



# JSNA

Joint Strategic Needs Assessment

# VULNERABLE GROUPS

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# Table of Contents

## Vulnerable Groups

Table of Contents .....	2
COVID-19 Impact on the JSNA Report .....	4
1. Adults with Autistic Spectrum Disorder .....	5
1.1 Introduction .....	5
Autism and Communication.....	6
Sensory Differences .....	7
Autism and Patterns of Behaviour .....	7
Autism and Employment.....	7
Autism and Social Isolation .....	8
Transition .....	8
Criminal Justice System.....	9
Autism and Gender .....	9
Autism in Black Ethnic, Asian Ethnic and Minority Ethnic Groups.....	9
1.2 Diagnosis and Identification .....	9
1.3 Co-morbidities .....	10
1.4 Prevalence and level of Need in the Population .....	11
Adults aged 18+ years .....	12
Limitations to the Data.....	13
1.5 Current Services on Offer .....	14
1.6 Barriers .....	14
1.7 Interventions/Approaches according to the Evidence Base .....	15
2. Physical & Sensory Disabilities .....	15
2.1 Introduction including Context and Policy/Guidance .....	16
Richmond Market Position Statement .....	16
2.2 Prevalence and Level of Need in the Population.....	17
Need for Social Care.....	18
Employment/ Income and Cost of Living .....	19
Preventative Support and Ageing .....	19
Limitations to the Data/Information.....	19
2.3 Barriers, Disability Prejudice, Social Isolation and Loneliness.....	20
2.4 Current Services on Offer .....	20
Young People .....	22
2.5 Barriers .....	22
2.6 What Interventions/Approaches Work According to the Evidence Base .....	22
3. Learning Disabilities .....	23

3.1 Introduction .....	23
Identification and Diagnosis.....	24
3.2 Level of Need and Prevalence .....	24
Health .....	26
Social Isolation .....	27
Meaningful Activity, Employment, Training and Education .....	27
Housing .....	27
Data Limitations .....	28
3.3 Transition.....	28
3.4 Current Services on Offer .....	28
3.5 Settled Accommodation .....	30
4. Unpaid Carers.....	31
4.1 Introduction, Context and Policy Guidance.....	31
4.2 Identification of Carers .....	32
Young Carers .....	32
Parent Carers and Sandwich Carers .....	34
Carers from Black Ethnic, Asian Ethnic and Minority Ethnic Groups .....	34
4.3 Carers’ health and well-being.....	34
4.4 Social Isolation.....	36
4.5 Need and Estimated Population Prevalence .....	36
Projection of carer numbers .....	37
4.6 Deprivation .....	38
4.7 Cared for Person.....	39
4.8 Carers Receiving Services and Support.....	40
4.9 Current Services on Offer .....	40
4.10 Interventions/Approaches.....	41
Acronyms .....	43
References .....	44
Acknowledgements.....	49

## COVID-19 Impact on the JSNA Report

The COVID-19 pandemic has had multiple and wide ranging impacts on the population. It has increased and expanded the role of both statutory and voluntary sector organisations, and other community led services. The Pandemic has created a whole new set of challenges for carers, hospitals, GPs and care homes, leaving in its wake health and social care service backlogs, establishment and management of a new and significant vaccination programme. The impacts span the life course and wide-ranging issues from political, economic, social, technology, lifestyle and health.

The pandemic has highlighted more starkly, issues such as health and social inequalities and deprivation, anxiety and mental ill-health, and many others. The JSNA health outcomes and wider determinants data presented in this JSNA generally predate the pandemic and could be expected to deteriorate in areas such as life expectancy, mortality and morbidity rates. Mortality from COVID-19 has had an unequal impact on different population sub-groups and exacerbated health inequalities. However, this will not be fully reflected in this JSNA as the data is not yet available at a local level.

It remains important to monitor pre-Covid time trends to understand the baseline from which to measure the local effects of Covid-19 on key statistics. The Protect Well chapter has more detail of the impact of COVID-19 on health outcomes. It is expected that detailed COVID-19 information will be available for analysis and consideration over the next 12 months.

# 1. Adults with Autistic Spectrum Disorder

“Young people and adults with autistic spectrum conditions (ASCs) living in the London Borough of Richmond on Thames should be able to live fulfilling and rewarding lives within a society that accepts and understands them. People should be able to receive a diagnosis and any support required. Peoples with ASCs can depend on mainstream public services to treat them fairly as individuals.

Richmond Market Position Statement

## 1.1 Introduction

Autism is defined as a lifelong developmental disability that affects how people perceive the world and interact with others. Autism is characterised by impaired social interaction and communication, severely restricted interests and highly repetitive behaviours (see diagnostic criteria for details). Autism can manifest in different ways meaning people need different levels of support. Some people with autism also have learning disabilities but autism itself is not a learning disability. There is also a greater prevalence for some mental health and physical health conditions.

Terminology can vary and an autistic person might be described as having:

- Autistic Spectrum Condition (ASC)
- Autistic Spectrum Disorder (ASD)
- Atypical autism
- Classic autism
- Kanner autism
- Pervasive developmental disorder
- High-functioning autism
- Asperger syndrome
- Pathological demand avoidance
- Social (pragmatic) communication disorder

In this report we use autism as a term that covers all these diagnoses. Neuro-typical is a term that is often used to describe people who do not display autistic patterns of thought or behaviour. and is used as a comparative term on occasion within this report.

Most self-advocates and groups of people with autism prefer the term “autistic person” to “person with autism” and that is the wording that has been used in this chapter.

National Strategy is governed by the Autism Act 2009 and Think Autism, Strategy Governance Refresh – the 2018 Update to the Autism Strategy. The Strategy has 19 objectives under 5 headings:

- Measuring, understanding and reporting needs of people with autism
- Workforce development
- Health, care and well-being
- Specific support
- Participation in the local community.

Most services focus on children and young people, but autism is a lifelong condition and can have a significant impact into adulthood. In addition, a significant number of autism diagnoses take place in adulthood. Autistic adults with a diagnosis are entitled to a Care Act Assessment but may not be eligible for support. Richmond is in the process of developing a new local strategy for autism that will cover all age groups. This section of the JSNA looks at the barriers faced by autistic adults in society and, where data is available, in Richmond in particular. It is important to remember that as a spectrum condition, autism can affect each individual differently. The following sections are a generalisation and not all statements will apply to each autistic person individually.

### Autism and Communication

People with autism have difficulties with interpreting both verbal and non-verbal language. They may find it particularly difficult to understand:

- facial expressions
- tone of voice
- jokes and sarcasm.

Some people with autism may not speak or may have limited speech. They will often understand more of what is said to them than they are able to express but may struggle with abstract concepts. Some people with autism benefit from using sign language or visual symbols instead of speech. Others may have good language skills but struggle to understand the expectation of others within conversations. This can manifest itself in a number of ways including repeating what the other person has said or talking at length about their own interests.

Sometimes a diagnosis of auditory processing disorder can occur alongside autism. This condition impairs the ability of the person to understand what they hear and convert it into meaning. This condition can also occur separately to autism and there is currently no definitive understanding of how the two conditions are linked. Eye contact can be hard for some people with autism to the point of causing physical pain if forced. This can often make normal social interactions difficult.

People with autism can find it hard to decode everyday speech, especially when the person talking is using sarcasm, “kind lies” or “half-truths”. This inability to see subtext in a conversation can make people with autism vulnerable to exploitation, especially when friendship is being offered.

Masking is a behaviour where people with autism will try to imitate neuro-typical behaviour in order to avoid social stigma. However, this can cause people with autism intense strain which can make coping harder.

Information overload is a familiar term when talking about email communications and social media, however people with autism will often experience this in everyday life. If there is too much information (including sensory information) some people with autism can be distressed or shut down, unable to interact further. Some people with autism can use pre-intentional communication by talking to themselves to help them keep calm, focussing, or as a reaction to an exciting or distressing situation.

These communication difficulties mean that many people with autism can:

- appear to be insensitive
- seek out time alone when overloaded
- fail to seek comfort, help or support from other people
- appear to behave “strangely” or inappropriately

- become physically or verbally aggressive towards themselves or others when overwhelmed
- retreat into themselves and be unresponsive.

Failure to recognise the communication needs of people with autism can exacerbate the communication barrier and lead to people with autism shutting down or being labelled as having “challenging” behaviour.

### **Sensory Differences**

Some people with autism process sensory information differently to neuro-typical people. However, this can vary from person to person, from sense to sense and be either over or under sensitive to different inputs.

For example:

- an oversensitivity to touch might cause someone to feel a seam in an article of clothing as not only uncomfortable but giving them overwhelming pain
- an under-sensitivity to sound may mean that someone is unable to even recognise someone talking to them without extreme effort to concentrate
- an oversensitivity to sound may mean that someone is overwhelmed and unable to function because of a background noise that a neuro-typical person may not even notice

Sometimes sensory differences will mean people with autism might have an obsession with certain patterns, shapes, colours, sounds or sensations. This can lead to compulsively touching people and objects or making the sounds that obsess them.

This over and under sensitivity can manifest in all or just some of the senses and each autistic person will be affected differently.

### **Autism and Patterns of Behaviour**

People with autism can often find the world confusing or overwhelming. Often, they prefer a regular daily routine so that they know what is going to happen every day, and a set of rules that they can follow without variation. They can often find changes upsetting, especially if those changes are unexpected.

Many people with autism have intense or highly focussed interests. These can change and develop over time but can be lifelong. This can often be channelled into studying, work, volunteering, or other occupation fundamental to their well-being.

Some people with autism will use stimming or self-stimulating repetitive behaviours such as fiddling with an object or rocking in place. This is thought to be a way of imposing some control over intense emotions or thoughts.

### **Autism and Employment**

There is a significant employment gap for people with autism, more than that when all disabilities are considered:

- 80% of people are in full or part time paid employment
- 47% of people with disabilities are in full or part time paid employment
- 32% of people with autism are in full or part time paid employment.

Only 16% of autistic adults are in full-time paid employment and this figure has remained steady since 2007. In addition, 77% of those who are not employed, say that they would like a job and 25% of those employed part time

would like to work more hours. 51% of people with autism in employment reported that they had skill levels higher than the job required.

Where people with autism are in work, 48% have experienced bullying or harassment in their workplace and only 58% have disclosed their autism. Where people have disclosed their autism, only 32% were asked what adjustments they would need in the workplace.

Barriers to employment for people with autism include:

- **The interview and application process:** One of the defining characteristics of autism (see above) is communication difficulties. An autistic person might need more time to formulate their answers to interview questions or may have difficulties coping with the interview process at all.
- **The work environment:** Since many people with autism have sensory sensitivities, a work environment that is noisy, brightly lit or busy can be overwhelming. 35% of people who had disclosed their autism to employers said that the adjustments made were poor.
- **Lack of employer understanding about autism:** 60% of employers stated that they do not know where to go for support or advice about employees with autism, 60% said they would worry about getting the support they offered to an employee wrong and 40% believed it would cost them more to employ someone with autism.

### Autism and Social Isolation

[The Adult Psychiatric Morbidity Survey in 2007](#) showed the prevalence of autism was higher amongst single respondents than married ones. [Research in America](#) has shown that only 5% of autistic adults ever marry and 67% have no interest in romantic relationships. While the participants for this study are more likely to be on the lower functioning end of the spectrum (most of the participants were diagnosed in the 1970s/80s when the criteria was stricter); the results do suggest that autistic adults are less likely to form romantic relationships.

Many people with autism find it hard to form friendships, even when they want to. Understanding and communicating with other people is particularly difficult for people with autism and can leave people feeling lonely. As many as 79% of people with autism and 70% of their families feel socially isolated. 81% say they feel lonely some of the time because of anxiety relating to their autism. 81% of young people with autism believe they spend less time socialising than their peers.

