



Joint Strategic Needs Assessment



VULNERABLE GROUPS

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COVID-19 Impact on the JSNA Report

The COVID-19 pandemic in 2020 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 detailed COVID-19 health outcomes and impact. It is expected that the first post-COVID information will be available in the next 12 months as we continue to monitor the available information.

1. Adults with Autistic Spectrum Disorders (ASD)

1.1 Introduction

“Young people and adults with Autistic Spectrum Conditions (ASCs) living in the London Borough of Wandsworth 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. People with ASCs can depend on mainstream public services to treat them fairly as individuals.”

Wandsworth Market Position Statement

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 1.2 diagnostic criteria for details). Autism can manifest in different ways meaning people need different levels of support. Some autistic people also have learning disabilities but autism itself is not a learning disability. There is also a greater prevalence of some mental health and physical health conditions amongst autistic people.

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.

In this JSNA we use autism as a term that covers all these diagnoses.

The evidence suggests that most self-advocates and groups of autistic people prefer the term “autistic person” to “person with autism” and that is the wording that has been used in this chapter¹.

National strategy is governed by the Autism Act 2009 and the 2018 Think Autism Strategy Governance Refresh. The strategy has 19 objectives under five headings:

- measuring, understanding and reporting the needs of autistic people
- workforce development
- health, care and well-being
- specific support
- participation in the local community.

Children and young people with autistic spectrum disorders are covered in the JSNA Start Well Chapter. There is an estimate of 1,530 adults with autism living in Wandsworth, nearly 1 in 100 of the adult population.

This section of the JSNA looks at the barriers faced by autistic adults in society and, where data is available, in Wandsworth in particular. Most services focus on autistic children and young people. However, autism is a lifelong condition and can have a significant impact on adults. 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 necessarily be eligible for support. Wandsworth is in the process of developing a new local strategy for autism that will cover all age groups.

¹ Autism Speaks (2017), National Autistic Society (2018)

It is important to remember autism can affect people differently. The following sections are a generalisation and not all statements will apply to each autistic person.

Autism is unique in being the only condition that has its own Act, but there is no requirement to provide statutory social care services for autistic people.

Autistic people are more likely to be:

- unemployed or under-employed
- socially isolated
- at greater risk of some physical and mental health conditions
- vulnerable to suicide
- undiagnosed, particularly if they are women, BAME or older people
- communication impaired
- hypo or hyper-sensitive to sensory stimuli
- bullied, victims of hate crimes and exploitation
- in the Criminal Justice System.

1.2 Diagnostic Criteria

Diagnosis is the formal identification of autism, usually by a Multidisciplinary Diagnostic Team (MDT). Although autism is a lifelong condition and often diagnosed in childhood, there are significant numbers of adult diagnoses. Nationally, between April to December 2018, 5,255 adults were referred for assessment where their need was suspected autism².

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).

1.3 Comorbidities

Some conditions are commonly diagnosed alongside autism. These include Attention Deficit Hyperactivity Disorder (ADHD) and Pathological Demand Avoidance (PDA). While these are starting to be seen as potential characteristics of autism, PDA is also seen as a diagnosis in neurotypical people.

A learning disability is defined as a reduced intellectual ability and difficulty with everyday activities³ (for example, household tasks, socialising or managing money) which affects someone for their whole life. Research into the overlap between autism and learning disabilities varies in the estimation of the proportion of autistic people who also have a learning disability. Most studies show between 44% and 52% of autistic people may have a learning disability and between 31% and 36% of people with a learning disability may also be autistic⁴.

Some physical health conditions are more prevalent amongst autistic adults than in neurotypical adults. These include⁵:

- immune disorders such as allergies and asthma
- metabolic disorders such as diabetes
- heart disease
- motor disorders such as cerebral palsy.

² NHS Digital (2019)

³ NHS (2018)

⁴ Emerson (2010)

⁵ Autism Speaks (2017)

Some autistic people may avoid going to a doctor due to stress, fear of change (especially with unfamiliar doctors) and worry about procedures such as colonoscopies. This means 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 autism than the neurotypical population, and up to a third of autistic people may experience epileptic seizures compared to 1-2% of the neurotypical population⁶.

Amongst autistic children, an estimated 30-60% are also diagnosed with attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD), compared to 6-7% of neurotypical children. Autism can disrupt sleep for children and adults⁷.

Some Common Mental Disorders (CMD) can be prominent amongst autistic people. 40% of autistic people have symptoms of at least one anxiety disorder compared to 15% of the neurotypical population. This is often combined with depression. A combination of factors that lead to vulnerability to stress include:

- 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 autistic people. This is thought to be because of a combination of genetic factors and psychological predisposition. Diagnosis of OCD in autistic people is difficult because it may be mistaken for repetitive behaviour.

It is estimated 20% of the population will experience a period of depression in their lifetime, this is more common in autistic people. They can also find it harder to seek help for depression because change can be daunting and raise anxiety levels. It can be difficult for them to explain their feelings, symptoms, and concerns.

1.3 Prevalence and the Level of Need in the Population

There are around 700,000 people with autism in the UK, more than 1 in every 100 of the population.

The Adult Psychiatric Morbidity Survey (APMS) included a measure for autism for the first time in 2007. It showed 1% of the adult population had autism (decreasing 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.

There is no register of adults with autism. However, in Wandsworth there are 737 children with a diagnosis of autism known to schools, approximately 1.65% of the population. This is higher than the London average of 1.5%, and England average of 1.37%. The lower prevalence in adults found in the APMS is probably due to:

- an increase in diagnosis over time, either due to an increased prevalence of the condition or better diagnostic criteria now compared to the 1970s and 80s
- lower life expectancy for autistic people.

Using age-related national prevalence rates based on a total national population of 1%, it is estimated that the number of people in Wandsworth with autism in 2020 is approximately 2,700, 1.02% of Wandsworth's population.

Table 1 assumes that the percentage of the population with autism remains steady.

