compared to for mental health clients, although it is higher than the spend on physical disabilities spend per head in the three boroughs.

Spend is broadly similar per learning disabilities population in Kensington and Chelsea and Westminster but lower in Hammersmith and Fulham.

Chart 7f: Spend per head of relevant population on employment services, 2012/13



8. SAFEGUARDING, ABUSE AND CRIME

Key messages

- The rate of **referral for safeguarding abuse** in Hammersmith and Fulham is twice as high as the London average, similar in Kensington and Chelsea, and lower and declining in Westminster. In Hammersmith and Fulham, there has been an increase in the proportion of referrals judged to be substantiated or partially substantiated, the proportion now being in line with the London average and the other two boroughs in tri-borough
- In 4 out of 10 cases, abuse was **physical**, which is broadly similar to other client groups. Generally, those with learning disabilities are more likely to have referrals for **neglect** and less likely to have referrals for **financial** issues, compared to other service users
- As part of the **Winterbourne View Concordat**, the Department of Health required a review of all hospital placements to be carried out. Of the 17 patients in placements in the Tri-borough area, all have been reviewed and all have a register in place and maintained, as at June 2013
- Studies suggest around a quarter of **offenders** have a learning disability, although data from Wormwood scrubs prison is much lower, at 2.4-3.1%, suggesting there may be some under-recording. A unified approach among agencies has been recommended to enable appropriate diversion and sentencing

Recommendations

- Investigate, as part of the wider 2012-13 AVA findings action plan, the reasons for the high rate of safeguarding referral in Hammersmith and Fulham, in particular the reasons for the high proportion of repeat referrals
- Investigate the nature of the physical abuse alleged, in particular the relationship between the vulnerable person and the alleged perpetrator and the outcome of the allegation (for example whether it involved specific measures such as criminal proceedings as a result of hate crime)
- In accordance with the Winterbourne View Concordat, those in hospital placements should be moved out of hospitals by June 2014, unless being actively treated in hospital

8.1 Safeguarding and abuse

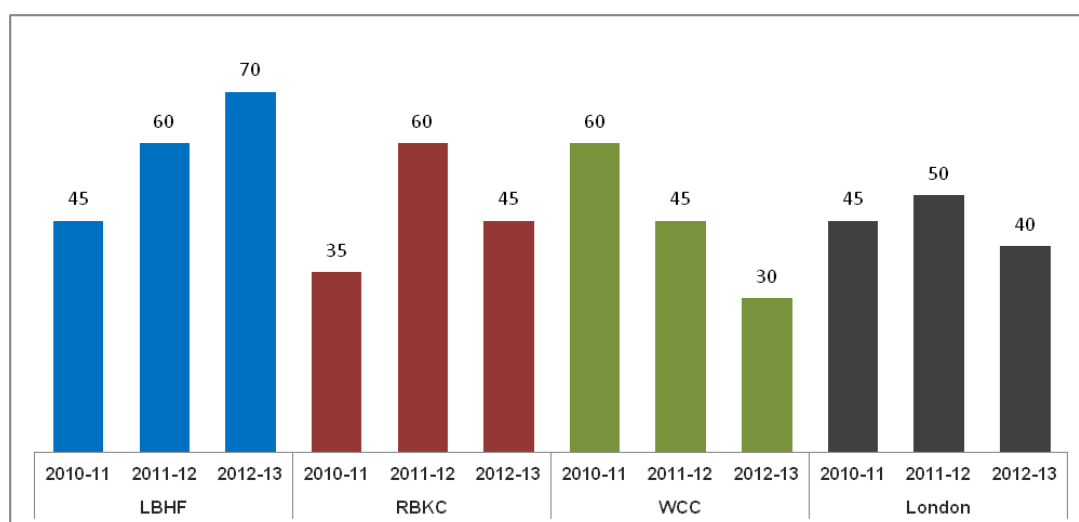
Referrals for abuse

The rate of safeguarding referral for abuse (in both community and residential care) has been rising in Hammersmith and Fulham and is now almost twice as high as the London rate.⁶⁴ In contrast, Westminster has seen a declining rate, while Kensington and Chelsea had a broadly similar rate to London in 2012/13. The great majority of referrals are for people aged 18-64, and just over half are for men.

Table 8a: Number of safeguarding referrals for abuse among people with learning disabilities, over time

Borough	2010/11		2011/12		2012/13	
	18-64	65+	18-64	65+	18-64	65+
H&F	55	5	80	10	95	0
K&C	40	5	70	5	50	0
Westminster	115	10	75	0	50	0

Chart 8a: Rates of safeguarding referrals for abuse among people with learning disabilities, aged 18-64, per 100,000 population



One of the reasons for the high rate of referral in Hammersmith and Fulham is the high *repeat* referral rate. In 2012/13, repeat referrals accounted for over a third (37%) of all referrals for people aged 18-64 with learning disabilities, compared to 20% in Kensington and Chelsea (similar to the London average) and 10% in Westminster (which has dropped over the last three years).

In Hammersmith and Fulham, the high rate of safeguarding referral for younger adults with learning disabilities is mirrored in a high rate for those with mental health needs and physical disabilities. This trend, along with others reported here, are being followed-up by the tri-borough safeguarding measuring effectiveness group as part of the 2012-13 AVA findings action plan.

Conclusion status

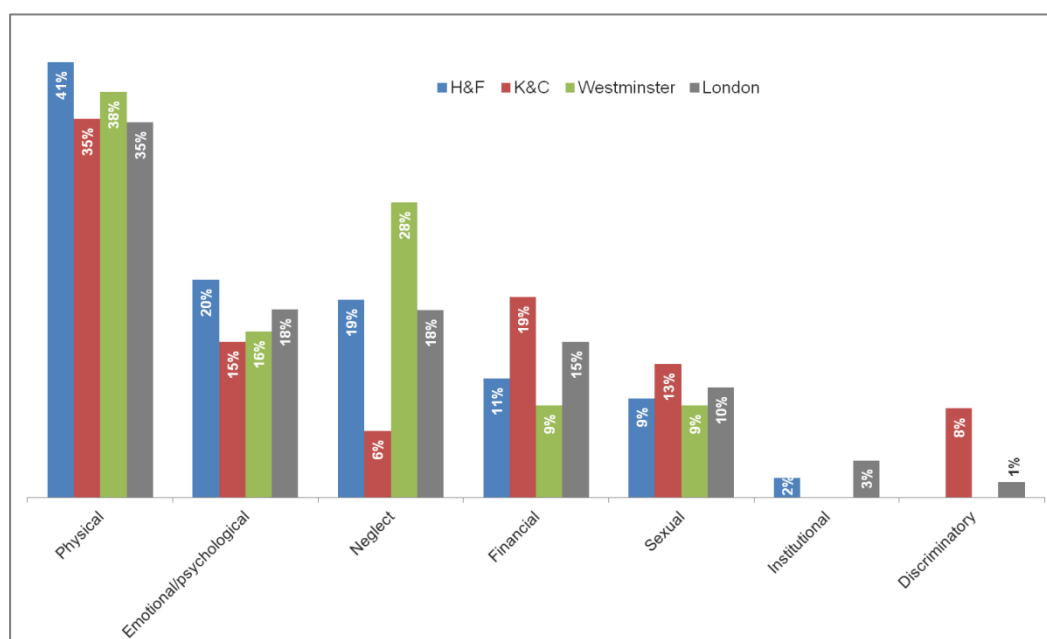
In Hammersmith and Fulham, the proportion of completed referrals among 18-64 year olds judged to have been substantiated or partially substantiated has shown a marked increase: in 2012/13, just under half (47%) of concluded referrals were judged to be substantiated or partially substantiated, compared with under a quarter in the previous two years. This is a little above the London average (46%) and only a little below the corresponding proportions for Kensington and Chelsea (50%) and Westminster (50%).