Some of the factors that impact on social isolation include:

- struggles in social situations (see diagnostic criteria above)
- autism is a hidden disability and can be misunderstood by people around them
- prevalence of anxiety and depression that can cause loneliness and social isolation
- The employment gap for Autism (see above) limits the opportunities to make connections with other people
- 70% of autistic adults feel that they need more support to become less socially isolated.

### Transition

At ages 16–25 years young people with autism have particular challenges due to the change in their lives and Services and the negative impact change has on many people with autism. Changes include:



- moving from a structured school environment to more self-directed learning, employment or unemployment
- adjusting to changing friendship groups and building adult relationships
- changes in support, many will have had additional support in school and then be ineligible for adult social care support in the same way.

### **Criminal Justice System**

Not only are people with autism vulnerable to exploitation, bullying and hate crime there is evidence that people with autism are overrepresented in the Criminal Justice System. This is thought to be due to:

- susceptibility to influence, exploitation and manipulation
- inability to think beyond the immediate impact of an action
- difficulties expressing thoughts and emotions leading to a physical response to frustration.

### **Autism and Gender**

More men are diagnosed with autism than women and the condition can often manifest itself in different ways by gender. Various studies have shown the ratio of male to female of people with autism varies significantly. [A survey of adults](#) (published in 2009) living in households throughout England found that 1.8% of men and boys had an autism diagnosis compared to 0.2% of women and girls. A [2017 study](#) showed a male to female ratio approximately 3:1. A study of people with a learning disability and autism showed a ratio of closer to 2:1.

The male : female ratio has been challenged and there are a number of theories to explain the gender split.

These include:

- autistic girls and women have characteristics that do not fit the profile usually associated with men and boys, and diagnostic tools are based on characteristics found in groups of males
- bias from practitioners who see autism as a primarily male condition
- autism is an exaggeration of normal gender differences
- the effects of foetal testosterone on brain development are a causal factor in autism
- a range of biological factors may mean men and boys have a higher prevalence
- women and girls on the higher-functioning end of the Spectrum may be better at masking their autistic traits
- autism traits in girls are underreported in schools.

### **Autism in Black Ethnic, Asian Ethnic and Minority Ethnic Groups**

Research suggests that children and adults from Black, Asian and Minority Ethnic groups can experience difficulties with obtaining an autism diagnosis leading to lower numbers of diagnoses and an increased possibility of misdiagnosis for other conditions. Work needs to be done nationally to expand our knowledge of autism and Black, Asian and Minority Ethnic groups.

## **1.2 Diagnosis and Identification**

Diagnosis is the formal identification of autism, usually by a multi-disciplinary diagnostic team. Although autism is a lifelong condition and often diagnosed in childhood, there are significant numbers of adult diagnoses where the condition was not recognised during their childhood.

Although autism is different in every person, for a diagnosis to be made a person will usually have:

- persistent difficulties with communication and social interaction
- restricted and repetitive patterns of behaviours, activities or interests that limit and impair everyday functioning

Tools used for a formal diagnosis of autism vary and include:

- Diagnostic Interview for Social and Communication Disorders (DISCO)
- Autism Diagnostic Interview – Revised (ADI-R)
- Autism Diagnostic Observation Schedule (ADOS)
- Developmental, Dimensional and Diagnostic Interview (3Di)

As autism diagnosis in children has improved, there have been more diagnoses in recent years than in the past and many autistic adults, particularly older adults, never received a diagnosis or support during their early years. Current knowledge of older people and autism is limited and under-diagnosis in older adults may lead to a lack of support in managing the impact of their condition such as social isolation at home or in accommodation-based care.

Estimated numbers of people with autism in the population are subject to a large margin of error and studies to determine population prevalence give varied results dependent on the criteria used. Diagnostic criteria have also evolved as we gain a greater understanding of autism.

While increasing numbers of people are diagnosed in childhood, there are still a number of people with autism who receive a diagnosis in adulthood or who have not been diagnosed and are unable to access appropriate support services. Current knowledge of older people and autism is limited.

In particular there are two suspected under diagnosed groups:

- **Women and girls:** More men are diagnosed with autism than women and the condition can often manifest itself in different ways by gender. There are a number of theories to explain the gender split but there is no conclusive evidence currently, whether the split is due to genetic factors (i.e., men more likely to be autistic) or social and diagnostic factors (i.e., women less likely to be diagnosed)
- **Black, Asian and Minority Ethnic groups:** Evidence suggests that children and adults from Black, Asian and Minority Ethnic groups can experience difficulties with obtaining an autism diagnosis and are more likely to be diagnosed incorrectly with other conditions

### 1.3 Co-morbidities

Some conditions are commonly diagnosed alongside autism. These include Attention Deficit Disorder (ADD) / Attention Deficit Hyperactivity Disorder (ADHD). Another condition often seen alongside autism is Pathological Demand Avoidance (PDA). While this is starting to be seen as a potential characteristic of autism, it is also seen as a diagnosis in neuro-typical people.

A learning disability is defined as a reduced intellectual ability and difficulty with everyday activities (for example, household tasks, socialising or managing money) which affects someone for their whole life. Research into the overlap between ASD and learning disabilities varies in the estimation of the proportion of people with autism who also have a learning disability and there is no definitive answer. Most studies show between 44% and 52% of people with autism may have a learning disability, and between 31% and 36% of people with a learning disability may also be autistic.

Some physical health conditions are more prevalent amongst autistic adults than in neuro-typical adults:

- immune disorders such as allergies and asthma
- metabolic disorders such as diabetes
- heart disease

- motor disorders such as cerebral palsy.

Some people with autism may avoid going to a doctor due to stress, fear of change (especially with unfamiliar Doctors) and worry about procedures such as colonoscopies etc. This means that diagnosis and treatment of other conditions can be delayed which can have a long-term physical health impact.

Studies have also found that gastrointestinal disorders are more common amongst children with ASD than the neuro-typical population and that up to a third of people with autism may experience epileptic seizures compared to 1–2% of the neuro-typical population.

Amongst autistic children, an estimated 30–60% are also diagnosed with ADD or ADHD. Compared to 6-7% of neuro-typical children. autism can also disrupt sleep amongst both children and adults.

Some Common Mental Disorders (CMD) can also be more common amongst people with autism. 40% of people with autism have symptoms of at least one anxiety disorder at any time compared with 15% of the neuro-typical population. This is often combined with depression. It is thought that a combination of factors that lead to vulnerability to stress can explain why the prevalence is so high:

- biological differences in brain structure
- history of social difficulties (including decreased self-esteem and an overestimation of threats)
- problems finding flexible responses to change and apparent threats.

Obsessive Compulsive Disorder (OCD) is also more common in people with autism. This is thought to be because of a combination of genetic factors and psychological predisposition. Diagnosis of OCD in people with autism is difficult as it may be mistaken for repetitive behaviour.

It is estimated that at least 20% of the population will experience a period of depression in their lifetime and this is more common in people with autism. People with autism can also find it harder to seek help for depression partly because change can be daunting and raise anxiety levels, and partly because they can find it difficult to label their feelings making it hard to communicate symptoms and concerns.

## 1.4 Prevalence and level of Need in the Population

Autism is a lifelong condition that affects 1.1% of the population. Despite this relatively high prevalence, the causes are still largely unknown. Factors that can increase the likelihood of an autism diagnosis include:

- an autistic sibling
- older parents
- certain genetic conditions
- very low birth weight
- some maternal metabolic conditions.

It is likely that there are some genetic factors responsible for some forms of autism with multiple genes combined with their interaction with environmental factors rather than a single genetic cause. Identifying a predisposition to autism through genetic testing is, therefore, not possible.

There are around 700,000 people with autism in the UK, more than 1 in every 100 of the population<sup>1</sup>. Nationally, between April to December 2018, 5,255 adults were referred for assessment where their need was suspected autism.

There are estimated to be 1,530 autistic adults living in Richmond, nearly 1 in 100 of the adult population. A Swedish study showed the average age of death for an autistic person is 58 years for those without a learning disability and 39.5 years for those with a standardised general population age of 70<sup>2</sup>. Leading causes of death were found to be neurological disorders such as epilepsy (previously been linked to autism) and suicide. People with high-functioning disorders had a nine-fold suicide risk compared to the neuro-typical population.

An [American Study](#) in 2017 found the life expectancy for people with autism to be 36 years old compared to 72 years for the general population.<sup>3</sup> It found 28% died due to an injury including suffocation, asphyxiation and drowning. This study looked primarily at lower-functioning disorders.

[The Adult Psychiatric Morbidity Survey \(APMS\)](#) included a measure for autism for the first time in 2007 and showed 1% of the adult population studied had autism (this decreased by age from 1.1% aged 16-44 to 0.8% aged 75+). The Department of Health funded a project to build on this study and found that the actual prevalence was closer to 1.1% of the population. The APMS carried out in 2014 showed a prevalence of between 0.5% and 1.3% of the population – the large range is due to the low prevalence combined with the size of the sample.

In Richmond, there are 432 children with an autism diagnosis known to schools, approximately 1.15% of the school population. This is lower than the London average of 1.5% and England average of 1.37%.

### Adults aged 18+ years

There is no register of autistic adults. Using age-related national prevalence rates based on a total national population of 1%, it is estimated that the number of people in Richmond with autism in 2020 is in the region of 1,530<sup>4</sup>, 0.98% of Richmond's population. Assuming that the prevalence rates remain steady and show a continuous increase in line with the population increase. **Table 1** shows it is estimated that there will be a 1.8% increase from 2020 to 2030.

**Table 1: Estimated Number of People with Autism, 2016, Richmond**

	2020	2030	2040	2050
<b>18+ Population</b>	155,700	158,800	162,000	164,900
<b>Autistic adults</b>	1,530	1,550	1,580	1,610
<b>% population</b>	0.98%	0.98%	0.98%	0.97%
<b>Increase from 2020</b>		1.8%	3.7%	5.4%

Source: GLA population estimates & Office of National Statistics

<sup>1</sup> The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care

<sup>2</sup> Hirvikoski, T et al (2018) . Premature mortality in Autism spectrum disorder. British Journal of Psychiatry. Jan 2018

<sup>3</sup> Guan, Joseph & Li, Guohua (2017). Injury mortality in individuals with Autism. American Journal of Public Health. April 2017

<sup>4</sup> Brugha, T. et al (2009) Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey, 2007. Leeds: NHS Information Centre for Health and Social Care. Available to download at <http://www.hscic.gov.uk/catalogue/PUB01131> [Accessed 10/05/2021]

The lower prevalence in adults found in the APMS is probably due to:

- an increase in diagnosis in childhood over time, either due to an increased prevalence of the condition or better diagnostic criteria now compared to the 20<sup>th</sup> century
- lower life expectancy of people with autism
- the difficulty older adults have in getting an autism diagnosis.

Nationally 17,975 new referrals were made between April and December 2018 where the need was suspected autism<sup>5</sup>. While 71% of these were children, there were 5,255 who were adults. Of these:

- 33% were 18-24 years
- 27% were 25-34 years
- 18% were 35-44 years
- 21% were 45 years and over
- 64% of all referrals were men and boys.

Autism itself is not a social care need. However, there are some people with a social care need who also have autism. In 2017-18, there were 36 new assessments by adult social care of people with autism:

- 16 of these were people also had a learning disability
- 12 of these were people also had a mental health need.

People with autism are not usually eligible for statutory adult social care support unless they also have a learning disability or mental health need. This can mean services are not always known, supported or provided to assist people in overcoming the barriers they face.