⁶ Autism Speaks (2017)

⁷ NHS (2019)

Table 1: Estimated number of autistic people in Wandsworth

	2020	2030	2040	2050
18+ Population	267,305	307,388	327,070	330,802
Autistic adults	2,734	3,133	3,311	3,329
% population	1.02%	1.02%	1.01%	1.01%
Increase from 2020		15%	21%	22%

Source: GLA population estimates & Office of National Statistics (2016)

Most new diagnoses of autism occur in children. However, because of improved diagnostic criteria and an increase in awareness, more adults are being diagnosed. Nationally 17,975⁸ new referrals for suspected autism were made between April and December 2018. 70% of these were children and 5,255 were adults. If this rate is consistent it would suggest that nationally, approximately 7,000 adults will be referred for a new autism diagnosis. 64% of all referrals were men and boys. (The data does not show how many people received a diagnosis).

Autism is not regarded as a social care need. However, there are some people with a social care need who also have autism. In 2017-18, there were 87 new assessments in Wandsworth Adult Social Care for autistic people:

- 52 had a learning disability
- 15 had a mental health need.

1.4 Current Services

While providing a social care assessment is a statutory requirement, unless autistic people have other needs such as learning disabilities, it is unlikely that they will be eligible for statutory social care support. Most support services designed for autistic people are non-statutory. In Wandsworth, work is underway as part of the refresh of the Autism Strategy, to review services and develop actions to improve the experience of autistic people in accessing local autism services.

The Wandsworth Autism Advisory Service (WAAS) is a multi-professional team that supports schools, organisations and families in Wandsworth to achieve the best possible outcomes for autistic children and young people. The service supports education establishments to enable all children with autism and social communication disorders to achieve their full potential.

WAAS offers a service which is available to all Wandsworth residents with a child or young person with a diagnosis of autism, Wandsworth schools, early years settings, services and professionals. The service also provides a more specialist and targeted offer which is accessed through referral to the service.

The WAAS works closely with partners across Wandsworth to provide a planned and graduated support for parents and families who have a child with autism (and those on the specialist pathway). The service provides a point of contact for specialist advice and support. It aims to up-skill families through a bespoke parent / carer training programme. Parent support is available to all Wandsworth residents regardless of the child/ young person's educational placement. Up to date details of the parent offer can be found on the Wandsworth Local Offer.

Choice Support is commissioned by the Council to provide employment support for autistic people, with or without a learning disability. The service includes support in obtaining and maintaining employment, working both with the individual and their employer.

The National Autistic Society provides support and guidance for adults and children with autism, and their families. Their "Autism at Work" service works with employers to support autistic people in the workplace⁹.

⁸ NHS Digital (2019)

⁹ National Autistic Society (2018)

1.5 Predictive Factors

Autism is a lifelong condition that affects 1.1% of the population¹⁰. Despite this relatively high prevalence, the causes are still largely unknown. Factors that can increase the likelihood of a diagnosis of autism include:

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

It is probable there are genetic factors responsible for some forms of autism. It is more likely to have multiple genes and an interaction with environmental factors rather than a single genetic cause. Identifying a predisposition to autism through genetic testing is, therefore, not possible¹¹.

1.6 Related Effects of Autism

Autism and communication

Autistic people 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 autistic people 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 and may struggle with abstract concepts. Some autistic people 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 interests¹².

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, there is currently no definitive understanding of how the two conditions are linked¹³.

Eye contact can be hard for some autistic people to the point of causing physical pain if forced. This can often make normal social interactions difficult¹⁴.

Autistic people 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 autistic people vulnerable to exploitation, especially when friendship is being offered¹⁵.

Masking is a behaviour where autistic people will try to imitate neurotypical behaviour in order to avoid social stigma. However, this can cause autistic people intense strain which can make coping harder¹⁶.

“Information overload” is a familiar term when talking about email communications and social media. However, autistic people will often experience this in everyday life. If there is too much information (including sensory information) some autistic people can be distressed and shut down, unable to interact further. Some autistic people

¹⁰ Brugha (2009)

¹¹ NHS (2019)

¹² National Autistic Society (2018) and NHS (2019)

¹³ Ibid

¹⁴ Madipakkam (2017)

¹⁵ National Autistic Society (2018) and NHS (2019)

¹⁶ Ibid

can use “pre-intentional” communication, talking to themselves to help them keep calm and focussed, or as a reaction to an exciting or distressing situation¹⁷.

These communication difficulties mean that many autistic people 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 autistic people can exacerbate the communication barrier and lead to autistic people shutting down or being labelled as having challenging behaviour.

Sensory differences

Some autistic people process sensory information differently to neurotypical people. This can vary from person to person, from sense to sense, and be either over or under sensitive to different inputs¹⁸.

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. However, an oversensitivity to sound may mean that someone is overwhelmed and unable to function because of a background noise which a neurotypical person may not even notice.

Sometimes sensory differences means autistic people might be obsessed with certain patterns, shapes, colours, sounds and sensations. This can lead to compulsively touching people and objects or making obsessive sounds.

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

Autism and patterns of behaviour

Autistic people can find the world confusing and overwhelming. Often, they prefer a regular daily routine so that they know what is going to happen, and a set of rules that they can follow without variation. They can find changes upsetting, especially if they are unexpected¹⁹.

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

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

Autism and life expectancy

A Swedish Study²⁰ 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 learning disability, compared with an age standardised general population age of 70. Leading causes of death were found to be neurological disorders such as epilepsy (which has previously been linked to autism) and suicide. People with high-functioning disorders have a nine-fold suicide risk compared to the neurotypical population.

¹⁷ Ibid

¹⁸ Ibid

¹⁹ Ibid

²⁰ Hirvikoski (2018)

An American Study in 2017²¹ found the life expectancy for autistic people to be 36 years old compared to 72 years for the general population. It found 28% died due to an injury including suffocation, asphyxiation and drowning. This study looked primarily at lower-functioning disorders.

Autism and employment

There is a significant employment gap for autistic people when all disabilities are considered²²:

- 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 autistic people are in full or part time paid employment.

Only 16% of autistic adults are in full-time paid employment. 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 autistic people in employment reported that they had skill levels higher than their job requires²³.

When autistic people are in work, 48% have experienced bullying or harassment in their workplace. Only 58% have disclosed their autism. Where people have disclosed their autism, only 32% were asked what adjustments they would need in the workplace²⁴.