Type of alleged abuse

Based on the last three years, the most frequently mentioned type of abuse is physical abuse, accounting for about four out of ten allegations. Next is emotional/psychological abuse and neglect, each of which accounts for about two out of ten allegations, then financial abuse and sexual abuse. There is some variation by borough, with Westminster having a higher proportion of allegations for neglect.

Referrals for those with learning disabilities in London tend to be similar to referrals for all other clients groups in London, apart from slightly higher proportions for neglect and slightly lower proportions for financial abuse.

Chart 8b: Main type of alleged abuse, average of 2010/11 to 2012/13, as a proportion of all types of abuse alleged



Winterbourne View Concordat

In December 2012 the government published its final report into the events at Winterbourne View Hospital. One of the key findings was that many people who were in hospital didn't need to be there, in terms of receiving assessment and treatment and many stayed for far too long beyond their assessed need.

As part of the Department of Health Winterbourne View review Concordat, health and care commissioners have been tasked with reviewing all current hospital placements and supporting everyone inappropriately placed in hospital to move to community-based support as quickly as possible, and no later than 1 June 2014.

The Department of Health **Winterbourne View Concordat** identifies that commissioners are required to ensure that by 1st June 2014:

- All people with challenging behaviour in inpatient assessment and treatment services are appropriately placed and safe, and if not, make alternative arrangements for them as soon as possible. It is expected that the majority of people will spend less than 12 months in assessment and treatment units.
- They review funding arrangements for these people and develop local action plans to deliver the best support to meet individuals' needs;
- They review existing contracts to ensure they include an appropriate specification, clear individual outcomes and sufficient resource to meet the needs of the individual and appropriate information requirements to enable the commissioner to monitor the quality of care being provided;
- Everyone has a named care co-ordinator;
- They improve the general healthcare and physical health of people with learning disabilities – for example, all individuals in these services have a comprehensive health check within 6 months and a health action plan;
- They involve children, young people and adults with challenging behaviour and their families, carers and advocates in planning and commissioning services and seek and act on feedback about individual experience;
- planning starts early with commissioners of children's services to achieve good local support and services for children and better transition planning for children with disabilities moving from children's to adult services;
- From April 2013, health and care commissioners, set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of children, young people and adults with challenging behaviour in their area. This could be undertaken through the health and wellbeing board and could be considered as part of the local Joint Strategic Needs Assessment and Joint Health and Well-Being Strategy (JHWS) process;

Of the 17 patients in placements in the Tri-borough area, **all have been reviewed and all CCGs have a register in place and maintained**, as at June 2013.⁶⁵

8.2 Crime

Criminal justice system

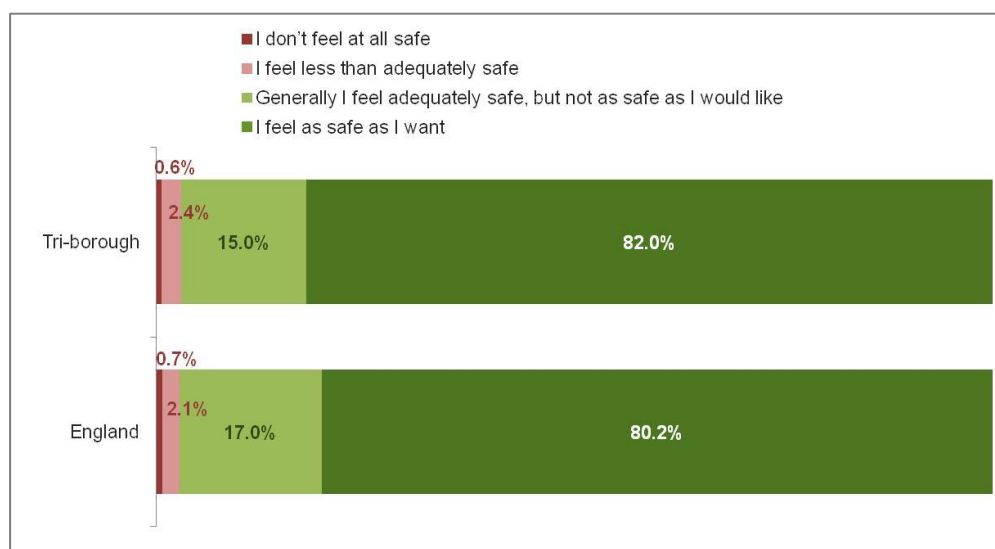
Studies suggest that between 20 to 30% of offenders have a learning difficulty.⁶⁶ One study found that 23% had an IQ score under 70, and 36% had scores between 70-79⁶⁷. More recent data suggests 7% have an IG of below 70 and 25% have an IG below 80.¹⁵ Rates of learning disability among those in Wormwood Scrubs were substantially lower than this (2.4-3.1%)¹⁴, suggesting there may be under-recording of learning disabilities. People with learning disabilities who offend usually have complex social care needs.