The number of people diagnosed as having autism has increased significantly in recent decades. [A recent study](#) showed that at least 60% of the increase in Denmark was due to the change in diagnostic criteria and the inclusion of outpatient contacts. [An American study](#) showed that the situation was more complex involving multiple potential biologic and environmental factors as well as changes in diagnostic practices. The Centre for Disease Control have increased their estimate of autism prevalence amongst Children in the USA to 1 in 59. Their evidence shows that previously there has been persistent undercounting and put the significant increase down to improved identification, particularly amongst girls and minority groups. While most new referrals for diagnoses in the UK are children, there are still a number of adults receiving a new diagnosis

### Limitations to the Data

The number of people receiving social care services is small and analysis of trends and future needs is therefore subject to large margins of error. Much of the other data are extrapolated from national prevalence rates and are therefore just estimates based on the age of Richmond's population and not the specific socio-economic profile of the Borough.

Prevalence rates are often based on diagnosed conditions and therefore may be an underestimate of the actual level within the population. The APMS developed their statistics using a self-completed test. This test is a tool used as part of a diagnosis, not a diagnosis in itself. Evidence shows that the AQ questionnaire produces a large number of false

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<sup>5</sup> The data does not show how many people received a diagnosis, only those referred where autism is suspected.

negatives i.e., people who score as not having autism on the questionnaire but, after a formal testing period, do receive a diagnosis. In addition, the sample was comparatively small, and the results are therefore subject to a larger margin of error.

## 1.5 Current Services on Offer

While providing a Social Care Assessment is a statutory requirement, unless an autistic person has other needs (e.g., a learning disability) it is unlikely that they will be eligible for statutory social care support. Most support services designed for people with autism are, therefore, non-statutory. In Richmond, work is in progress, as part of the refresh of the autism strategy, to review services and develop actions to improve the experience of people with autism in accessing local services.

In Richmond, diagnostic and post-diagnostic support is available through “Your Healthcare”. This service provides specialist diagnostic assessments and healthcare interventions. Individuals can self-refer, or referrals can be made by professional groups. The service also provides psychotherapeutic support for those with complex emotional needs.

Choice Support are commissioned by the Council to provide employment support to people with autism, with or without a learning disability. The services include support in obtaining employment and maintaining employment for the autistic person and their employer.

The National Autistic Society provides support and guidance for both adults and children with autism and their families. This includes help and support and their Autism at Work Service that works with employers to support people with autism in the workplace.

## 1.6 Barriers

People with autism experience many barriers in day to day living, and because autism is a hidden disability these are not always known, understood or acknowledged.

Communication difficulties mean that many people with autism can:

- appear to be insensitive
- seek out time alone when overloaded
- fail to seek comfort, help or support from other people
- appear to behave strangely or inappropriately
- become physically or verbally aggressive towards themselves or others when overwhelmed
- retreat into themselves and be unresponsive.

Many people with autism react negatively to change and prefer a regular daily routine so that they know what is going to happen every day, and a set of rules that they can follow without variation. Unexpected changes can be debilitating for an autistic person and they take them time to adapt to the new situation.

There is a significant employment gap for people with autism, more than when all disabilities are considered. Only 16% of autistic adults are in full-time paid employment and only 32% in any form of paid employment.

Many people with autism find it hard to form friendships and autistic adults are less likely to form romantic relationships. As many as 79% of people with autism and 70% of their families feel socially isolated.

The lower life expectancy for autistic adults can also skew prevalence rates. People with autism but without a diagnosis or the corresponding support are at a higher risk of life reducing mental health conditions.

## 1.7 Interventions/Approaches according to the Evidence Base

Autism affects people in a broad variety of ways and a good understanding of the condition, and the potential impacts, is required to effectively design and deliver support services tailored to the individual need which can be a challenge as rarely will two people with autism will need the same support. Training of front-line staff in autism (including reception and administrative staff) has been found to have a positive impact on people's experience of services with environments such as waiting areas which are more autism friendly and sensitive.

Research has found that social skills training may be effective for people with autism and show significant positive effects on empathy, depression, anxiety and social behaviour. However most existing training is aimed at young adults and it is unknown whether the impact on adults aged 30 years + would be the same.

There are a number of weaknesses that have been identified with the current evidence base for support for autistic adults. This is partly due to the lack of services specifically for adults with the condition as they are often not eligible for social care support unless they also have another condition, such as a learning disability or mental health condition, and care is then focussed on that condition.

NICE guidelines recommend psychosocial interventions but not medication. This is because there has been no evidence that medication is effective in managing autism.

Applied behaviour analysis, although a common treatment, has been heavily criticised because it seeks to impose neuro-typical behaviours on people with autism. A strength-based approach has been shown to be more effective, as it works with the positives that autism can bring to people's lives as well as the individual strengths of the autistic person.

Services that provide general support aimed towards improving independent living have proven success with a wide range of people with autism. Peer Support Groups are another valued service and provide people with autism opportunities for social interaction and share experiences.

A multidisciplinary approach can reduce service costs, increase diagnosis rates, reduce service use (including crisis services) and increase employment rates for people with autism.

## 2. Physical & Sensory Disabilities

Sensory and physical disabilities can isolate individuals from accessing mainstream services and from the community, whether that be, although not limited to, through physical access issues or difficulty communicating to others. It is important to also recognise the interactions with non-disabled people, and sadly the stigma related to people's behaviour. The most vulnerable of this cohort may be socially isolated and unable to access services to support their health and well-being. Future services and decisions must strive to achieve equality for all people, across all aspects of life.

Because of the small numbers in this contingent it is often hard to identify a strategic way forward based on Richmond data, and each case needs to be considered on the person's individual strengths and needs.

## 2.1 Introduction including Context and Policy/Guidance

Physical and sensory impairments affect people across all ages of the life course. Impairments can be caused by a condition, injury or the result of ageing. Some may present from birth or maybe sustained after a life-changing event. These Impairments can be a great challenge for those in a world designed for able-bodied people. Depending on the impairment, a person may have issues with transport, access and communication. The Government has prioritised all disabilities through the Equality Act 2010. However, there is still significant progress required to improve the lives of people living with a disability.

Physical and sensory disabilities can have a wide range of causes and conditions and can impact in many different ways during people's lives. Some children are born with a physical or sensory Impairment and continue to face different barriers as they grow into adults. Some people have a sudden illness or injury causing a dramatic change in their needs and the way they interact with the world. Others may develop a degenerative condition which worsens as they age.

"All people should have the opportunity to be active citizens, live a meaningful life and make positive contributions to their community. People with a physical or sensory Impairments have the same aspirations as everyone else. They would like to be independent, have a job, have their own home, make and keep friends, form relationships and choose what they do in their spare time. People with physical and sensory disabilities should be recognised as equal and enjoy the same life opportunities as others. We want services in our Borough that actively work with people to define their goals and plans to achieve them; services that consider the whole of a person's life and to work with providers that are aware of varied areas of provision and make all links across the care landscape."

Richmond Market Position Statement

Defining disability is complex and contentious. The "Social Model" of disability states that disability is created by barriers in society including the environment, people's attitudes and organisations. The "Medical Model" is based on a belief that disability is caused by an individual's health condition or impairment.

Examples of definitions include:

- **The Equality Act 2010:** Disability is having a physical or mental impairment that has a substantial and long-term negative effect on the ability to do normal daily activities. Long-term is defined as at least 12 months
- **The World Health Organisation:** Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An Impairment is a problem in body function or structure; an Activity Limitation is a difficulty encountered by an individual in executing a task or action; while a Participation Restriction is a problem experienced by an individual in involvement in life situations.

For the purposes of this chapter physical and sensory disabilities are defined as follows: A person who faces barriers in undertaking day to day tasks due to a physical, mobility or sensory need.

This fits with the national reporting model for social care which groups people by their Primary Support Reason (PSR). The Social Care PSRs covered in this section are:

- Physical Support: Mobility Need
- Physical Support: Personal Care Need



- Sensory Support: Visual Impairment
- Sensory Support: Hearing Impairment
- Sensory Support: Dual Impairment

Key UK legislation includes:

- The Equality Act 2010 is the UK's legal framework designed to protect disabled people from discrimination.
- The Care Act 2014 which is the UK's legal framework for Local Authority provision for adults with care and support needs under the principle of promoting well-being which includes:
  - Personal dignity
  - Physical and mental health and emotional well-being
  - Protection from abuse and neglect
  - Control by the individual over day to day life
  - Participation in work, education, training or recreation
  - Social and economic well-being
  - Domestic, family and personal
  - Suitability of living accommodation
  - Contribution to society.

Within the legislative framework as above, Local Authorities have a duty to promote well-being and ensure equality of opportunity for people with disabilities within the Borough. People with physical and sensory disabilities will often face barriers to undertaking day to day tasks that may require equipment, adaptation and support or social and cultural change within communities to overcome.

## 2.2 Prevalence and Level of Need in the Population

Using local prevalence rates, it is estimated that, in 2020, there are over 21,000 people aged 18-64 years living in Richmond whose ability to do day to day tasks is limited by long-term condition or illness including physical, sensory and learning disabilities and mental health conditions, 7.9% of Richmond's 18-64 year old population. Over 8,000 of these people state they feel their lives are limited.

Applying national age-related prevalence rates to Richmond's population it is estimated that 5.5% of the 18-64 years population (6,800 people) have mobility impairments, 1.0% (1,300 people) have visual impairments and 0.7% (800 people) have severe hearing loss (in total 10.7% of the population, 13,300 people, have some hearing loss). All these numbers are expected to increase over the next 30 years as shown in **Table 2** below.

**Table 2: Estimates of the Number of People with Disabilities in Richmond**

		2020	2030	2040	2050	% increase
<b>Mobility</b>	People	6,800	7,400	7,500	7,400	9.3%
	% population	5.5%	5.7%	5.7%	5.7%	
<b>Visual Impairment</b>	People	1,300	1,400	1,400	1,400	9.0%
	% population	1.1%	1.1%	1.1%	1.1%	
<b>Some Hearing Impairment</b>	People	13,300	14,400	14,600	14,400	9.3%
	% population	10.7%	11.1%	11.0%	11.1%	
<b>Severe Hearing Impairment</b>	People	800	900	900	900	9.0%
	% population	0.7%	0.7%	0.7%	0.7%	

Source: GLA population estimates; Deloitte Access Economics (2017) and Office for Disability Issues, (2011b)

In 2018-19, there were a total of 208 adults aged 18-64 years receiving social care services in Richmond for physical health and sensory needs (**Table 3**).

**Table 3: People receiving social care services in Richmond**

	2018-19	Estimated 2050
<b>Community-based services</b>	188	206
• Direct Payments	117	
• Home Care	65	
• Day Care	21	
• Short-term residential or respite	4	
<b>Accommodation-based care services</b>	31	34
• Supported Living <sup>6</sup>	6	
• Extra Care (55 and over only)	3	
• Residential Care	16	
• Nursing Care	9	
<b>All People</b>	208	227

Source: internal data

Of 208 people receiving social care services for physical and sensory impairment in Richmond, 95% have a physical impairment needing mobility assistance only (14%) or mobility and personal care support (81%). On that basis, the figure of 9.3% increase was used to estimate an increase to 2050. Because of the small numbers involved the projections have a large margin of error but it can be seen that within this group a large increase in social care need is not expected provided there are no significant external factors.

### Need for Social Care

Nationally the number of people receiving social care support aged 18-64 years with a primary physical or sensory support need is second only to those receiving learning disability support and the cost is over £1.25 million a year. This is a large financial expense for a relatively small number of adults with high needs. By identifying and understanding need, services can better support disabled people with complex care needs. Today, the use of residential and nursing care homes is actively avoided for people living with physical and sensory disabilities. In return, services that support

<sup>6</sup> Not including HSPS services

the person to live as independently as possible are encouraged to provide more local support. Improving community services will empower people with disabilities to have fulfilling lives with meaningful activities. In Richmond Social Care, the new approach to services is strengths-based, focusing on the abilities of what people can do and empower them to have choice and control.