Barriers to employment for autistic people include²⁵:

- The interview and application process: One of the defining characteristics of autism 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
- The work environment: Since many autistic people 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 2007²⁶ showed the prevalence of autism was higher amongst single respondents than married people. Research in America²⁷ has shown that only 5% of autistic adults marry and 67% have no interest in romantic relationships. While the participants for this study were 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 autistic people find it hard to form friendships, even when they want to. Understanding and communicating with other people is particularly difficult and can leave autistic people feeling lonely. As many as 79% of autistic people, and 70% of their families, feel socially isolated. 81% say they feel lonely some of the time because of autism related anxiety rel. 81% of young autistic people believe they spend less time socialising than their peers²⁸.

Some of the factors that impact on social isolation include²⁹:

- struggles in social situations
- autism as a hidden disability and can be misunderstood by people around them

²¹ Guan (2017)

²² National Autistic Society (2016)

²³ Hurley-Hanson (2019) and National Autistic Society (2016)

²⁴ Ibid

²⁵ Ibid

²⁶ Brugha (2009)

²⁷ Farley (2018), Fisher (2013) & Research in Practice (2020)

²⁸ Ibid

²⁹ Ibid

- prevalence for anxiety and depression can cause loneliness and social isolation
- the employment gap for those with autism limits the opportunities to make connections with other people
- 70% of autistic adults feel that they need more support to reduce social isolation.

Transition

At ages 16-25 young autistic people have challenges due to the impact of sudden change in their lives.

Change may 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 or lack of support.

Criminal Justice System

Not only are autistic people vulnerable to exploitation, bullying and hate crime, there is evidence autistic people are overrepresented in the Criminal Justice System. This is thought to be due to³⁰:

- 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. The condition can often manifest itself in different ways by gender. Various studies have shown the ratio of male to female autistic people varies significantly. A 2009 survey of adults 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 of approximately 3:1. A study of people with a learning disability and autism showed a ratio closer to 2:1³¹.

The male and female ratio has been challenged and there are a number of theories to explain the gender differences. These include³²:

- girls and women with autism have characteristics that do not fit the profile usually associated with men and boys (diagnostic tools are based on characteristics found in groups of males)
- bias from practitioners who see autism as primarily a 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 autistic spectrum may be better at masking their traits
- autism traits in girls are underreported in schools.

Autism diagnosis post-childhood

While autism diagnosis in children has improved, there have also been more adult diagnoses in recent years. Current knowledge of older people and autism is limited. Under-diagnosis may lead to a lack of support for managing the impact of their condition such as social isolation at home, or in accommodation-based care³³.

The lower life expectancy for adults with autism distort prevalence rates. Autistic people without a diagnosis and the corresponding support, are at a higher risk of life reducing mental health conditions.

³⁰ National Autistic Society (2018)

³¹ Brugha (2009)

³² National Autistic Society (2018)

³³ Ibid

1.7 What are the limitations to the data/information?

The number of people receiving social care services is small. 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 estimates based on the age of Wandsworth's population, not the specific socio-economic profile of the Borough³⁴.

The Department of Health and Social Care is putting measures in place to improve diagnostic data collection and analysis. Access to autism diagnosis varies across the UK, local areas use different diagnostic tools meaning diagnostic criteria is inconsistent³⁵.

The number of people diagnosed with autism has increased significantly in recent decades. A 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 has increased its estimate of autism prevalence amongst children in the USA to 1 in 59. Their evidence shows that previously there has been persistent undercounting. They suggest the significant increase is due to improved identification, particularly amongst girls and minority groups. While most new referrals for diagnoses in the UK are children, there are still adults receiving a new diagnosis³⁶.

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 the diagnosis process but not definitive. Evidence shows that the Autism-Spectrum Quotient Test, AQ questionnaire produces many false negatives. People who score as not having autism may receive a diagnosis following further investigations. In addition, the sample was comparatively small, and the results are therefore subject to a larger margin of error³⁷.

1.8 Diagnosis and Identification

Estimated numbers of autistic people in the population are subject to a large margin of error. Studies to determine population prevalence give varied results dependent on the criteria used. Diagnostic criteria has evolved as a greater understanding of autism has been developed. While increasing numbers of people are diagnosed in childhood, there are still several autistic people 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 limited³⁸.

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 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)³⁹
- BAME Groups: Evidence suggests BAME children and adults can experience difficulties with obtaining a diagnosis of autism, and more likely to be diagnosed incorrectly with other conditions⁴⁰.

Services and Support

Autistic people experience many barriers to day-to-day living, and because autism is a hidden disability these are not always known, understood or acknowledged.

³⁴ Internal data

³⁵ NHS Digital (2019)

³⁶ Blumberg (2013) Brigha (2009) Elsabbagh (2012), Hansen (2015) Kim (2011), Lotter (1966), NICE (2012), ONS (2016), Principal Investigators (2012) Rice (2011) Wing (2002) WHO (1992)

³⁷ Ashwood (2016)

³⁸ Blumberg (2013) Brigha (2009) Elsabbagh (2012), Hansen (2015) Kim (2011), Lotter (1966), NICE (2012), ONS (2016), Principal Investigators (2012) Rice (2011) Wing (2002) WHO (1992)

³⁹ Brugh (2009) & National Autistic Society (2018)

⁴⁰ Beeger (2008) & Slade (2014)

Communication difficulties mean that many autistic people 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 autistic people react negatively to change. They prefer a regular daily routine so that they know what is going to happen, and a set of rules that they can follow without variation. Unexpected changes can be debilitating, and they take more time to adapt to the new situation.

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

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

Health

Some physical health conditions are more prevalent amongst autistic adults than in neurotypical adults⁴¹.

These include:

- immune disorders such as allergies and asthma
- metabolic disorders such as diabetes
- heart disease
- motor disorders such as cerebral palsy.

Some Common Mental Disorders (CMD) are also more prevalent amongst autistic adults:

- 40% of autistic people have symptoms of at least one anxiety disorder compared with 15% of the neurotypical population
- Obsessive Compulsive Disorder (OCD) is more common in autistic people
- depression is often linked with anxiety.