The “Positive Practice, Positive Outcomes”(DOH 2007) and The Bradley Report, 2009 recommended a unified approach from all relevant agencies to ensure early identification of offenders with learning disabilities and to enable appropriate diversion and sentencing. It is therefore important that criminal justice staff work together with the relevant agencies, such as health and social care, housing, education and employment to help them tackle their offending behaviour.⁶⁸

Feeling safe

Around 3% of people locally with learning disabilities feel less than adequately safe or not safe at all, which is broadly similar to nationally. People with learning disabilities state they are more likely to feel safe than other client groups, both locally and nationally.⁵⁹

Chart 8c: How safe people with learning disabilities feel, Adult Social Care Survey 2011-12



9. CITIZENSHIP

Key messages

- People with learning disabilities locally generally state they have adequate **social contact** with people, with the rate being similar to nationally. A range of opportunities are currently provided, including training, confidence-building and access to gyms and swimming
- Seven out of ten people can also **get to the places** in the local area that they want, better than nationally
- Nationally, only a small proportion of people with learning disabilities **vote**, but work has been carried out locally to increase levels

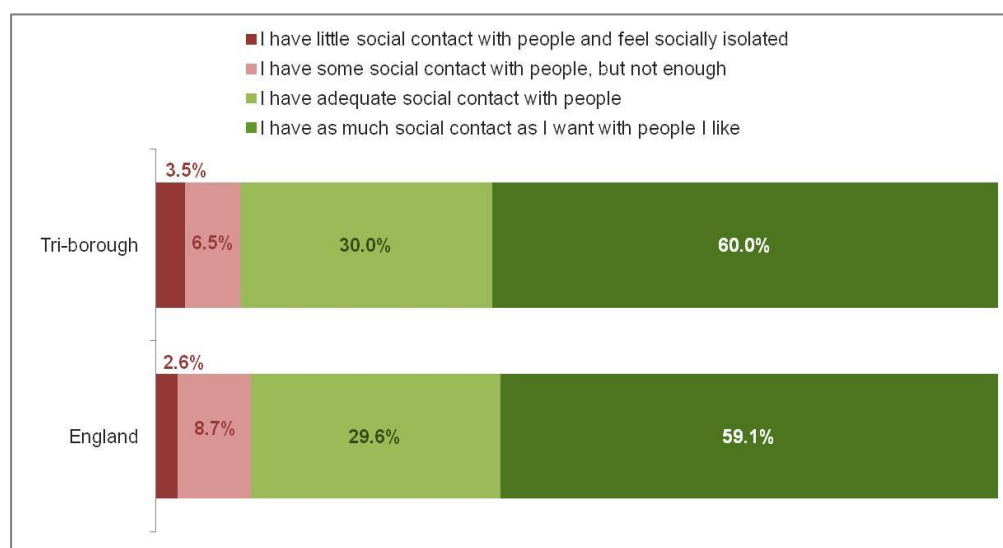
Recommendations

- All three boroughs should build on the good practice developed in response to the 2010 elections and support more people to understand how they can have a say in how the country is run, through voting

9.1 Social contact and Relationships

One in ten people don't have enough social contact locally, including around 1 in 30 who feel isolated. The proportions are broadly similar to nationally. People from other client groups are around three times more likely to say they don't have enough social contact, compared to those with learning disabilities.

Chart 9a: How much social contact people have, Adult Social Care Survey 2011-12⁵⁹



Some examples of opportunities for people with learning disabilities to experience accessible leisure, arts and culture include the following:

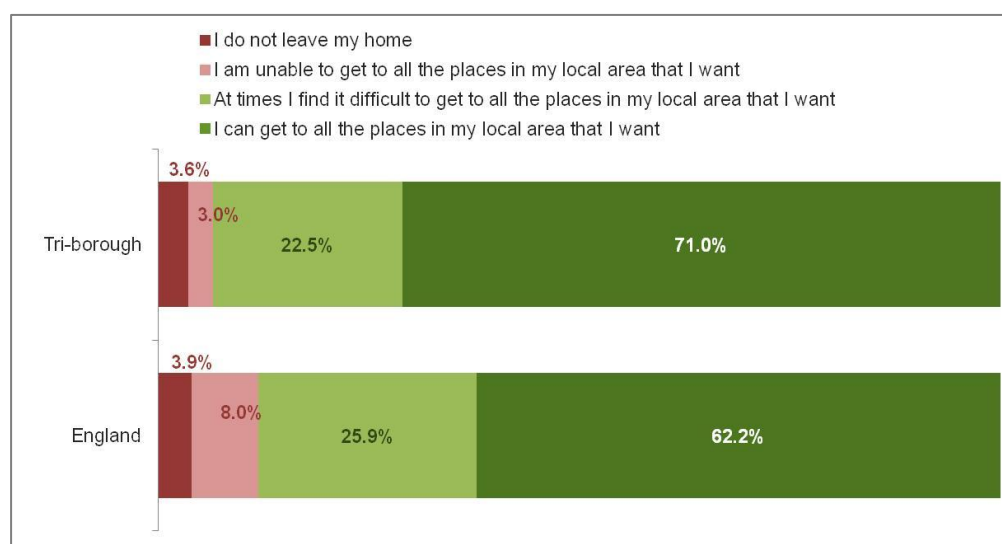
- Sessions provided by *LDN for You* on cooking, photography, confidence in going out and planning activities in night time
- Travel training, a football team, and supporting those who are isolated to access community services, provided by *Pip*
- Gym sessions for people with disabilities in Queen's Park
- Access to arts programmes at the National Portrait Gallery

9.2 Transport issues

The tri-borough vision around transport for clients with learning disabilities is that people should have the right travel support when they need it, which means that people can access the full range of transport options and support available.

Seven out of ten respondents with learning disabilities locally say they can get to all the places in their local area that they want, higher than nationally. Just over one in 20 can't get to the places that they want. As with other questions from the Adult Social Care Survey, those with learning disabilities have much more positive outcomes than other client groups.

Chart 9b: Getting to places in the local area, Adult Social Care Survey 2011-12⁵⁹



A Tri-borough **Adult Social Care Travel Support strategy** was published in the summer of 2012 and covered the future commissioning of such services as accessible buses to day services, taxis, parking badges, taxi cards, freedom passes, community transport and travel mentors. A Tri-borough tender for buses and taxi services then commenced during the winter of 2012/13 for a framework of accessible bus providers and taxi companies.

A Person Centred Travel Support Plan developed in Kensington and Chelsea will be piloted and consulted on in Tri-borough during the summer and autumn of 2013, with the intention to implement a revised version in 2014. The travel plan looks at what the person wants to do during the day and what support and transport they may need.

Travel Mentoring and Training, which is supporting a person to use public transport safely and efficiently is currently commissioned in various ways across the three boroughs. A full mapping and review of all these services will be completed by the end of 2013.

9.3 Rights

Professional 1:1 Advocacy

Professional 1:1 Advocacy is *“Taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.”*

From the Advocacy Charter 2002

A Tri-borough strategic review of Professional 1:1 advocacy services was completed in 2012, involving local and national providers and users and potential users of services including disabled people, people with learning disabilities, older people and people with mental health needs. Further to the review, a Tri-borough service for people with learning disabilities will be procured to commence in April 2014. The service will specialise in dealing with people with learning disabilities from mild/moderate needs to those with more complex needs including where communication support is required.

Both users and professionals were clear in the review that people with learning disabilities benefit from a specialist advocacy service, as in most instances they will require specialist communication support and may take a greater amount of time to gain a clear understanding of issues involved. People with learning disabilities stated they wanted a local, accessible, flexible and respectful service.