### Employment/ Income and Cost of Living

The Care Act 2014 demands that Local Authorities provide support and services in a way that promotes individual choice and improved well-being for the person. For disabled people, improving access to mainstream services, education and employment, will lead to better health, social and economic outcomes as the person is able to live a more connected and meaningful life.

**Table 4** shows that there is a significant difference in economic activity and employment rates between people with and without disabilities.

**Table 4: Comparing Economic Activity of People With and Without Disabilities**

	% in employment	% unemployed	% not economically active
<b>People with disabilities</b>	53.2%	6.7%	43.0%
<b>People without disabilities</b>	81.8%	3.7%	15.0%

Source: House of Commons Library, 2020

- When People with Disabilities are in employment, they are more likely (34% compared to 23%) to be working part time.
- Median pay is also significantly lower for people with disabilities, earning an average of 12.2% less per hour than people without disabilities. The disability pay gap is wider in London than any other area of the country at 15.3% less per hour and, nationally, the pay gap for people employed as managers, directors and senior officials is the largest at 13.1% and the pay gap was also larger for people aged 30-49 years.
- Life costs more for people with disabilities and their families who have to spend, on average, an estimated 47% more than people without disabilities on the costs of everyday living (equivalent to a national average £585 extra per month).
- One in five disabled people face extra costs of over £1,000 a month.

### Preventative Support and Ageing

Physical and sensory disabilities are more prevalent with age, along with other long term conditions such as diabetes, and may impact on mobility and personal care needs. The average age of the disabled 18-64 year olds population in London is 43.7 compared to 37.5 for people without disabilities. Preventative support at a younger age may delay, reduce or entirely prevent the onset of further conditions or reduce deterioration.

To protect and ensure the sustainability of services, people need to be supported to take responsibility for their own health outcomes. Identifying need and tailoring community services to support people to manage their disabilities and gain independence will in the long-term reduce the reliance on social care services. With greater independence people can build their own support networks and are more able to access services, such as the GP, before a point of crisis and rapid deterioration. Thus, reducing the burden on services and supporting disabled people to live fulfilled lives.

### Limitations to the Data/Information

The number of people receiving social care services is small and analysis of trends and future needs is therefore subject to large margins of error. Much of the other data is extrapolated from national prevalence rates and are therefore just estimates based on the age of Richmond's population but not the specific socio-economic profile of the Borough. Some

people are reluctant to identify themselves as disabled due to the potential stigma or prejudice they may face. Others may be deterred from formal services due to access difficulties (e.g., booking appointments via a telephone system).

## 2.3 Barriers, Disability Prejudice, Social Isolation and Loneliness

Some of the barriers disabled people face involve opportunities to make and sustain social contacts and lead to isolation and loneliness. This is an area that people with diverse impairments and personal circumstances have in common. The barriers that people face include:

- physical barriers such as limited access to social and community groups for someone with mobility issues or visual impairment
- communication barriers such as those faced by people with hearing impairments
- social barriers with 49% of a national survey of people without disabilities stating that they did not believe they had anything in common with disabled people and 26% admitting that they have avoided engaging in conversation with a disabled person
- in a [national survey](#) one in three disabled people felt that there is a lot of prejudice against people with disabilities and another half feel there is some prejudice. However, when the same question was asked of people without disabilities, only one in five stated there was a lot of prejudice.

These barriers have a tremendous impact on the welfare and quality of life of disabled people with 53% of people in a [national survey](#) reporting feeling lonely regularly and 23% saying they will feel lonely on any typical day:

- 14% of people with a visual impairment say they never or rarely have as much social contact as they like and feel very or completely cut off from people
- 30% of people with mobility issues say they are always or often lonely
- 74% of people with an acquired brain injury (ABI) say their social life has been affected as a result of their impairment
- 22% of people living with cancer are affected by loneliness.

Loneliness and social isolation are known to impact both on emotional and mental health but also on physical health with weak social connections being as harmful to physical health as smoking 15 cigarettes a day. Lonely individuals are at a higher risk of the onset of disability.

## 2.4 Current Services on Offer

The national agenda for personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care. Richmond Council follows a strength-based approach focusing on the abilities of the individual rather than their disabilities and focussing their care and support around their abilities and overcoming any barriers they may face.

The Community Independent Living Service (CILS) is a partnership of 20 local charities supporting adults of all ages to live independently, improve well-being and stay connected with their local community.

The services include:

- information and advice: including housing, health, social care, well-being and leisure opportunities
- health and well-being support including activities, befriending and companionship, peer support, volunteering, transport, employment support, volunteering opportunities and learning.

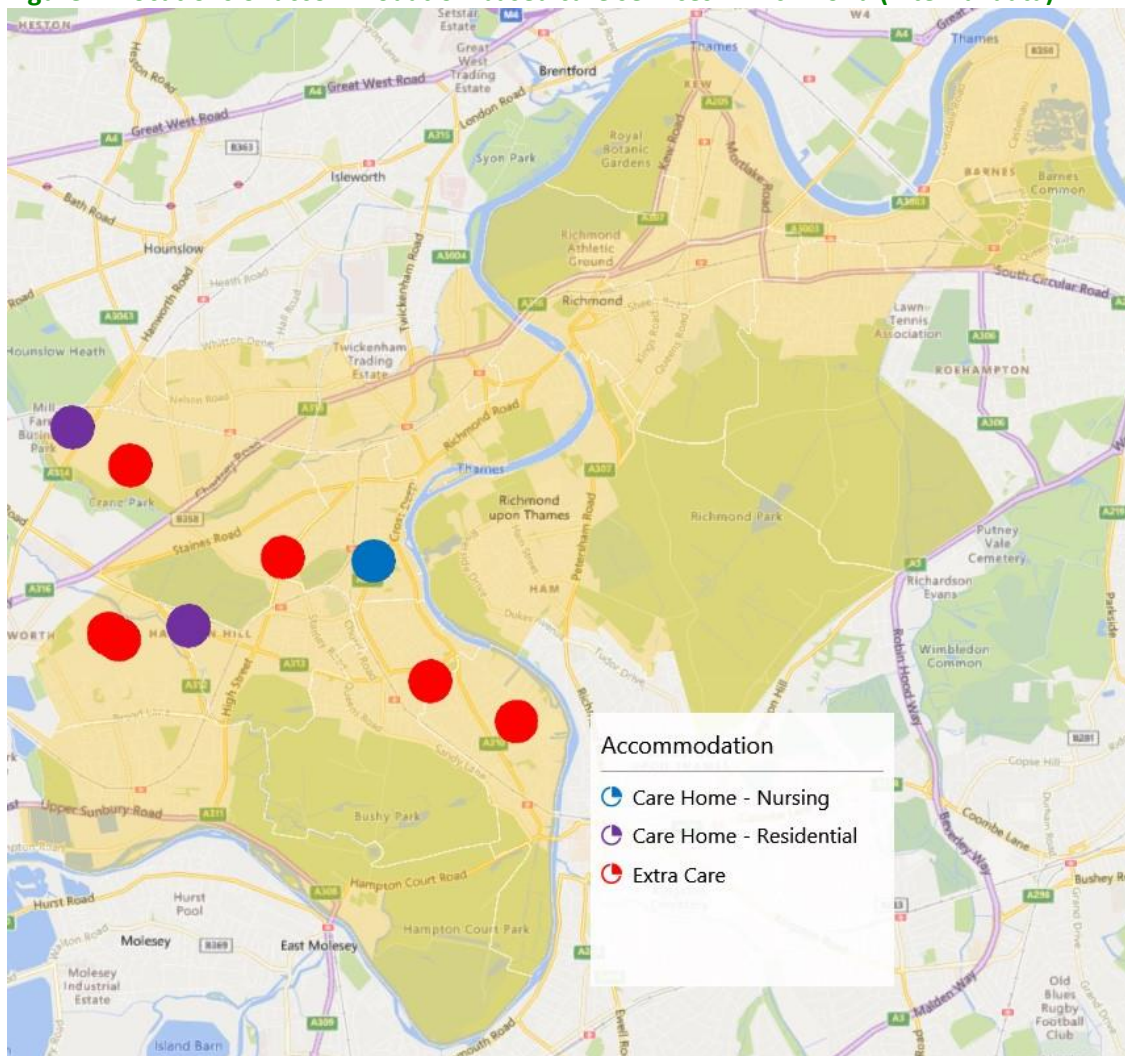
The Local Authority continues to promote direct payment uptake to support choice and control and expects providers to continue to offer and develop a wider range of personalised and bespoke services. Currently 62% of this cohort are choosing to use this option to direct their own care.

Where a person with eligible social care needs chooses not to manage their own care through direct payment, Richmond Council organise appropriate community-based services such as home care and day care.

There are no accommodation-based services that specifically cater for this group in Richmond. However, there are two residential and one nursing home in Richmond that are not for any specific group (Figure 1). Between them, these homes have accommodation for 17 people. While recent admission figures are low for this group, evidence is that out of Borough placements are used to ensure people are placed in appropriate accommodation for their specific needs.

There are six extra care housing schemes that accept people from age 55 years and over. Two of these schemes are commissioned by Richmond Council and the other four are privately run schemes.

**Figure 1: Locations of accommodation-based care services in Richmond (internal data)**



A recent local analysis of accommodation-based care needs suggested that there may be a need for some locally based supported living accommodation along the lines of extra care provision for younger adults. This was due to all current

placements being out of Borough. However, the conclusion was that, at this stage, there was insufficient evidence and further work needs to be undertaken before decisions are made.

There is a specific sensory services team in Richmond Council who provide support to people with sight loss in the Borough, supply specialist equipment, support, information and advice to those who need it. Richmond Association for the Blind runs a Recourse Centre in partnership with Richmond Council and the Middlesex Association for the Blind and provide funds to provide befriending services, technology training, social club, rapid response, counselling services, an employment service, and a mobile resource unit. The Visually Impaired Society of Richmond provides support with social activities, including day trips, holidays and weekly pub quizzes.

### Young People

There is a lack of services targeted at young people with a physical or sensory disability living in Richmond and the Council has set a priority to improve services for this cohort. Specifically, around the following areas:

- information and advice
- access to adapted housing
- use of assistive technologies
- use of personal assistance and other innovative uses of direct payments.

Preventative support at a younger age may delay, reduce or entirely prevent the onset of further conditions or reduce deterioration.

## 2.5 Barriers

People with physical and sensory disabilities face a number of barriers.

These include:

- stigma surrounding disabilities and negative experiences can present a barrier to accessing support services
- opportunities to make and sustain social contacts can be limited which can lead to isolation and loneliness
- sighted-guides and communicator-guides are often difficult to obtain and there is some difficulty in getting requests through once passed to the locality teams due to lack of sensory knowledge.
- barriers to employment mean that people with physical and sensory disabilities are less likely to be employed and, when they are employed, they tend to have fewer hours and lower hourly pay than people with equivalent skills and experience
- on average, a person with a disability has to spend 47% more on the costs of day to day living.

Richmond is committed to working within communities and with local organisations to reduce the impact of these barriers within the Borough.

## 2.6 What Interventions/Approaches Work According to the Evidence Base

Strengths or asset-based approaches focus on individuals' strengths and not on their disabilities. It is holistic, multidisciplinary, and works with the individual to promote their well-being. It is outcomes led rather than services led. It is implicit in the Care Act 2014, supported by the Social Care Institute for Excellence, as an appropriate tool for social care.

## 3. Learning Disabilities

“All people should have the opportunity to be active citizens, live a meaningful life and make contributions to the community of which they are part of.