Some people with may avoid going to a doctor due to stress, fear of change, and worry about procedures. They can also find it harder to seek help for CMD because change can be daunting and raise anxiety levels. They can also find it difficult to describe their feelings, making it hard to communicate symptoms and concerns.

Studies show people with high-functioning disorders have a nine-fold suicide risk compared to the neurotypical population. It is a leading cause of the reduced life expectancy for autistic people.

1.9 Interventions/Approaches According to the Evidence Base

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

The National Institute for Clinical Evidence guidelines recommend psychosocial interventions rather than medication. There has been no convincing evidence that medication is effective in managing autism⁴².

Applied behaviour analysis, although a common treatment, has been heavily criticised because it seeks to impose neurotypical behaviours on autistic people. A strength-based approach has been shown to be more effective because it works with the positives autism brings to people's lives, especially their individual strengths.

⁴¹ Autism Speaks (2017),

⁴² NICE (2012)

A good understanding of autism is required to design and deliver support services tailored to individual need. This can be a challenge because people have a variety of characteristics. Autism training for front-line staff has been found to have a positive impact on people's experience of services and autism friendly environments.

Research has found social skills training may be effective for in the reduction of depression, anxiety and inappropriate social behaviour. However most existing training is aimed at young adults and it is unknown whether the value for adults aged 30+ would be the same⁴³.

Services that provide general support for independent living have proven successful. Peer support groups are another valued service and provide autistic people opportunities for social interaction and sharing experiences.

A multidisciplinary approach can reduce service costs, increase diagnosis rates, reduce crisis interventions, and improve employment rates.

2. Physical and sensory disabilities

2.1 Introduction

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 can be 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 2010⁴⁴. However, further progress is required to improve the lives of disabled people:

“All people should have the opportunity to be active citizens; live a meaningful life and make positive contributions to the community they are part of. People with a Physical or Sensory Impairment 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 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 links across the care landscape.”

Wandsworth Market Position Statement

Defining disability is complex and contentious. The 'social model of disability' states people with disabilities encounter 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 impairment⁴⁵.

Examples of definitions include:

- The Equality Act 2010 defines disability as 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 in the guidance in terms of at least 12 months
- The World Health Organisation states that a 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.”

⁴³ Research in Practice (2020)

⁴⁴ Equality Act 2010

⁴⁵ Office for Disability Issues (2011a) and WHO (2001)

For the purposes of this chapter, we are defining physical and sensory disabilities as **“a physical, mobility or sensory condition that causes a person to face barriers in undertaking day to day tasks”**. This fits with the national reporting model for social care which groups people by their primary support reason (PSR).

The social care Primary Support Reasons (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 which is the UK’s legal framework designed to protect disabled people from discrimination⁴⁶.
- 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 wellbeing which includes⁴⁷:
 - personal dignity
 - physical and mental health and emotional wellbeing
 - protection from abuse and neglect
 - control by the individual over day-to-day life
 - participation in work, education, training or recreation
 - social and economic wellbeing
 - domestic, family and personal
 - suitability of living accommodation
 - contribution to society.

Physical and sensory disabilities become more prevalent with age, along with other long-term conditions, such as diabetes and may impact on mobility and personal care requirements. The average age of the adult disabled person in London is 43.7 years compared to average of 37.5 years for people without disabilities. Preventative support at a younger age may delay, reduce or entirely prevent the onset of further conditions or reduce deterioration⁴⁸.

An estimated 30% of people with a long-term physical health condition also experience mental health problems, most commonly depression and anxiety, which can be exacerbated by social isolation. This can lead to significantly poorer health outcomes and a reduced quality of life. It is estimated that mental health problems increase the cost of NHS treatment of limiting long term physical health conditions by an additional £8,000 million to £13,000 million annually. The lowest estimate equates to £1 in every £8 spent on limiting long term physical health conditions⁴⁹.

Barriers

People with physical and sensory disabilities face several barriers.

These include⁵⁰:

- stigma surrounding disabilities and negative experiences can become a barrier to accessing support services
- opportunities to make and sustain social contacts can be limited and lead to isolation and loneliness
- sighted-guides and communicator-guides are often difficult to obtain, and there is some difficulty in getting requests through 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, or be employed for fewer hours and lower hourly pay, than other people with equivalent skills and experience⁵¹

⁴⁶ Equality Act 2010

⁴⁷ Care Act 2014

⁴⁸ Scope (2020)

⁴⁹ Tough (2017), Naylor (2012) and Barnett (2012)

⁵⁰ Scope (2018) and Sense (2017)

⁵¹ Office for National Statistics (2019)

- On average, a person with a disability spends 47% more on the costs of day-to-day living⁵²

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

2.2 Prevalence and Level of Need in the Population

Using 2020 local prevalence rates, it is estimated there are over 46,300 people aged 18-64 (6.4%) whose ability to do day to day tasks is limited by long-term condition or illness including physical, sensory, learning disabilities and mental health conditions. Over 19,800 state they are significantly limited.

Applying national age-related prevalence rates to Wandsworth 18-64 population it is estimated:

- 4.1% (22,000) mobility impairments
- 0.8% (4,200) visual impairments
- 0.5% (2,800) severe hearing loss
- 7.8% (41,600) some hearing loss.

All these numbers are expected to increase over the next 30 years as presented in **Table 2**.

Table 2: Estimates of the number of people with disabilities in Wandsworth

		2020	2030	2040	2050	percentage increase
Mobility	People	9,678	11,077	11,750	12,040	25%
	% population	4.1%	4.2%	4.2%	4.4%	
Visual Impairment	People	1,849	2,121	2,259	2,297	25%
	% population	0.8%	0.8%	0.8%	0.8%	
Some Hearing Impairment	People	18,181	20,877	22,325	22,790	26%
	% population	7.7%	7.8%	8.1%	8.3%	
Severe Hearing Impairment	People	1,248	1,420	1,510	1,527	23%
	% population	0.5%	0.5%	0.5%	0.6%	

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

However, these are based on national age-related prevalence rates and because of current and historical good services for hearing impaired people in Wandsworth, the actual numbers of this group may be higher, particularly in younger people with profound hearing impairments.