Examples of advocacy projects

- Full of Life are working with the local police commander and families to raise awareness of hate crime so it is reported and are promoting an App that allows individuals to either: store info on incidents or forward it to the local police
- All About Us have supported local people to campaign for a crossing on St Marks Road, North Kensington
- Big Voice have approached GPs to find out why not all are offering health checks

Voting in local and general elections

A key element of citizenship is contributing to society. One way in which everyone can do this is to vote in elections. In the general election prior to 2010, only about 16% of people with a learning disability voted. In 2010 the Westminster Learning Disability Partnership Board worked closely with the Cabinet Member for Adult Social Care, cabinet support officers, the electoral services department, and the Advocacy Project to raise awareness of the then forthcoming local and general elections in support of a national campaign being led by United Response.

As part of the campaign, United Response produced a range of accessible materials on voting and politics and sent a tool-kit to all MPs urging them to use of jargon-free language (see www.everyvotecounts.org.uk/index.php). One of the aims of the campaign was to increase the percentage of people with learning disabilities who vote in the general election to 40%. Among people supported by the Westminster Society for People with Learning Disabilities as many as 32 people from across supported housing and residential services were supported to vote in the general election on 6 May 2010.

Among the 18 people then supported by the *Pursuing Independent Paths* organisation, 12 were supported to register to vote and nine voted.

Similar activities have also occurred in the other two boroughs, such as supporting people to vote in council and London Mayor elections, and informing them about the political parties participating.

Tri-borough aims around citizenship

- To ensure that people with a learning disability lead full and rewarding lives and are free from discrimination, bullying and harassment
- To provide opportunities to promote equality and citizenship for people with a learning disability through active community involvement and inclusion
- To ensure that people with a learning disability have the same freedom, choice, dignity, autonomy and control as other citizens in the community
- To have effective advocacy
- To offer support that enables people with learning disabilities to travel safely.
- We aim to have enhance choice and control by ensuring opportunities are promoted in an accessible way
- To assume people have capacity for free choice and support self determination
- To break down barriers that exclude people from exercising their rights to vote

10. CARING RESPONSIBILITIES

Information about provision of short breaks has been detailed in the *Community Social Care* section of this document.

Key messages

- Local carers of people with learning disabilities who took part in the **national 2012-13 Carers Survey** generally find information and advice useful and also feel consulted in discussions about support and services provided. However, only 6 out of 10 found it easy to find information about advice, support, services or benefits
- In the survey just over a quarter of the carers of people with learning disabilities could be described as having a poor quality of life, about the same as the proportions for other carers
- Eight out of ten carers of people with learning disabilities said that they did not do enough of the things they **valued or enjoyed**; seven out of ten that they did not have enough **control over their lives**, and six out of ten that they did not have enough **social contact**
- Local carers have identified real challenges maintaining **paid employment** as well as caring for someone with learning disabilities and are worried about loss of benefits if they start working
- In Westminster and Hammersmith and Fulham, there has been a significant fall in the proportion of carers who have received an **assessment or annual review**. However, data for 2013-14 indicates that this trend has been reversed, with end of year projections indicating that over three quarters of carers will have received an assessment or review by the year end

Recommendations

- To review current local strategies and action plans around carers, to address:
 - Methods to identify carers early, via GP Practices, hospitals and other routes across the tri-borough
 - Making further improvements to existing carers' information and advice literature, including websites, to raise awareness amongst carers and stakeholders of the support available
 - Reviewing employment, training and volunteering opportunities, and promoting schemes to encourage carers to take a break
 - Standardise the way in which teams record carers assessments on the new social care IT system across Tri-borough (on Frameworki)

10.1 Number of carers of people with learning disabilities

The estimated number of carers of people with learning disabilities in 2012/13 (which was based mainly on the number of people living in the family home⁶⁹) was just under 400 across the tri-borough area, broken down as follows:

- Hammersmith and Fulham – 140 carers
- Kensington and Chelsea – 100 carers
- Westminster – 158 carers

10.2 Experiences of carers

Situation of carers

The National Carers Survey 2012/13⁵⁰ highlights that, compared with other carers, carers of people with learning disabilities are on average more likely to have been a carer for a longer period of time, to be living in the same household as the person they care for, and to provide a greater number of hours of care each week.

Quality of life

The survey included six questions about carer-related quality of life. These asked carers:

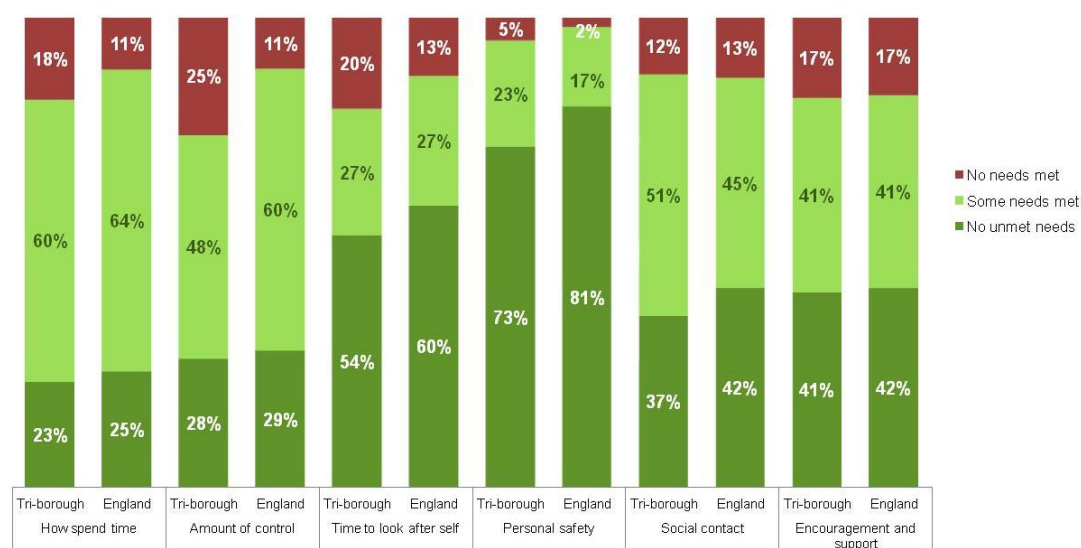
- Whether they were able to do things they valued or enjoyed with their time
- How much control they had over their daily lives
- Whether they had time to look after themselves
- Whether they had any worries about their personal safety
- How much social contact they had with people they liked
- Whether they felt encouraged and supported in their caring role

In each case respondents were asked to answer with reference to a three point scale, which corresponded to the following categories: “No unmet needs”, “Some needs met”, or “No needs met”.

Chart 10a below shows the responses to these six questions for those respondents across tri-borough who said they were looking after someone with learning disabilities, compared with England as a whole. Although the number of carers in this group was small (41), the pattern of responses locally was very similar to the national one.