The focus of the commissioning model for learning disability services is to reduce reliance on residential care, move service users towards supported living and greater independence where possible, with fewer out of Borough placements. In addition, the Council encourages provision of meaningful daytime activities and life skill development opportunities. There is a drive to develop and increase employment and supported employment opportunities increasing the number of people with learning disabilities who are in paid (full or part time) employment or purposeful and meaningful voluntary roles. The Council wishes to see services that cater for both the younger learning disability population with more complex needs that are transitioning and an increasingly ageing learning disability population.”

Richmond Market Position Statement

### 3.1 Introduction

A learning disability is a reduced intellectual ability and difficulty with everyday activities (e.g., household tasks, socialising or managing money) which affects someone for their whole life. The NHS defines a learning disability as affecting “the way a person learns new things throughout their lifetime, which means they can have difficulty understanding new or complex information, learning new skills, and coping independently”. The severity of learning disabilities exists on a spectrum from mild to profound. At its greatest severity, a profound learning disability leaves a person with multiple disabilities, including cognitive, sensory, and physical disabilities.

Although the two terms are occasionally used interchangeably, a learning difficulty differs from a learning disability. A learning disability is a condition that affects all aspects of life where a learning difficulty is an obstacle to a specific form of learning but does not affect other aspects of life.

Learning disabilities are now taking a more prominent position nationally and subsequently on local agendas. The Care Act (2014) requires Local Authorities to meet a person’s needs holistically. This encompasses an acknowledgement of the wider determinants of well-being, such as employment or socialisation. The Care Act legislation is strengthened by the Mental Capacity Act (2005) to protect the right of individuals and their families to make their own decisions.

To ensure that Richmond Council is providing the best outcomes to residents with learning disabilities, a Learning Disability Partnership Board ensures that services in the Borough are meeting the needs of people with learning disabilities. Importantly, the Board includes representation of people with a learning disability and their families. Service implementation is guided by key principles of the Richmond Learning Disability Strategy “Our Big Plan” (2015-2020), that focuses on:

- **Rights:** that people with a learning disability and their families have the same rights as others
- **Independent Living:** supporting people with a learning disability to live as independently as possible
- **Control:** making sure accessible information is made available so that people with a learning disability and their families have choice and control
- **Inclusion:** enabling people with a learning disability to participate in the wider community

The number of people living with a learning disability is expected to increase in line with the general population increases and demand in all areas is expected to rise. A learning disability occurs when the brain is still developing (before, during or soon after birth) and there are several causal factors including:

- genetic factors
- illness or accident to the mother while pregnant
- lack of oxygen or trauma during birth
- premature births
- early childhood illnesses, accidents, or seizures.

Diagnosis of learning disabilities generally occurs in childhood. Mild learning disabilities are mostly commonly diagnosed during the school age when issues with reading, writing and numeracy are highlighted. Other issues with socialising may also present. These are often known as ‘hidden’ learning disabilities.

### Identification and Diagnosis

Evidence suggests that either there is a significantly lower prevalence of milder learning disabilities in Richmond, or there may be large numbers of people with a learning disability in Richmond who have not been identified on the GP register. Early diagnosis will enable the person and their GP to better manage their disability, thus improving long term health outcomes and daily quality of life.

Strengths or asset-based approaches focus on individuals’ strengths and not on their deficits. It is holistic and multidisciplinary and works with the individual to promote their well-being. It is outcomes led rather than services led. It is implicit in the Care Act 2014 and supported by the Social Care Institute for Excellence as an appropriate tool for Social Care.

## 3.2 Level of Need and Prevalence

National prevalence rates applied to the age-related population in Richmond show a predicted increase of 4% in the numbers of the 18-64 population by 2050. However, the increase in the 65+ population is expected to be significantly higher **Table 5**.

**Table 5: Estimated Numbers of Residents with a learning disability, 2008, Richmond**

	2020	2030	2040	2050	% increase
<b>18-64 All LD</b>	3,007	3,107	3,152	3,171	4%
<b>65+ All LD</b>	663	734	830	921	65%
<b>18-64 Severe or moderate</b>	692	714	725	729	4%
<b>65+ Severe or moderate</b>	89	97	109	121	56%

Source: GLA population estimates & Emmerson & Hatton 2008

Comparing the number of people on the GP Learning Disability Register shows a relatively low percentage per population in Richmond. On average, 49 in every 10,000 people in London are on the GP Learning Disability Register. However, the number in Richmond is far lower at approximately 39 people. This suggests a relatively low prevalence within the Borough. However, social care numbers show a proportion of the population that is slightly above the London average with 31 people per 10,000 population in Richmond and 28 in London **Table 6**.



**Table 6: Key statistics for learning disabilities in Richmond**

	Receiving support from social care services per people on GP register	GP register, per 10,000 population	Social care services, per 10,000 population
<b>London</b>	56%	49	28
<b>South West London (6-Borough)</b>	60%	53	32
<b>Richmond on Thames</b>	79%	39	31

Source: Public Health Profiles

These figures suggest:

- There is a significantly lower prevalence of milder learning disabilities in Richmond than the national average, although the proportion of the population receiving support from the Local Authority is similar. This could be because Richmond has a lower threshold for providing support or because it has a higher threshold for adding people to the GP Learning Disabilities Register
- There are large numbers of people with milder learning disabilities in Richmond whose disability is not on the GP Learning Disability Register.

In 2018-19, there were 406 people aged 18-64 years with a learning disability receiving services, and a further 76 people aged 65 years and over. Direct payments were the most popular way to support people with a learning disability in the community, given the emphasis on choice and control **Table 7**.

**Table 7: People with a learning disability receiving social care services in Richmond (internal figures)**

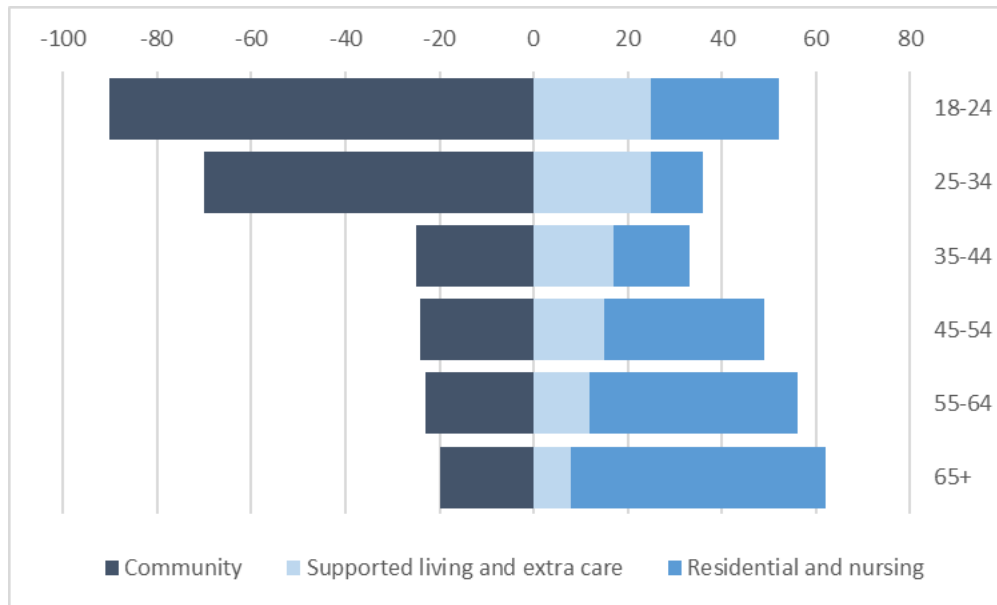
	2018-19		2050	
	18-64	65+	18-64	65+
<b>Community Based Services</b>	232	20	240	30
• Direct Payments	171	3		
• Home Care	56	12		
• Day Care	15	4		
• Respite & short term residential	22	5		
<b>Housing</b>	219	62	230	100
• Supported living (not including HSPS)	94	8		
• Extra Care	0	0		
• Residential Care	131	53		
• Nursing Care	1	1		

Source: internal figures

The estimated increases to 2050 are based on the estimated population rises of severe and moderate learning disabilities. The number of people in nursing care looks low. This is because these figures are based on the primary care need of the person, not on all people with a learning disability. As a person with a learning disability ages, their primary need may become physical health or dementia.

**Figure 2** shows the number of people with a learning disability receiving community-based (left hand side) and accommodation based (right hand side) care by age in Richmond. Older people with a learning disability in Richmond are more likely to be placed in accommodation-based support than receive community-based care.

**Figure 2: People with a learning disability receiving social care services in Richmond**



Source: internal figures

More independent accommodation-based care arrangements (supported living and extra care) make up more than half the accommodation-based care placements from 18-44 years. After that people with a learning disability are more likely to be placed in residential care homes.

The larger population aged 18-34 years receiving support reflects both local and national prevalence rates for people whose primary need is defined as learning disability by age. Part of this figure is because as people age, their primary need may change to physical or memory and cognition needs.

**Health**

On average females with a learning disability live for 18 years less than the general population, and males with a learning disability for 14 years less. This is for a variety of reasons including certain health conditions that have been found to be more prevalent amongst people with a learning disability. For example, epilepsy is 25.2 times more prevalent and severe mental health conditions are 8.4 times more prevalent than in people without a learning disability.

A National Survey of 47% of people with a learning disability who were registered with a GP showed there is lower attendance for health checks. For example, only 31% of women have had smear tests compared to 73.2% of the general population. A person with a learning disability may also require a higher level of explanation regarding a diagnosis or health deterioration, including easy-read format information and the use of advocates. Research found that 38% of people with a learning disability died from an avoidable cause, compared to 9% in a comparable population.

In Richmond, 59% of adults with a learning disability who were on GP registers had a Health Check during 2017-18. This is higher than the England (52%) and London (57%) averages.

Some other conditions are linked to learning disabilities:

- about 1 in 3 people with a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely that the person will also have epilepsy

- people with Down's syndrome will typically have some level of learning disability, but the extent of the learning disability will vary individually. As many as half of the people with cerebral palsy also have a learning disability
- studies vary in the overlap between autism and learning disability but most show between 44% and 52% of people with autism with an may also have a learning disability and between 31% and 36% of people with a learning disability may also be autistic
- people with a learning disability (particularly those with Down's Syndrome) are at increased risk of developing dementia
- older people with a learning disability experience age-related issues at a younger age than the general population.

### **Social Isolation**

Evidence reveals that high-quality friendships are associated with better physical health and lower risk of early mortality. A lack of social interactions can increase the likelihood of high blood pressure, heart disease, obesity, weakened immune system, anxiety, depression, and cognitive decline. A recent survey stated that 45% of people with a learning disability felt they did not spend enough time with friends, with 18% feeling alone and cut off from other people.

People with a learning disability can also have limited opportunities for exposure to a variety of social groups and situations, which may be limited by availability, services, or carer preference. In some communities there are low levels of awareness and understanding from the public who may not meaningfully involve and value people with a learning disability.

Many people with a learning disability have the same aspirations for loving relationships as those without. However, only 3% of people with a learning disability live as a couple compared to 70% of the general adult population. Support workers and family members may be influential in either supporting or preventing people developing and sustaining these relationships.

### **Meaningful Activity, Employment, Training and Education**

Less than two in ten people with a learning disability are in employment, which decreases further for those living with a severe learning disability. In Richmond, the latest published statistics show 14.8% of people with a learning disability known to services are in paid employment compared to the London average of 7.5% and England average of 6.0%. The gap in employment rate in Richmond is correspondingly lower than the London and England averages of 62%.

Meaningful activity should be tailored to the individual needs of the person involved. The assumption that all people with a learning disability need the same service runs counter to both the strengths-based approach to social care and to the personalisation agenda. For example, activities need to fit the interests of the person as well as being age appropriate.