In 2018-19, there were a total of 451 adults aged 18-64 receiving social care services in Wandsworth for physical health and sensory needs, **Table 3**.

⁵² Scope (2019)

Table 3: People receiving social care services in Wandsworth with physical and sensory needs

	2018-19	Estimated 2050
Community-based services	420	525
• Direct Payments	173	
• Home Care	256	
• Day Care	32	
• Short-term residential or respite	8	
Accommodation-based care services	48	60
• Supported Living ¹	4	
• Extra Care (55 and over only)	15	
• Residential Care	10	
• Nursing Care	22	
All People	451	565

Source: internal data

The proportion of people in this group receiving direct payments is 41%. While there is no specific benchmarking data for this group, the overall proportion of people aged 18-64 receiving their community-based services through direct payment is 28%, slightly lower than the England (31%) and London (29%) averages.

Out of the 451 people, 97% had a physical impairment. 21% needed mobility assistance only, and 75% required mobility and personal care support. An increase of 25% was used to estimate need by 2050. Due to the small numbers involved, the projections have a large margin of error. Within this group, an increase in social care need is anticipated and subject to change with unexpected external factors.

The proportion of the 18-64 year olds with mobility, visual and hearing impairments is expected to increase by 2050. It is unknown how the impact of the COVID-19 pandemic will have in terms of increasing the number of people with long-term ill health or receiving social care services. The projections and analysis of future trends is therefore subject to significant margins of error. Much of the other data are extrapolated from national prevalence rates. The estimates are based on the age of Wandsworth'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. Others may be deterred from formal services due to access difficulties (e.g., booking appointments via a telephone system).

2.3 Current Services on Offer

Within the legislative framework Wandsworth has a duty to promote wellbeing and ensure equality of opportunity for people with disabilities. People with physical and sensory disabilities often face barriers to undertaking day to day tasks which may require equipment, adaptation and support, or social and cultural change within communities. The national agenda for personalisation means putting individuals strengths and preferences at the centre of their care. Wandsworth follows a strength-based approach focussing on the abilities of the individual rather than their disabilities in order to overcome barriers and find solutions.

The Council 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 14% 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 a Direct Payment, Wandsworth organises appropriate community-based services such as homecare and day care.

Housing and Accommodation

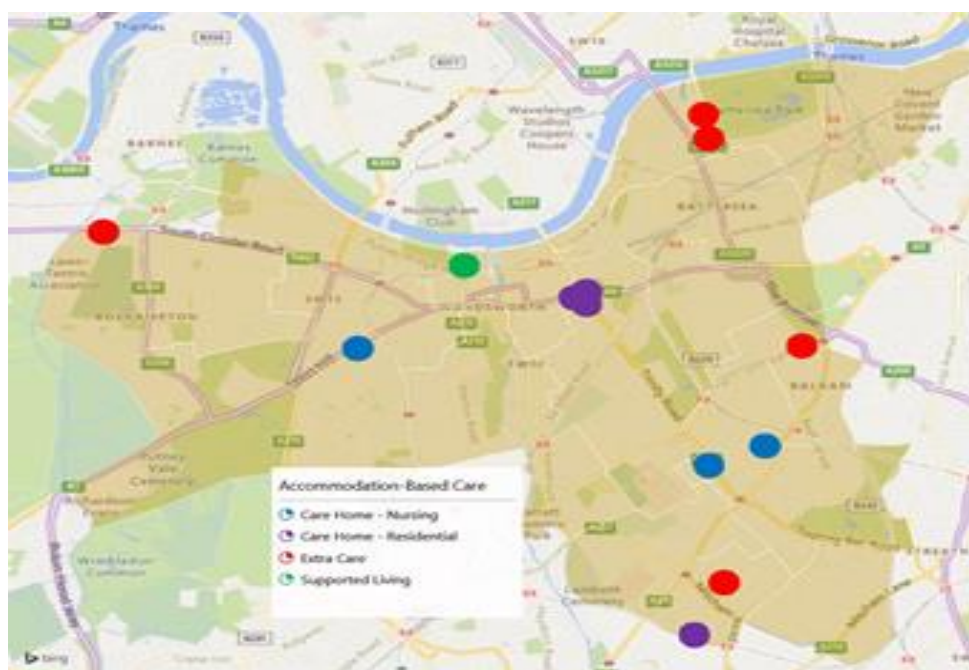
There are no accommodation-based services that specifically cater for this group in Wandsworth. However, there are four residential and three nursing homes that will take working age adults with physical and sensory disabilities. While recent admission figures are low for this group, evidence is that Out of Borough Placements are used to ensure people are placed in appropriate accommodation for their specific needs. There are five Extra Care Housing Schemes that

accept people from age 55+ (**Figure 1**). Three of these schemes are commissioned by Wandsworth Council and the other two are privately run.

A recent analysis of accommodation-based care needs suggested⁵³ that there may be a need for some locally based supported living accommodation such as extra care provision for younger adults. This was due to all current placements being out of Borough. However, the conclusion was there was insufficient evidence for this need and further work is to be undertaken to inform decisions.

There is a Sensory Impairment Service in Wandsworth which provides services to visually impaired people including advice, equipment and training. Facilities at Liden Lodge School include Wandsworth Hearing Support and Vision Support Services. Voiceability Wandsworth is commissioned by the Council to support sensory disabilities, and Blind Aid provides support for reading and responding to mail.

Figure 1: Location of accommodation-based care services in Wandsworth



Source: internal data

2.3 Disability Prejudice, Social Isolation and Loneliness

Some of the barriers disabled people face involve lack of opportunities to make and sustain social contacts, leading to isolation and loneliness. This includes people with diverse impairments and personal circumstances.

The barriers that people face include⁵⁴:

- 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
- a national survey of people without disabilities 49% stated that they did not have anything in common with disabled people, 26% admitting that they have avoided engaging in conversation with a disabled person
- one in three disabled people in a national survey feel that there is a lot of prejudice against people with disabilities, another half feel there is some prejudice. When the same question was asked of people without disabilities, only one in five stated there was a lot of prejudice

⁵³ Internal data

⁵⁴ Scope (2018) and Sense (2017)

These barriers have a tremendous impact on the welfare and quality of life of disabled people⁵⁵.