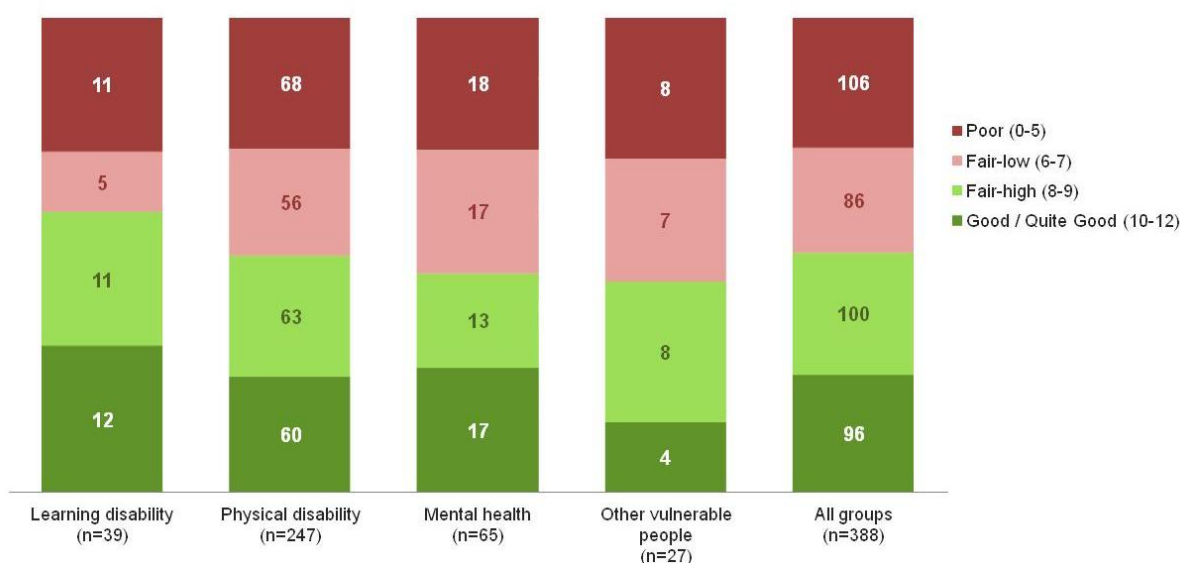
With the exception of personal safety and having time to look after themselves, the majority of respondents locally and nationally indicated that they had unmet needs, with over 70% doing so in the case of how they spent their time and how much control they had over their lives, and with about 60% doing so in the case of social contact with others and feeling supported in their caring role. In each of these four areas between 10% and 25% of respondents indicated that none of their needs were met.

Chart 10a: Whether carers of people with learning disabilities had any unmet needs in relation to six areas about their quality of life (Carers Survey 2012/13)



When each respondent's replies to each of these six questions were combined to produce an overall quality of life score, just over a quarter of respondents (28%) could be described as having a 'poor' carer-related quality of life (a score of 5 or less). This was very similar to the corresponding proportions for those carers who were looking after people in other care groups. But compared with other carers, carers of people with learning disabilities were more likely to achieve scores of 8 or above indicating a "Fair-high" or "Quite good/ Good" quality life. (Table 10.b)

Chart 10b: Proportion of respondents who fell into different groups on the basis of their responses to six questions about their carer-related quality of life (Carers Survey 2012/13) all three tri-borough surveys combined



Experience of support and services

Both locally and nationally, carers of people with learning disabilities rate the support or services they receive similarly to ratings from other types of carers. Compared to nationally, carers locally appear to rate services more positively, although sample sizes are too small to be confident.

Satisfaction with support and services provided *Carers Survey 2012/13*

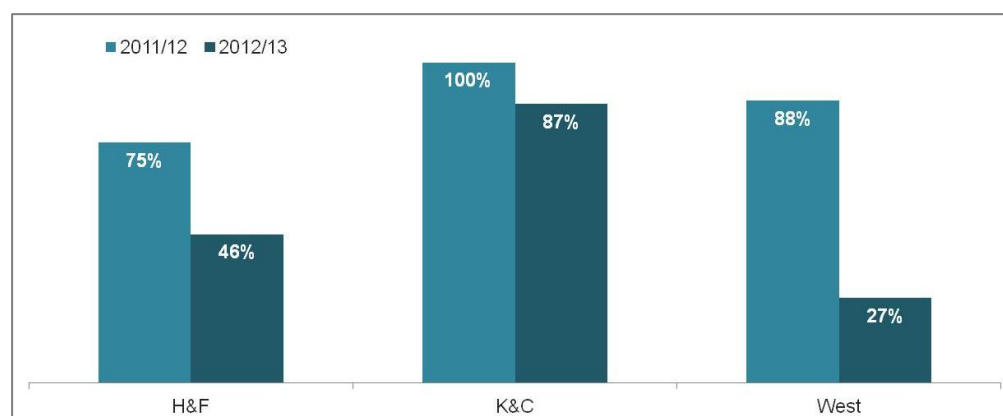
- 6 out of 10 carers of people with learning disabilities said they found it very/fairly easy to find information and advice about support, services or benefits in 2012/13. This is similar to nationally
- 9 out of 10 said they found the information or advice very/ quite helpful, including 4 out of 10 finding it very useful. This is slightly higher than nationally
- 8 out of 10 said they always/ usually felt consulted in discussions about support or services provided. This compares with about 7 out of 10 carers nationally

What carers have said locally: Views collected at the consultation events for The Big Plan, 2009-2012³⁶

- Some carers would like to have a job but it can be hard to work and care for someone
- Carers who work need understanding employers
- Carers are worried that it will be harder for people with learning disabilities to get jobs because of job cuts
- Carers are worried that they or the people they care for will lose their benefits if they work
- They also worry that people with learning disabilities will be forced to work when they don't want to

10.3 Carers assessments and reviews

In 2012/13, there was a significant fall in the proportion of carers who had an assessment or review during the year in Westminster, and to a lesser extent in Hammersmith and Fulham. Monitoring information for the first six months of 2013/14 suggests that this trend has been reversed, with 40% or more of carers in each borough having had an assessment or review by the mid-year point.

Chart 10c: Proportion of carers receiving an assessment/ review, 2011/12 and 2012/13 (provisional)³⁰

10.4 Future need for carers of people with learning disabilities

National modelling suggests the number of older people living with learning disabilities will rise considerably in the coming years, primarily as a result of improving life expectancy. If local areas follow national patterns, there will be a 13% rise in numbers of those over the age of 50 by the year 2030. Those with learning disabilities are increasingly likely to outlive their parents.⁷⁰

Given the reliance on family members for the provision of unpaid care and housing in many instances among the learning disabilities population, there are likely to be substantial financial implications relating to this rise in the coming years, with unpaid care being substituted by paid care.

10.5 The impact of welfare reform

The Welfare Reform Act 2012 is changing the way many housing options are funded, and the ability of local authorities to support independent living for people with a learning disability. Local Housing Allowance (LHA) will limit the amount of housing benefit for people living in private accommodation. LHA will not affect people who live in supported housing schemes. For people with a learning disability who need overnight care provision full housing benefit will still be available.