### **Housing**

Two thirds of people with a learning disability remain living with their families. As the family ages, this situation may become unsustainable. If appropriate plans are not in place to support a person with a learning disability, they may be moved to inappropriate accommodation or be subjected to multiple moves.

In Richmond, 71.6% of people with a learning disability known to services are in settled accommodation, lower than the London (73%) and England (77%) averages. An alternative measure of people with a learning disability in stable and appropriate accommodation showed 72.7% in Richmond, again slightly lower than the London average of 75.1%

### Data Limitations

The number of people receiving social care services is small, and analysis of trends and future needs is therefore subject to large margins of error. Much of the other data are extrapolated from national prevalence rates and are therefore just estimates based on the age of Richmond's population and not the specific socio-economic profile of the Borough.

Data collection of learning disabilities only occurs at a formal point of contact, such as schools, social care, and GP practices. Evidence has shown people with a learning disability are less likely to be registered with formal service such as a GP. This limitation of data may result in the most vulnerable and isolated people with a learning disability remaining unreached by services and isolated from their community. Ultimately, before data collection can occur, a person must firstly be diagnosed, and they and their family need to recognize their disability and have contact with formal services.

### 3.3 Transition

Young people with a learning disability transitioning into adulthood face a variety of challenges.

These include:

- some young people with special educational needs and disabilities (SEND) receiving support in childhood, may not be eligible for adult social care support as the criteria is at a much higher level, an area of potential unmet need making this group vulnerable to exploitation and anti-social behavior
- young people and their families who do transition into adult social care services may find the budget for their support considerably lower than their budget when under 18 years and may find that they must contribute towards the cost of their support
- young people with profound or multiple learning disabilities may find it difficult to comprehend the changes that are occurring with their life and support packages
- as a young person with a learning disability grows up, they may find that they, as with their peers, want to live more independently. Moving out of the family home can cause more challenges and the young person may need more support, either accommodation-based or community-based.

The transition into adulthood and adult based services can be deeply stressful for many young people with a learning disability. It is a key area of priority within Richmond, as well as providing support where young people are not eligible for adult social care services.

### 3.4 Current Services on Offer

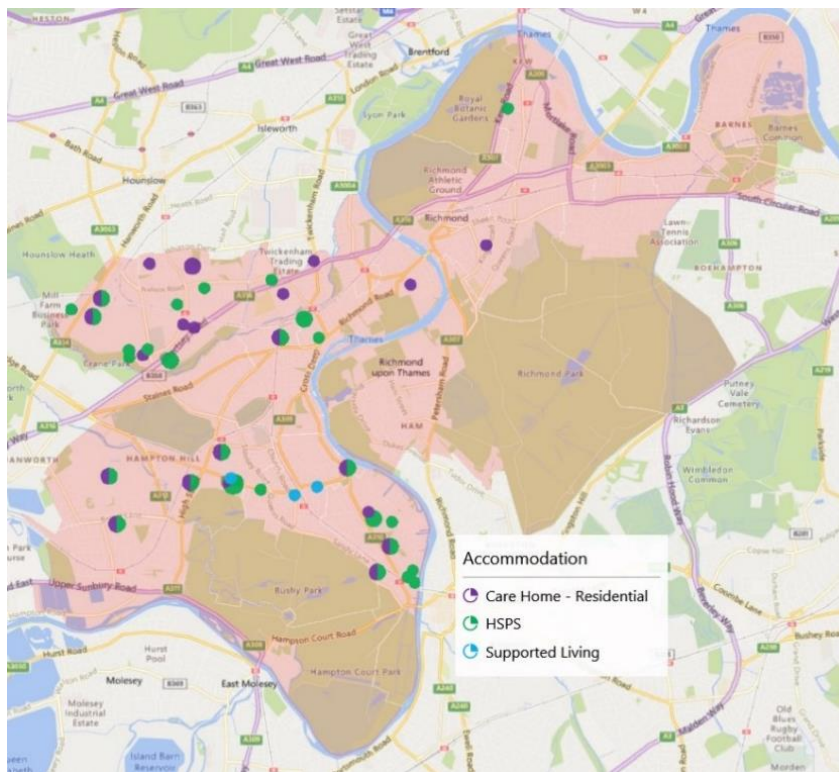
Partnerships with the NHS and voluntary sector add to the variety of services that support the well-being of people with a learning disability in Richmond. Hounslow and Richmond Community Healthcare (HRCH) has an Adult Learning Disability Health Team who support local people who have been referred by their GP. The service predominately focuses on improving physical and mental health outcomes. Richmond AID is a service user led charity supporting people with all types of disabilities. YourHealthCare, a social enterprise, provides a wide range of integrated health and social care community services to enable community residents to have the best quality of life. The holistic approach of the services provides information and advice to leverage the same opportunities for people with a disability as the wider population. Employment opportunities are specifically promoted through courses provided by Hillcroft Adult Community College and Choice Support, who work in partnership with Richmond Council to assist people with a learning disability into paid employment. Overall, the services in Richmond adhere to the Care Act 2014, which advocates a holistic approach to the well-being of the person, upholding the importance of meaningful activity through employment and socialisation.

Spend on services for people with a learning disability aged 18+, against the learning disability is proportionately high due to the cost of long-term care, particularly for people aged 18-64 years in a care setting. Richmond is committed to helping people with a learning disability achieve better health, well-being, and quality of life outcomes by supporting them to live as independently as possible. The focus for new accommodation-based admissions is to place people in more independent situations such as Supported Living. Historically, there has been a high spend in care homes which is linked to the closure of Normansfield Long-stay Hospital. Further exploration of the high-cost placements is being undertaken.

There are several out-of-borough residential care placements amongst Richmond residents. Some of these homes have more availability and can be less costly. Moving a person with a learning disability regularly can be disruptive, particularly if there are family or social networks are disrupted. The focus for new placements is to keep people in the Borough wherever possible. However, bringing people back into the Borough can be equally disruptive.

There are 22 residential care homes in Richmond that are designed specifically for people with a learning disability and another two general needs care homes. There are no specific nursing care homes for learning disabilities but there is a general care home that accepts people with a learning disability. There are three supported living and 32 Housing Support and Preventative Services (HSPS) homes for people with a learning disability (Figure 3).

**Figure 3: Locations of accommodation-based care services for learning disabilities in Richmond**



In Richmond, HSPS is an additional block contract which is spot purchased. HSPS is a local term which refers to services that would formerly have been commissioned under the Supporting People Programme. Whilst both HSPS and Supported Living provide a range of support to tenants, there are key differences:

- HSPS is not regulated by the CQC except for element of personal care
- HSPS provides housing related support services only and does not include either personal care or domestic support.

High support HSPS is considered a form of support equivalent to supported living. Although the number of units varies there are approximately 150 units at any one time, of which:

- 59% of units are high support
- 23% of units are medium support
- 18% of units are low support.

### 3.5 Settled Accommodation

Two thirds of people with a learning disability remain living with their families. As the family ages, this situation may become unsustainable. In Richmond, the number of people with a learning disability in settled accommodation is lower than the London and England averages. While these figures may be skewed by the lack of identification of people with a mild learning disability, this is an area which needs further exploration.

There is a high proportion of older people with learning disability needs who receive support in care homes. Further analysis should be undertaken to explore if older people with learning disabilities have the services available for them to remain living independently at home if preferred.

A high proportion of people with a profound learning disability are cared for in out-of-Borough placements, highlighting the lack of appropriate support available locally for those with the greatest need. Moving people with a learning disability away from familiarity and their families can cause emotional stress for all involved.

## 4. Unpaid Carers

A detailed needs assessment was carried out in 2019, this section summarises the key points and updates some of the figures.

“Our vision in Richmond is to raise awareness of the vital roles played by carers and young carers; to collectively provide good quality personalised support to carers, and young carers and those they care for; to build solid networks ensuring that carers and young carers know where to go for information and support; to enable carers and young carers to balance their own lives with their caring roles, and; to ensure that local service providers understand these needs and are committed to working together to meet them.”

Richmond Market Position Statement

### 4.1 Introduction, Context and Policy Guidance

Unpaid carers provide invaluable support to the people they look after and to health and social care services. However, the life of a carer can be hugely challenging. Carers may be at risk of social isolation, losing employment or education opportunities, and experience a detrimental impact on their physical and mental well-being. Carers must remain a high priority for central and local government to ensure that carers feel respected, valued and have support choices.

A carer is anyone who provides unpaid care to a friend or family member who, because of a limiting long-term condition or addiction, is unable to cope independently. It is estimated that nationally the economic value of the contributions of unpaid carers amounts to over £132 billion, the same as the NHS Budget. Nationally, it is estimated the number of unpaid carers will increase by 60% to 3.4 million people by 2030.

The Care Act 2014 and the Children’s and Families Act 2014 both recognise the importance of carers and aim to promote their physical and mental well-being. As a result, all carers including young carers and adult carers of children, have a right to a carer’s assessment and to have their needs identified and provided for.

[The 2010 National Carers Strategy](#) aimed that by 2018 every carer should:

- be recognised and supported as an expert care partner
- enjoy a life outside caring
- not be financially disadvantaged
- be mentally and physically well and treated with dignity
- children carers will be thriving and protected from inappropriate roles.

The National Carers Action Plan 2018-20 outlines a range of cross-cutting governmental actions based around five key themes:

- services and systems that work for carers
- employment and financial well-being
- supporting young carers
- recognising and supporting carers in the wider community and society

- building research and evidence to improve outcomes for carers.

The social, financial and health impacts upon carers can be considerable. People providing unpaid care may be unable to protect their current and future financial security (Carers UK, 2017).

## 4.2 Identification of Carers

Carers often do not recognise their role and just associate with their primary relationship to the person, such as a partner, daughter, son or friend. The lack of identification is a key barrier to recognising the effects on health and well-being. Furthermore, it prevents carers from accessing support and services available to them.

The vast majority of care is provided by family, friends and relatives, and the care they provide is worth an estimated £132b per year (Carers UK, University of Sheffield, University of Leeds, 2015). This is notably more than total spending on the NHS, which was 124.7 billion in 2017/18 (Carers UK and the King's Fund, 2017). This equates to an average of £20,300 per year from each unpaid carer in the UK. If this average was applied to the Richmond carers, it is estimated that they provide approximately £360 million worth of care a year.

Despite the significant contribution carers are making to society and the health system, the [2017 State of Caring Survey](#) found that 73% of carers felt that their contribution was not valued or understood by Government. Therefore, it's vital that carers are given the recognition and support they need to continue to provide care.

Parents who provide care to their children often do not identify themselves as carers and may not always be aware of the support available for them. Data show that 37% of parent carers took longer than five years to recognise themselves as a carer (compared with 24% of all carers) as the parent and carer roles are intertwined.

Sandwich carers are those who combine care for an older relative with a range of other responsibilities, such as looking after their own children or caring for another family member or friend. Often, they do not identify as carers, especially because higher numbers of this group are caring from a distance.

### Young Carers

Many young carers take on their role because of multiple care needs in the family, and it is becoming increasingly common to find multiple caring families. Growing up in an environment such as this, young carers mature quickly and gain practical skills that aid independence. However, national research shows that caring can have an adverse impact on educational attendance or attainment, physical and emotional health, social activities and aspirations. For young adult carers, responsibilities may delay moving out or away from home and decrease employment possibilities or the ability to pursue further education.

Transition arrangements are therefore crucial to minimising the negative impact that caring can have on a young person's employment or higher education opportunities. Carers aged between 16-18 years are twice as likely not to be in education, employment or training. Of those who are in education, 56% of young carers at college or university said they were struggling with their studies alongside their caring role and 30% say they may have to drop out (17% because of their caring role and 13% for financial reasons). Young carers are three times more likely to have a mental health condition than their peers.