- 53% from a national survey reported feeling lonely regularly, 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 negatively impact both on emotional, mental and physical. Weak social connections can be as harmful to physical health as smoking 15 cigarettes a day. Lonely individuals are at a higher risk of increasing disability.

2.4 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 wellbeing. 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.

There is a significant difference in economic activity and employment rates between people with and without disabilities⁵⁶. The national estimates have been applied to the Wandsworth figures in **Table 4**.

Table 4: Comparison of estimated economic activity of people with and without disabilities in Wandsworth

	% in employment	% unemployed	% not economically active
People with disabilities	53.2% (~24,600)	6.7% (~3,100)	43.0% (~19,900)
People without disabilities	81.8% (~157,700)	3.7% (~7,100)	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 time⁵⁷.

Median pay is 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 being paid to people with disabilities. Nationally, the pay gap for people with disabilities employed as managers, directors or senior officials is the largest, at 13.1%. In addition the pay gap was largest for people aged 30-49⁵⁸.

Life costs more for people with disabilities and their families who have to spend, on average, an estimated 47% more than people without disabilities (equivalent to a national average £585 extra per month). One in five disabled people face extra costs of over £1,000 a month⁵⁹.

⁵⁵ Ibid

⁵⁶ House of Commons Library (2020) and Office for Disability Issues (2011b)

⁵⁷ Office for National Statistics (2019)

⁵⁸ Ibid

⁵⁹ Scope (2019)

3. Learning Disabilities

3.1 Introduction

The focus of the commissioning model for learning disability services is to reduce reliance on residential care. Service users are provided with supported living and greater independence where possible, with fewer out of Borough placements. In addition, the Council encourages the provision of meaningful daytime activities and life skill development opportunities with stronger pathways towards a measurable outcome. 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 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 ageing cohort of people with learning disabilities.

Wandsworth Market Position Statement

A learning disability is a reduced intellectual ability and difficulty with everyday activities such as household tasks, socialising or managing money. The NHS defines a learning disability as **“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 learning, sensory and physical impairment⁶⁰.

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 within both national and local agendas. The Care Act 2014⁶¹ requires Local Authorities to meet a person’s needs holistically. This encompasses an acknowledgement of the wider determinants of wellbeing, such as employment or socialisation. The Care Act legislation is strengthened by the Mental Capacity Act 2005⁶² which protects the right of individuals and their families to make their own decisions.

All people should have the opportunity to be active citizens, live a meaningful life, and make contributions to the community.

To ensure that Wandsworth Council is providing the best outcomes to residents, a Learning Disability Clinical Reference Group ensures that services are the needs of local people. Importantly, the Group includes representation of people with a learning disability and their families. Service implementation is guided by key principles of the Wandsworth Learning Disability Commissioning Strategy 2021-26 that focusses on:

- My Voice is Heard – Coproduction
- Where I Live – Housing and Care Support
- What I Do – Employment and Day Opportunities
- Becoming an Adult – Transition
- I am Fit and Healthy – Improving Health Services
- I have Choice and Control in my Life.

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 while the mother is pregnant
- lack of oxygen or trauma during birth

⁶⁰ NHS (2018)

⁶¹ Care Act 2014

⁶² Mental Capacity Act 2005

- premature births
- early childhood illnesses, accidents or seizures.

Diagnosis of learning disabilities generally occurs in childhood. Mild learning disabilities are mostly commonly diagnosed during 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.

3.2 Prevalence and Level of Need

While the analysis in this section is pre-COVID, it is undeniable that COVID-19 is going to have an impact on the needs of people with learning disabilities in Wandsworth. National evidence shows that 30% of the deaths of people with a learning disability between March and September 2020 were from COVID-19. When the full impact of the pandemic is known, including the potential long-term impacts of the virus, the analysis will be revisited.

National prevalence rates applied to the age-related population in Wandsworth show a predicted increase of 16% 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: Projections of Wandsworth residents with a learning disability 2020-2050

	2020	2030	2040	2050	percentage increase
18-64 All LD	5,789	6,220	6,559	6,719	16%
65+ All LD	664	739	847	956	80%
18-64 Severe or moderate	1,325	1,423	1,501	1,537	16%
65+ Severe or moderate	89	98	113	127	73%

Source: GLA population estimates & Emerson & Hatton, 2008

Comparing the number of people on the GP Learning Disability Register shows a similar figure to the London average. 49 in every 10,000 people in London are on the GP Register of people with a learning disability, the number in Wandsworth is approximately 48 people. Similarly, the number of people receiving social care services with the primary need of learning disabilities is 33 compared to 32 South West London, **Table 6**.

Table 6: Key statistics on learning disabilities in Wandsworth

	Receiving support from social care services per people on GP register	GP register, per 10,000 population	Social care services, per 10,000 population
London	56%	49	28
South West London (6-Borough)	60%	53	32
Wandsworth	70%	48	33

Source: Public Health Profiles

In 2018-19, there were 829 people aged 18 to 64 years with a learning disability receiving services, and a further 131 people aged 65 and over, **Table 7**. Direct payments were one of the most common ways to support people with a learning disability in the community, given the emphasis on choice and control.