Future changes re universal credit (the limit on the amount of benefits a person can get) may result in reduction of benefits for those with low needs. Payments for Disability Living Allowance or Attendance Allowance are not included in the benefit limit, so people with moderate to high needs will not be impacted by the universal credit.

APPENDIX A

Further information on Reasonable Adjustments, from Equality and Human Rights Commission

Quoted from this page (please see link for further information):

<http://www.equalityhumanrights.com/advice-and-guidance/guidance-for-employers/the-duty-to-make-reasonable-adjustments-for-disabled-people/>

The duty to make reasonable adjustments for disabled people

Equality law recognises that bringing about equality for disabled people may mean changing the way in which employment is structured, the removal of physical barriers and/or providing extra support for a disabled worker. This is the duty to make reasonable adjustments.

The duty to make reasonable adjustments aims to make sure that, as far as is reasonable, a disabled worker has the same access to everything that is involved in doing and keeping a job as a non-disabled person.

When the duty arises, you are under a positive and proactive duty to take steps to remove or reduce or prevent the obstacles a disabled worker or job applicant faces. You only have to make adjustments where you are aware – or should reasonably be aware – that a worker has a disability.

Many of the adjustments you can make will not be particularly expensive, and you are not required to do more than what is reasonable for you to do. What is reasonable for you to do depends, among other factors, on the size and nature of your organisation.

If, however, you do nothing, and a disabled worker can show that there were barriers you should have identified and reasonable adjustments you could have made, they can bring a claim against you in the Employment Tribunal, and you may be ordered to pay them compensation as well as make the reasonable adjustments.

APPENDIX B

Moderate learning difficulties

In London and England, the number of school children with moderate learning difficulties has dropped by 13-14% over the last four years. The number dropped by 3% in local schools over the same period to a rate slightly lower than London.

In comparison to London and England, the number of schoolchildren in the Tri-borough area known to have moderate learning difficulties is high but dropping in Westminster schools, similar and dropping in Hammersmith and Fulham schools, and low and stable in Kensington and Chelsea schools.

Chart A1: Number with moderate learning difficulties per 100,000 state school population 2011

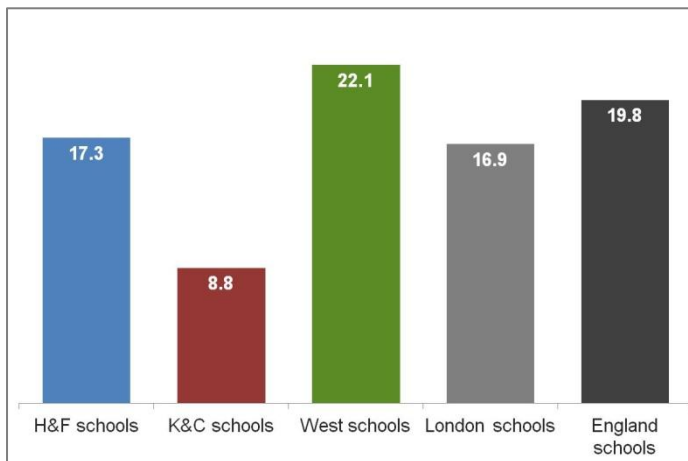
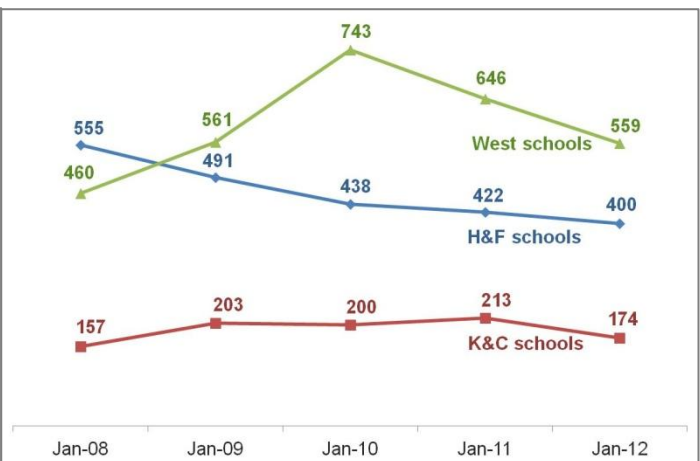


Chart A2: Number with moderate learning difficulties in state schools over time



Severe learning difficulties

In London and England, the number of school children with severe learning difficulties has dropped by 3-6% over the last four years. The number dropped by 22% in local schools over the same period to a rate well below London.

In comparison to London and England, the number of schoolchildren known to have severe learning difficulties is similar and rising in Hammersmith and Fulham schools, lower and dropping fast in Westminster schools, and low and stable in Kensington and Chelsea schools.

Chart A3: Number with severe learning difficulties per 100,000 state school population 2011

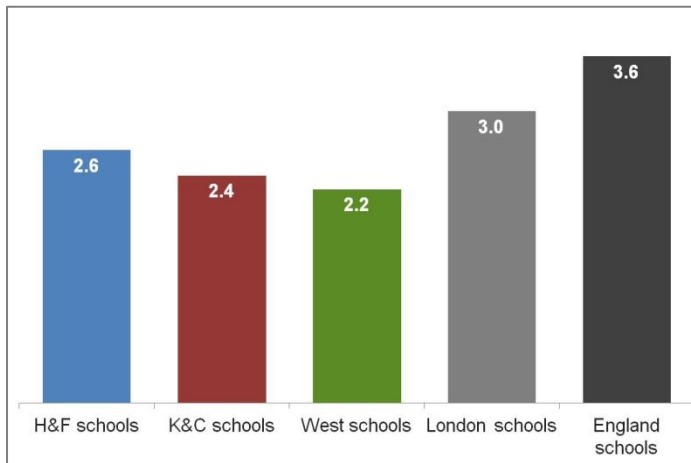
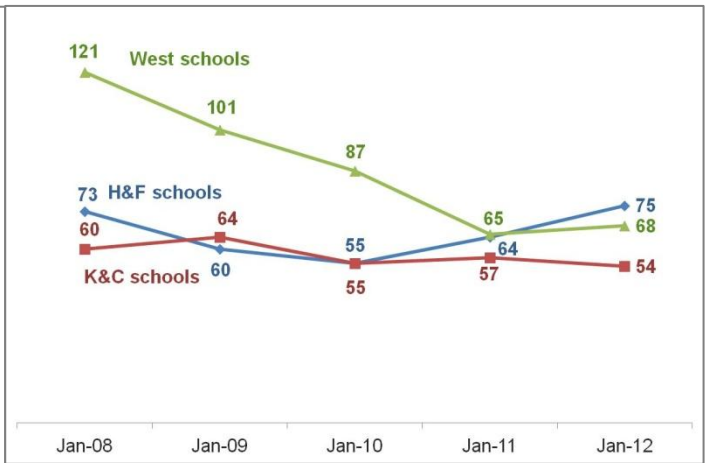


Chart A4: Number with severe difficulties in state schools over time



Profound and multiple learning disabilities

In London and England, the number of school children with profound and multiple learning difficulties has risen by 12-13% over the last four years. The number rose by 4% in local schools over the same period to a slightly lower rate than London.