55% of young carers provide care to a parent whilst 25% provide care to a sibling. 80% of young carers are helping with practical tasks such as cooking and household chores, and these responsibilities increase with age.



Young & young adult carers risk being hidden and not receiving appropriate support. Young carers remain hidden for many reasons including:

- they do not realise they are a carer or that their life is different to their peers
- their parents do not recognise that their children are carers
- they do not want to be different from their peers
- it has been well evidenced that young carers experience heightened levels of bullying (one in four young carers reported being bullied)
- worry that the family will be split up and they, or their siblings, may be taken into care
- their parent's condition may not be obvious, so people don't think that they need any help
- there has been no opportunity to share their story
- they experience no positive actions occurring as a result of telling their story.

Even where young carers are known to services, some will minimise their caring role and the affect it has on them for the same reasons.

The experiences of LGBTQ+ young adult carers can be even more challenging. Research by the Carers Trust indicates that LGBTQ+ young adult carers are three times more likely to experience bullying than young adult carers and are more than three times more likely to have a mental health problem than their peers (Carers Trust, 2016).

All young people who receive an Early Help Assessment (EHA) via the Single Point of Access (SPA) will be assessed holistically with their family and identified as a young carer if appropriate. These young carers are then referred to the Carers Hub Service/Richmond Carers Centre to receive the appropriate support. Current recording mechanisms are not synchronised and fail to indicate the total number of young people who are identified as young carers by the SPA. Therefore, a review of the systems and pathways for young carers is being conducted to improve recording, update the pathway if necessary and up-skill the workforce to improve the identification of young carers.

The 2011 Census identified that there are 864 carers in Richmond upon Thames aged younger than 24 years who provide unpaid family care. Assuming the same proportion applied to the 2020 population gives an estimate of 960 children and young adults providing care.

In September 2018 480 young carers were being supported by the Richmond Carers Centre. Based on information from the Richmond Carers Centre a greater proportion of young carers are from Black, Asian and Minority Ethnic groups than the average for all carers within the Borough (29% of young carers compared to 13% of all carers identified by the 2011 Census).

The 2014 Richmond Young People's Survey (emotional and well-being themed report, pages 2 and 4) showed that 11% of pupils in Years 5, 6 and 7, and 7% of pupils in Years 8 and 10, reported that they care for someone at home on a regular basis who is unable to care for themselves. Only 1% felt this stopped them from taking part in recreational activities, and 3% felt it sometimes stopped them. It is important to bear in mind that some young carers may minimise the affect caring has on their lives.

### Parent Carers and Sandwich Carers

Applying national research to Richmond's population it is estimated that there is a total of 2,100 parent carers in the Borough, making up around 13% of the carer population. Also, it is estimated that around 1,300 are caring for children with disabilities, and a further 800 are caring for young adults. However, in Richmond upon Thames, there is a total of 4,469 school pupils who have SEND. It is likely that not all of these pupils will be receiving care from their parents suggesting a discrepancy between the number of parent carers identified, and the true total number of parent carers in the Borough.

The number of sandwich carers (those looking after young children at the same time as caring for the older generation) is rising due to the pressures of an ageing population, combined with people starting families later. The number of middle-aged (50-64 years) female carers has risen by 13%, to 1.2 million in the last ten years. This disproportionately affects women, in Richmond upon Thames 23% of women aged 50 to 64 years are carers, compared to 13% of men.

Parent and sandwich carers are less likely to identify as carers and are more likely to be caring from a distance. In Richmond upon Thames the peak age for caring is 50-64 years. 34% of carers are aged between 25-49 years, and 38% between 50-64 years. However, whilst the 2011 Census shows that 72% of carers are aged between 25-64 years, just 48% of carers registered with the Richmond Carers Hub Service in April 2018 were aged between 19-64 years.

### Carers from Black Ethnic, Asian Ethnic and Minority Ethnic Groups

In Richmond, 2011 Census Data reveals that 14.1% of the population are from Black, Asian and Minority Ethnic groups, 14.5% of the population belong to non-British White Ethnic Groups and the remaining 71.4% are White British. The population of unpaid carers in Richmond has a similar ethnic composition although the proportion of White British carers is higher than in the total population (77.9% compared to 71.4%). The proportion of Black, Asian and Minority Ethnic groups and non-British White carers are both lower than the proportion of these ethnic groups within the total population at 12.6% and 9.4% respectively.

The differences in unpaid care provision between the broader ethnic groups are similar to the whole of England (Office for National Statistics, 2013b).

## 4.3 Carers' health and well-being

Carers working full-time and providing 50 hours or more unpaid care per week are 2.4 times (men) and 2.7 times (women) more likely to report their health as 'not good'.

There are 4.27 million carers of working age living in the UK. The employment rate for carers is at 67% and over half of those who are not working say that they want to do so. One in eight workers is a carer. One in three carers gives up employment because of their caring responsibilities and a further one in six reduced their hours of work to continue their caring role. In addition, it may be more difficult to return to work for carers after a period of unemployment.

In Richmond, men and women who provide care are less likely to be in full-time employment (38% compared to 52% of those who do not provide care) and more likely to be in part-time employment (20% compared to 14% of those who do not provide unpaid care).

Over half of carers have had to borrow money as a result of their caring responsibilities. Of these, 3 out of 5 have borrowed from friends or family, the rest have used overdrafts. Three in every five carers have used their savings to cover the cost of caring and nearly one in four have re-mortgaged or downsized their property as a result of the financial impact of their caring responsibilities.

The barriers to maintaining health and well-being are far greater for people who provide unpaid care, whether from lifting and moving strains, getting enough sleep, or having the time to make healthy meals. Those providing care for more than 50 hours a week are twice as likely to be in bad health as non-carers and 3 in 5 carers have a long-term health condition. This impact is frequently exacerbated by carers being unable to find time to attend medical appointments, or delaying them, due to ongoing caring responsibilities. Therefore, it is essential that services and systems work for carers and are informed of their health and well-being needs.

[National data](#) shows that 72% of carers experience mental ill health, and 61% live with physical ill health as a result of caring. However, 23% of carers reported refusing health and care support due to concerns over quality which demonstrates a clear need to provide high quality services that effectively meet the health needs of carers. In addition, carers are far more likely to postpone their own medical treatments to see to the needs of the person they care for.

Older carers are often living with their own disabilities or long-term health conditions. Often older people with social care needs only become visible to social care and hospitals at the point of crisis i.e., when their unpaid carer can no longer cope.

Richmond carers data from the 2011 Census (see level of need below) show 19.6% of carers who say their health is bad, very bad or fair, considerably higher than the 11.1% of those who provide no care. This risk of poor health increases with the number of hours of unpaid care that are provided.

The risk of poor health also increases with age. In Richmond upon Thames 60% of carers aged 65 years and over reported having at least one long-term health condition compared to 42% of carers aged 18-64 years.

Thirty-nine per cent (39%) of carers in Richmond have had to see a GP for health issues relating to their caring duties in the past 12 months. Just 2% of carers in Richmond reported that their caring responsibilities had no effect on their health. This is slightly lower than other South London Boroughs (average 6%).

Where carers are the parents of the cared for person, there is an increasing likelihood that their child will outlive their parent's ability to provide care and support.

Carers are known to be negatively impacted as a result of their caring role:

- 72% experience mental ill health
- 61% experience physical ill health
- 23% refuse health and social care support due to concerns about quality
- carers are more likely to postpone their own medical treatments to see to the needs of the person they care for
- carers are less likely to be in full time employment (38% compared to 52%)
- over half of all carers have borrowed money as a result of caring responsibilities
- 15% of carers in Richmond have little social contact with people and feel socially isolated
- where carers are the parents of the cared for person, there is an increasing likelihood that their child will outlive their parent's ability to provide care and support.

## 4.4 Social Isolation

'Social Cohesion' refers to the strength of community relationships and levels of participation in community activities and public affairs. It also refers to social contacts and networks (with family, friends and relatives), social support and a sense of belonging. Evidence shows that higher levels of social cohesion are associated with better levels of health including mental health and well-being, as well as other social and economic benefits. This can be particularly important for carers who are at risk of social isolation.

In Richmond, the results from Public Attitude Survey (MOPAC, 2018) suggest that overall levels of social cohesion are high compared to other parts of London. For example, 97% of residents agree that Richmond is a place where people from different backgrounds get on well together, which is the second highest proportion in London.

Carers often experience feelings of isolation and resentment, whereby they can become disconnected from friends and families. Carers are unlikely to have the time to enjoy their own hobbies or to socialise. Research also suggests that being a carer can influence the ability to participate in social activities. In Richmond upon Thames 21% of carers report having as much social contact as they want while 15% report that they had little social contact with people and felt socially isolated.

There has been a significant increase in the number of people providing unpaid care. Evidence suggests that an extra 4.5 million people in the UK have been providing unpaid care during the pandemic bringing the total number of unpaid carers to 13.6 million, an increase of 50%.

During the pandemic, day services and evening services have been closed and some other services have been reduced. This has meant that many unpaid carers have been left without support channels and had to take on more caring responsibilities. On average, carers have had to undertake an additional 10 hours a week of caring activity.

## 4.5 Need and Estimated Population Prevalence

Data shows that three in five people will be a carer at some point in their lives. Women are more likely to be carers (see level of need below) often with multiple caring responsibilities such as for children alongside elderly relatives. Older people are also more likely to become carers as health deteriorates with age, and many spouses may find themselves caring for their partner.

The 2011 Census showed that in the UK the proportion of the population who were carers had increased and evidence suggests this trend is likely to continue **Table 8**. The number of people aged 65 years and over is increasing more rapidly than the general population.

**Table 8: Cared for person by percentage of UK carers**

Caring for:	Percent %
Parents/parents in law	40%
Spouse/Partner	26%
Child	13%
Friend or neighbour	9%
Other relative	7%
Grandparent	4%
Other	1%

Source: ONS: Census 2011

Most carers care for one person (83%). However, 14% care for two people and 3% are caring for three or more people. The largest group receiving care is parents and parents-in-law (see below). Carers of older people make-up approximately three-quarters of all carers and middle-aged carers may also have dependent children in addition to caring responsibilities for older parents.

An analysis of Richmond carers from the 2011 Census shows that there were a total of 15,725 carers living in Richmond, 8.5% of the population. This varies by age with:

- 1.7% of the population aged 0-24 years 864 people
- 7.1% of the population aged 25-49 years 5,380 people
- 19% of the population aged 50-64 years 6,044 people
- 8.5% of the population aged 65 years+ 3,437 people

Carers in Richmond are less likely to be in good health than people who provide no care and people who do 50 or more hours of unpaid care each week are much more likely to be in bad, or very bad health **Table 9**. 39% of carers in Richmond saw a GP in 2018-19 for an issue related to their caring duties.