Table 7: People receiving social care services for a learning disability

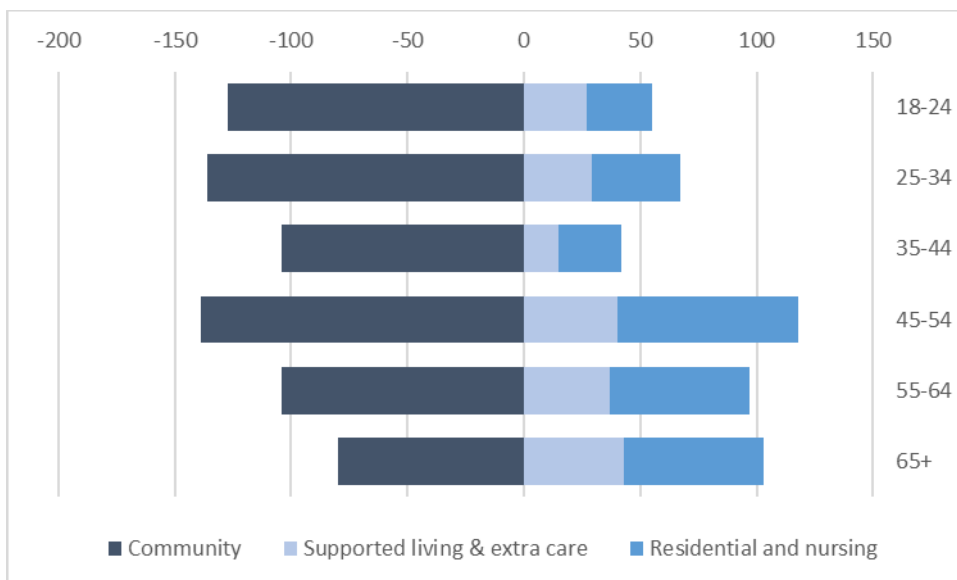
	2018-19		2050	
	18-64	65+	18-64	65+
Community Based Services	638	80	740	140
• Direct Payments	278	17		
• Home Care	60	16		
• Day Care	301	36		
• Respite & short term residential	54	0		
Housing	413	101	480	180
• Supported living (not including HSPS)	152	38		
• Extra Care	6	5		
• Residential Care	255	56		
• Nursing Care	6	4		

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 look 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 care (left hand side) and accommodation-based care (right hand side) care by age in Wandsworth. People with a learning disability aged 45+ are more likely to be placed in accommodation-based support. More independent accommodation-based care arrangements (supported living and extra care) make up more than half the accommodation-based care placements from 18 to 44. From 45 years, people with a learning disability are increasingly likely to be placed in residential care homes.

Figure 2: People receiving services for a learning disability



Source: Richmond and Wandsworth Council SSA Adult Social Services Commissioning Division

Life expectancy

The number of people living with a learning disability is expected to increase in line with increases in the general population. Demand in all areas is expected to rise. On average, females with a learning disability live for 18 years less

than the general population, 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 and severe mental health conditions is 8.4 times more prevalent than people without a learning disability⁶³:

- About 1 in 3 people with a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely the person will also have epilepsy
- People with Down's syndrome will typically have some level of learning disability, 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 autistic people 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.

Primary care

A national survey of 47% of people with a learning disability, registered with a GP, showed there is lower attendance of 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 higher levels of explanation regarding a diagnosis or health deterioration, including an easy read format and the involvement of advocates. Research found that 38% of people with a learning disability died from an avoidable cause, compared to 9% in a comparable population⁶⁴.

In Wandsworth, 53% of adults with a learning disability on GP Registers had a health check during 2017-18. This is similar to the England's average (52%) but slightly lower than the London average (57%).

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 people⁶⁵.

People with a learning disability may have limited opportunities for inclusion to a variety of social groups and may be limited by availability of services or carer preferences.

In some communities there are low levels of awareness and understanding from the general public who may not involve and value people with a learning disability.

Many people with a learning disability aspire to having a loving relationship. 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 can play an influential role 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 Wandsworth, the latest statistics show 11% of people with a learning disability (known

⁶³ Heslop (2013), Holt-Lunstad (2010) and Michael (2008)

⁶⁴ NHS (2018)

⁶⁵ Jo Cox Commission (2017)

to services) are in paid employment compared to the London average of 7.5% and England average of 6.0%. The gap in employment rates in Wandsworth is similar to the London (66%) and England (70%) averages⁶⁶.

Meaningful activity needs to be tailored to the individual needs of the person. The assumption that all people with a learning disability need the same service runs counter to the strengths-based approach to social care, and the personalisation agenda. Activities need to fit the interests of the person as well as being age appropriate. Wandsworth has a firm commitment to achieving equality for those with a learning disability and the wider population. Evidence shows people with a learning disability feel they do not get the social contact they need, and meaningful activity levels can be low⁶⁷.

Meaningful activity must be tailored to the individual needs. Wandsworth is committed to expanding a strength-based approach, commissioning services and support which are appropriate for everyone.

Research demonstrated 38% of people with a learning disability died from an avoidable cause versus 9% in a comparable population. Easy access to health care is key to helping people with disabilities live long and healthy lives⁶⁸.

Housing

Two thirds of people with a learning disability remain living with their families. As the family ages, this situation may become unsustainable. If long term support plans are not in place for the person with learning disability may result in multiple moves and placement in inappropriate accommodation⁶⁹.

In Wandsworth, 73% of people with a known learning disability are in settled accommodation, similar to the London average (73%), lower than the England average (77%). An alternative measure of people with a learning disability in stable and appropriate accommodation showed 74% in Wandsworth, similar to the London average of (75%).

Transition

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

These include⁷⁰:

- some young people receiving SEND support in childhood may not be eligible for adult social care support because the criteria is set at a higher level. This is an area of potential unmet need as this group are vulnerable to exploitation and anti-social behaviour
- different legislative frameworks relating to under 18 (children) and over 18 (adults) mean different expectations of available support
- contributions towards the cost of adult support is dependent on the income of the person with learning disabilities
- young people with a 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 want to live more independently
- moving out of the family home can cause more challenges and the young person may need specialised support, either accommodation-based or community-based.

The change into adulthood (and adult based services) can be deeply stressful for many young people with a learning disability and transition is, therefore, a key area of priority within Wandsworth. The 0–25 team in Wandsworth's Children's Services was set up to address these changing needs.

⁶⁶ NOMIS and Public Health England data

⁶⁷ Jo Cox Commission (2017)

⁶⁸ Heslop (2013)

⁶⁹ NHS (2018)

⁷⁰ Michael (2008), NHS (2018) NICE (2015) & CHOICE (2020)

3.3 What are the Limitations to the Data/Information?

The number of disabled people receiving social care services is relatively small⁷¹. The analysis of trends and future needs is therefore subject to large margins of error. Much of the data is extrapolated from national prevalence rates and therefore estimates based on the age of Wandsworth's population, not the specific socio-economic profile of the Borough.