The number of schoolchildren in Hammersmith and Fulham with PMLD is higher than London and England but has shown signs of decreasing in 2012. Both Westminster schools and Kensington and Chelsea schools have a lower rate (particularly Kensington and Chelsea). The number in Westminster is lower than four years previously, but may be rising. Kensington and Chelsea has experienced a slight rise.

Chart A5: Number with profound and multiple learning difficulties per 100,000 state school population 2011

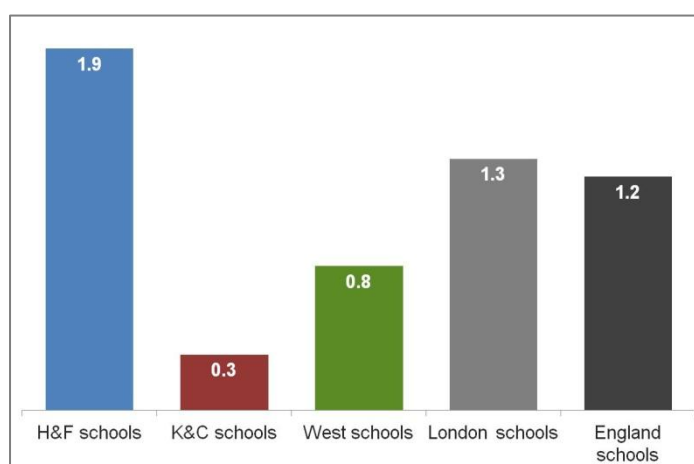
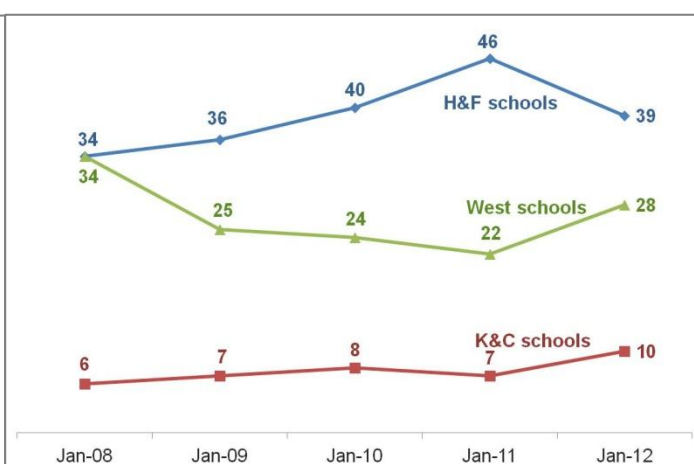


Chart A6: Number with profound and multiple learning difficulties in state schools over time



Autistic spectrum disorders (may or may not include children with learning difficulties)

In London and England, the number of school children with autistic spectrum disorders has risen by 40-50% over the last four years. The number rose by 91% in local schools over the same period, although the rate is still only two thirds the London and England rates.

In comparison to London and England, the number of schoolchildren known to have autistic spectrum disorders is similar to London and rising in Hammersmith and Fulham schools, lower but rising in Westminster schools, and very low and stable in Kensington and Chelsea schools.

Chart A7: Number with Autistic Spectrum Disorders per 100,000 state school population 2011

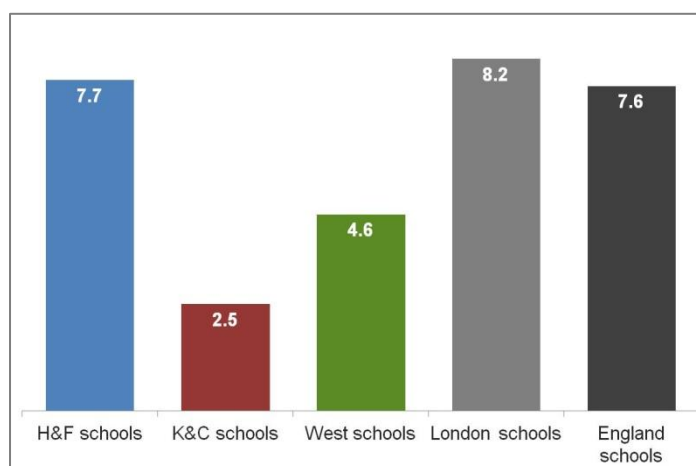
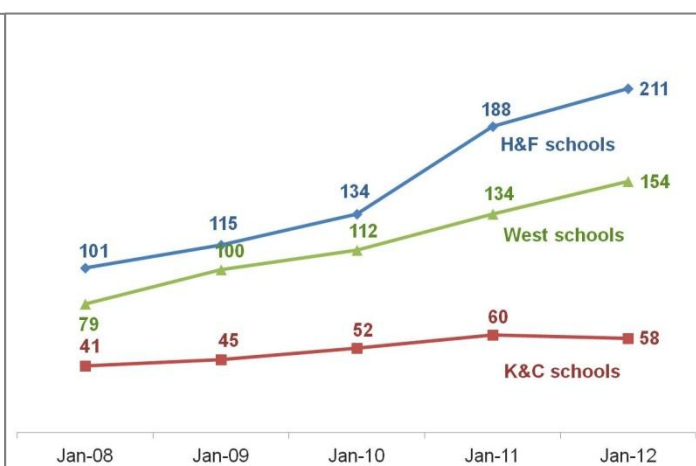


Chart A8: Number with Autistic Spectrum Disorders in state schools over time



APPENDIX C

Table A1: Numbers of people with learning disabilities with chronic diseases, by area of GP registration

Westminster estimated, based on 50% coverage

	H&F registered	K&C registered	Westminster registered (estimate)	Tri-borough
Epilepsy	70	71	108	250
Depression	69	46	82	197
Hypertension	49	50	73	173
Severe mental illness	41	36	83	160
Diabetes	35	27	50	112
Asthma	39	19	42	99
Hypothyroidism	24	22	48	94
CKD	34	14	30	77
Stroke & TIA	4	8	14	26
COPD	5	5	8	18
Atrial Fibrillation	4	8	6	17
CHD	5	3	8	17
Palliative care	1	0	0	1
Total learning disabilities	352	308	504	1164