**Table 9: Carers in Richmond by number of hours of care and self-described health**

	Bad or very bad health	Fair health	Good or very good health
<b>1–19 hours</b>	322 (2.7%)	1485 (12.6%)	9940 (84.6%)
<b>20–49 hours</b>	97 (6.1%)	300 (18.8%)	1203 (75.2%)
<b>50+ hours</b>	251 (10.6%)	634 (26.7%)	1493 (62.8%)
<b>No care</b>	5030 (3.0%)	13625 (8.1%)	149709 (88.9%)

Source: ONS: Census 2011

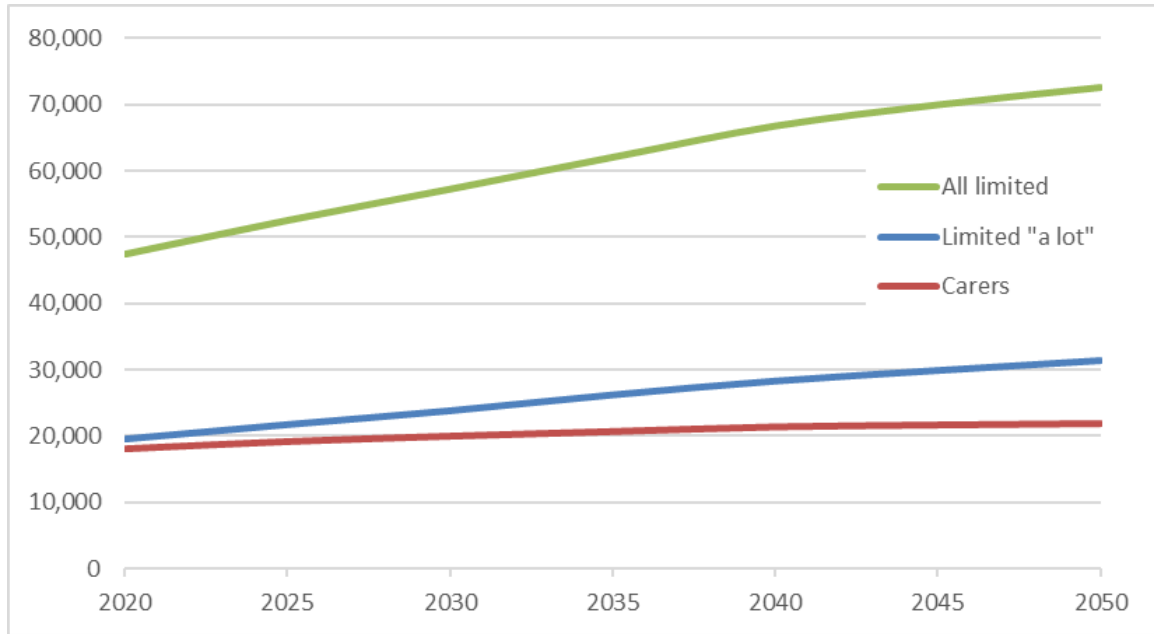
While some carers who live in Richmond may be caring for people living outside the Borough, there are some people living in the Borough who have carers living elsewhere. There is currently no data to show that either group has a significant impact on the figures below.

People are living longer with multiple morbidities and the population of Richmond is ageing with an estimated increase by 2050 predicted of 67% of people over 65 years compared to 7% of those aged 25-64 years. This is even higher in the 85+ age group which is expected to increase from 4,500 in 2020 to 11,700 in 2050.

### Projection of carer numbers

Projecting the percentage of carers from the 2011 Census to the estimated population gives an estimate of 18,000 carers in 2020, expected to rise by 21% by 2050 to 21,800. However, the number of people with long term conditions that limit their ability to do day to day tasks is expected to increase from an estimated 47,400 in 2020 by 52% to 72,500 in 2050. This is illustrated in **Figure 4**. The gap between the number of carers and the number of people with limiting long term conditions is increasing.

**Figure 4: Estimated projections of the number of Richmond residents with limiting long term illness and residents who are carers**



Source: ONS: Census 2011 & GLA population projections

This gap will need to be filled with support. This is likely to include an increased proportion of the population becoming carers, over and above the estimates shown above, and an increased burden on social care services supporting both the carers and the increasing numbers of people who will have nobody able to give that support.

The true extent of caring, particularly prevalence, can only ever be estimated due to the invisibility of carers within communities. A proportion of carers will not identify themselves as a carer as they see themselves as completing their duties as, for example, a husband, wife, parent, sibling or child. Particular groups where identification is low include parent carers and sandwich carers who may not identify themselves as carers, and young carers who may be reluctant to identify themselves in case there are consequences.

### 4.6 Deprivation

The percentage of residents who provide unpaid care is associated with deprivation. Consequently, given that Richmond upon Thames is one of the most affluent areas in the country, and is the least deprived Borough within London, as measured by the Index of Multiple Deprivation 2015, it is no surprise that carer levels are lower in the Borough as a whole.

However, as shown in (Figure 5) it is important to recognise that pockets of high deprivation exist within Hampton North, Ham, Petersham, Richmond Riverside and Heathfield which all have at least one LSOA in the most deprived 30% in the country. Levels of carer need is, therefore, likely to be higher in these more deprived areas compared with more affluent areas. There are also families and individuals scattered throughout other parts of the Borough who are experiencing above average levels of deprivation and likely to have greater needs.

**Figure 5: Deprivation in Richmond (IMD, 2019)**



Source: English Indices of Deprivation, 2019

## 4.7 Cared for Person

Nationally, according to the [Survey of Carers in Households](#), the most common conditions amongst people that are looked after by unpaid carers are physical disability (58% of carers), sight or hearing loss (20%), mental health problem (13%), learning disability (11%) and dementia (10%). The conditions of people who are cared for often dictate the types and duration of caring activities and understanding the prevalence of these conditions informs our knowledge of the health needs of carers.

This breakdown does not fully represent the care requirements of those cared for, as autism spectrum disorder is included within the category of learning disability, despite those with autism requiring significantly different care and support than others within this group. There is also no category for those with multiple long-term conditions, who would be included in this data under the category of their most debilitating condition.

The absence of a specific statistical breakdown for conditions such as autism, or for those with multiple morbidities, has implications for local efforts to categorise these individuals and tailoring the commissioning services tailored to individuals and carers.

The majority of carers provide care for older people. In 2017 15.3% were residents aged over 65 years, 6.8% are aged over 75 years and 2.2% over 85 years (GLA, 2017a). 96.6% of residents aged 65-75 years and 93.7% of those aged 75 years and over (ONS, 2011) live in the community. (please confirm these stats and age ranges). The percentage of people aged over 65 years in Richmond upon Thames is projected to increase to 19.4% in 2038 (GLA, 2017a).

## 4.8 Carers Receiving Services and Support

1,900 Carers are registered with the Carers Hub Service, this includes almost 500 young carers. An increasing number of residents with caring responsibilities are choosing not to register with the services but rather “dip in and out” when support is needed. This reflects one of the challenges noted earlier – many people with caring responsibilities do not recognise themselves as carers or choose not to be labelled as a carer. An average of 540 care assessments of adults caring for adults are carried out annually by Richmond Council. A programme of work to review the Carer's Assessment process has recently been undertaken **Table 10**.

**Table 10: Known Richmond Carers**

	Number of adult carers reported:	Number of young carers reported:
<b>Carers reported in the 2011 Census</b>	14,938 carers aged over 25 years	864 carers aged below 25 years
<b>Services for carers</b>		
• <b>Carers Hub Service</b>	Over 1,400 carers (Nov 2019)	
• <b>Carers Assessment</b>	During 2018/19 adult carers received a carers assessment	
• <b>South West London St George's Trust</b>	Unknown	
• <b>Children's services: single point of access (SPA)</b>	N/A	Young carers are not recorded through the SPA system and are only recorded if they access the Carers Hub Service
<b>General Practice: 1683 carers identified by GP (of a total of 28)</b>		
<b>Health and well-being services for all Richmond residents</b>		
<b>Health Check</b>	Unknown	Unknown
<b>Richmond Well-being Service</b>	Unknown	Unknown
<b>Community Independent Living Service</b>	Unknown	N/A

Source: Adult Social Services Directorate

## 4.9 Current Services on Offer

Richmond has an active and engaged Voluntary Sector that provides a range of services to people in the Borough. Services include:

- The Carers' Hub Service, a Local Authority funded service to provide universal and specialist information, training and individual and group support services to carers
- MIND's Acute Carers Recovery Worker
- Richmond Adult Social Care Services
  - Carers Assessments: these give carers the opportunity to discuss the physical, emotional and practical impact of caring on their life and enables social care practitioners to direct them to services which can support them
  - Carers Emergency Card is available for carers who have had a Carer's Assessment and enables them to access emergency respite if they are suddenly unable to provide care due to accident or other exceptional circumstances



- Shared Lives Dementia Scheme is a Council funded scheme which helps carers of people with dementia, by providing a shared Lives carer to look after the person they care for
- Telecare/Careline and a 24-hour Emergency Alarm Monitoring System which can help older and vulnerable people to remain living independently and safely in their own homes, giving peace of mind to carers who do not live with the person they look after.
- Achieving for Children: the single point of access (SPA) acts as a single gateway for all incoming contacts into the Richmond upon Thames Children's Services, providing telephone and web-based support for professionals, children, young people and parents. Children's Services refer adults for a self-directed support assessment where young people are identified as providing a caring role to an adult with disabilities or a long-term condition. Young carers identified by Adult Services are referred to Children's Services for appropriate assessment and support
- Seasonal Flu Vaccination: Carers are eligible for free seasonal flu vaccination. This is a service delivered by local health partners including GP surgeries, and some local pharmacies.

In addition, a range of universal services are available to improve the health and well-being of Richmond upon Thames residents. These services can benefit carers, especially those struggling to balance their own needs with their caring role. These include:

- The Richmond Well-being Service, a service for local people who experience mental health problems such as depression or anxiety
- Free Health Checks for people aged between 40-74 years
- Community Independent Living Service (CILS), a network of support, information, advice and signposting services for vulnerable adults. The aim of the service is to help people to live as independently as possible within the community
- Transport Services providing accessible buses to run fortnightly trips to supermarkets
- The Expert Patients Programme, a self-care programme which is free for people and carers living with long-term health conditions
- The NHS's Social Prescribing Service offers unpaid carers a chance to talk to link workers about the impact that their caring roles may have on their physical and mental health

The Richmond Carers Strategy 2020 – 2025 has identified four priorities that will be tackled over the next five years:

1. Improving the recognition of carers and our understanding of their needs
2. Mitigating the economic and academic impact of caring
3. Creating carer friendly services and communities
4. Improving carers health and well-being.

#### 4.10 Interventions/Approaches

Strengths or asset-based approaches focus on individuals' strengths and not on their deficits. It is holistic, multidisciplinary and works with the individual to promote their well-being. It is outcomes led and not services led. It is implicit in the Care Act 2014 and supported by the Social Care Institute for Excellence as an appropriate tool for Social Care.

Since 2014 the London Borough Council of Richmond upon Thames and the CCG have adopted an outcome-based commissioning model, so that community services are oriented towards delivering outcomes important for patients and service users. Therefore, a set of outcomes for carers has been developed through consultation with local stakeholders and carers groups. The three specific outcomes for carers across all groups and populations are the need for consistent, joined-up care across services, and for service users and carers to know whom to turn to when they need help. Attached to each outcome are a number of outcome-based goals to demonstrate specific objectives that services can achieve.

# Acronyms

ABI	Acquired Brain Injury
ADD	Attention Deficit Disorder
ADHD	Attention Deficit and Hyperactivity Disorder
AID	Advice and Information on Disability
APMS	Adult Psychiatry Morbidity Survey
ASC	Autism Spectrum Conditions
ASD	Autism Spectrum Disorder
BAME	Black, Asian and Minority Ethnic Groups
CILS	Community Independent Living Service
CILS	Community Independent Living Service
CLDHT	Community Learning Disabilities Team
CMD	Common Mental Disorders
EHA	Early Help Assessment
HRCH	Hounslow and Richmond Community Healthcare
HSPS	Housing Support and Preventative Services
JSNA	Joint Strategic Needs Assessment
LGBTQ+	Lesbian, Gay, Bisexual, Trans and Querying
LSOA	Local Super Output Areas
OCD	Obsessive, Compulsive Behaviour
PDA	Pathological Demand Avoidance
PSR	Primary Support Services
SEND	Special Educational Needs and Disabilities
SPA	Single Point of Access
WAAS	Wandsworth Autism Auditory Service

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