- ¹ <http://www.rcgp.org.uk/revalidation-and-cpd/centre-for-commissioning/~media/Files/CIRC/LD%20Commissioning/RCGP%20LD%20Commissioning%20Guide%20v1%200%202012%2009%2024%20FINAL%20pdf.ashx>
- ² <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> Page 2
- ³ http://www.improvinghealthandlives.org.uk/securefiles/130806_1255//IHAL%202012-11%20Health%20Inequalities_r1.pdf Page 1
- ⁴ Extracted from QMAS 2012/13
- ⁵ QOF 2011/12. Extracted from QOF pages <http://www.hscic.gov.uk/catalogue/PUB08135>
- ⁶ Extracted from NASCIS online analytical processor Table L2
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁷ SAF returns provided on request by NWL CSU
- ⁸ <http://www.improvinghealthandlives.org.uk/profiles/>
- ⁹ Special Educational needs in England January 2012
<https://www.gov.uk/government/publications/special-educational-needs-in-england-january-2012>
- ¹⁰ Provided on request from Tri-borough Commissioning, 2013
- ¹¹ <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> Page 37
- ¹² <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> Page 41
- ¹³ Provided on request from Tri-borough Commissioning, 2013
- ¹⁴ Prison JSNA <http://www.jsna.info/download/get/prison-health-needs-assessment-2013/44.html>
- ¹⁵ People with learning disabilities and the criminal justice system – Useful Information, Foundation for People With Learning Disabilities
<http://www.learningdisabilities.org.uk/content/assets/pdf/resources/criminal-justice-system.pdf>
- ¹⁶ Estimated from GP practice prevalence from QOF 2012/13 and location of registered population from Exeter 2012
- ¹⁷ Ward level data provided by Adult Social Care Team Dec 2012 to March 2013. There may be small discrepancies with other routine data sources
- ¹⁸ http://www.improvinghealthandlives.org.uk/securefiles/131021_1728//IHAL2012-04PWLD2011.pdf page 45
- ¹⁹ PCT data warehouse extraction Dec 2012
- ²⁰ <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> Page 47
- ²¹ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_10673_IHaL2011-05FutureNeed.pdf
- ²² http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf
- ²³ Market Position Statement for Learning Disability Service Requirements and Provision in London V14, London Procurement Programme Purchased Healthcare Team, 2013
- ²⁴ <http://www.improvinghealthandlives.org.uk/publications.php5?rid=1165>
- ²⁵ <http://www.improvinghealthandlives.org.uk/gsf.php5?f=17280&fv=18581> Page 5
- ²⁶ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf
- ²⁷ <http://www.bris.ac.uk/cipold/documents/short-interim-report.pdf>
- ²⁸ http://www.improvinghealthandlives.org.uk/securefiles/130218_1052//IHaL-2013%20-01%20Reasonable%20adjustments.pdf
- ²⁹ http://www.rnib.org.uk/aboutus/Research/reports/2011/Learn_dis_small_res.pdf
- ³⁰ Provided by Tri-borough Adult Social Care
- ³¹ Events held in each of the three boroughs over 2012/13. Data provided by NWL CSU
- ³² http://www.improvinghealthandlives.org.uk/securefiles/130806_1331//IHAL2013%20-%2002%20Health%20Checks%20guidance%20final.pdf
- ³³ <http://www.improvinghealthandlives.org.uk/numbers/healthcheck2012>
- ³⁴ 2012/13 data provided on request by NWLCSU
- ³⁵ Data provided on request from Hammersmith and Fulham learning disability service
- ³⁶ <http://www.jsna.info/download/get/jsna-westminster-learning-disabilities-the-big-plan-2009-12/32.html>

- ³⁷ Data provided on request by CLCH Community Dental Service
- ³⁸ http://www.improvinghealthandlives.org.uk/securefiles/130218_1052//IHaL-2013%20-01%20Reasonable%20adjustments.pdf
- ³⁹ http://www.rnib.org.uk/aboutus/Research/reports/2011/Learn_dis_small_res.pdf
- ⁴⁰ Reasonable adjustments to eye care services for people with learning disabilities
<http://www.improvinghealthandlives.org.uk/publications.php5?rid=1167&edit>
- ⁴¹ <http://www.improvinghealthandlives.org.uk/projects/reasonableadjustments>
- ⁴² PCT data warehouse extraction
- ⁴³ http://www.improvinghealthandlives.org.uk/securefiles/130806_1730//IHaL-2013-02%20Hospital%20admissions%20that%20should%20not%20happen%20ii.pdf
- ⁴⁴ <http://www.improvinghealthandlives.org.uk/profiles/>
- ⁴⁵ <http://www.mencap.org.uk/campaigns/take-action/death-indifference>
- ⁴⁶ Information provided by local services August-September 2013
- ⁴⁷ Support for Living? Joseph Rowntree Foundation <http://www.jrf.org.uk/sites/files/jrf/2092-housing-support-learning%20difficulties.pdf>
- ⁴⁸ Extracted from NASCIS online analytical processor Table ASCAR L2
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁴⁹ Extracted from NASCIS online analytical processor Table ASCOF 1G
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵⁰ Provided by Tri-borough Adult Social Care
- ⁵¹ May 2013 data provided on request by NWLCU
- ⁵² Extracted from NASCIS online analytical processor Table ASCAR S1
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵³ Extracted from NASCIS online analytical processor Table PSSEX Unit Cost Summary
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵⁴ Provided by Adult Social Care as part of routine monitoring, July 2013
- ⁵⁵ Extracted from NASCIS online analytical processor Table PSSEX UCS
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵⁶ Information provided by Adult Social Care on request, August 2013
- ⁵⁷ Extracted from NASCIS online analytical processor Table RAP A1, using RAP P1 as a denominator <https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵⁸ Extracted from NASCIS online analytical processor Table RAP A7
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁵⁹ Adult Social Care Survey data 2011/12 provided on request by Adult Social Care, August 2013
- ⁶⁰ Provided on request from Tri-borough learning disabilities commissioning, 2013
- ⁶¹ Extracted from NASCIS online analytical processor ASCOF 1E
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁶² Life Opportunities Survey 2009/11, from <http://odi.dwp.gov.uk/fulfilling-potential/index.php>
- ⁶³ Available on Tri-borough JSNA website www.jsna.info
- ⁶⁴ Extracted from NASCIS online analytical processor Table AVA
<https://nascis.ic.nhs.uk/Portal/Tools.aspx>
- ⁶⁵ Information correct as at July 2013. Provided on request from CSU Learning Disabilities Commissioning
- ⁶⁶ <http://www.ohrn.nhs.uk/resource/policy/NoOneKnowPrevalence.pdf>
- ⁶⁷ Harrington and Bailey, (2005). Report Commissioned by the Youth Justice Board entitled 'Mental Health Needs and Effectiveness of Provision for Young Offenders in Custody and in the Community'. YJB
- ⁶⁸ <https://www.gov.uk/government/publications/positive-practice-positive-outcomes-a-handbook-for-professionals-in-the-criminal-justice-system-working-with-offenders-with-a-learning-disability>
- ⁶⁹ Assumption that those in a family home are likely to have a carer. Provided on request by Adult Social Care
- ⁷⁰ JSNA Carers Evidence Packs, available on www.jsna.info