Data collection of learning disabilities only occurs at a point of contact, such as schools, social care or GP practices. People with a learning disability are less likely to be registered with formal services which limits data collection. This leads to people with a learning disability remaining unreached by services and isolated from their community. Before data collection can occur a person with learning disabilities must be registered with formal services.

3.4 Current Services on Offer

Partnerships with the NHS and the vibrant voluntary sector add to the variety of services that support the wellbeing of people with a learning disability in Wandsworth. The Community Learning Disability Health Team (CLDHT) run by South West London and St George's Mental Health Trust provide a specialist pathway to people with learning disability needs who may have difficulty accessing mainstream services. Specialist services include support of dieticians, dysphagia practitioners and speech and language therapists. One Trust is a registered charity that promotes the wellbeing of people with learning disabilities through day centre support. The organisation aims to 'maximise the potential' of all people by tailoring support specifically to the person and their families. In Wandsworth there are services available to ensure the specific health needs associated with learning disabilities are met. Partnerships with the voluntary sector also ensure that people with a learning disability receive holistic services that enable them to lead fulfilled lives.

There are several out-of-borough residential care placements for Wandsworth residents. Moving a person with a learning disability regularly can be disruptive for the individual, family and social networks. The priorities for new placements is to keep people in-borough, and to bring people back in-borough when possible.

There are 12 residential care homes in Wandsworth designed specifically for people with a learning disability, and another two general needs care homes.

There is one Supported Living and four Housing Support and Preventative Services (HSPS) schemes (some consisting of multiple homes) for people with a learning disability. In addition, some HSPS Support is given as floating support in locations around the Borough.

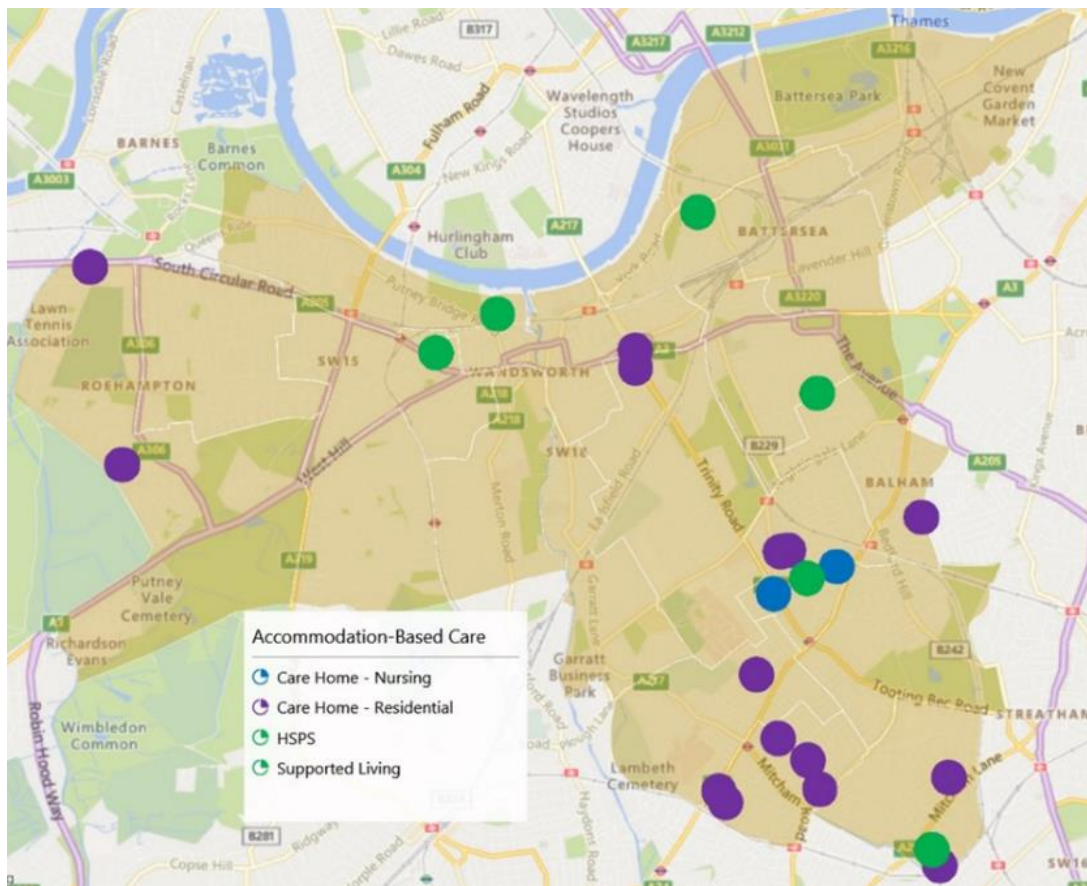
In Wandsworth HSPS operates as a Block Contract Service in addition to the supported living provisions which are spot purchased. HSPS is a local term which refers to services that would formerly have been commissioned under the Supporting People Programme. Whilst both HSPS and Supported Living provide a range of support to tenants, there are key differences:

- HSPS is not regulated by the Care Quality Commission (CQC).
- Supported Living is not necessarily regulated by CQC, but elements of personal care may be subject to personal care
- HSPS provides housing related support services only and does not include personal care or domestic support

Although the number of units varies over time, there are currently approximately 20 units (**Figure 3**).

⁷¹ Comparing internal figures and estimated population prevalence Emerson (2008)

Figure 3: Map of accommodation-based support for Learning disabilities in Wandsworth



Source: Richmond and Wandsworth Council SSA Adult Social Services Commissioning Division

Transition

The transfer to adult services can be deeply stressful for many young people with a learning disability. Wandsworth regards this as a priority for support and, where young people are not eligible for adult social care services.

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 Wandsworth, 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, an area which needs further exploration.

There is a high proportion of older people with learning disabilities who receive support in care homes. Further analysis should be undertaken to explore if older people with a learning disability have services which enable them to remain living independently at home if they wish.

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

The dynamics of learning disabilities in Wandsworth is varied with an increasing proportion of learning disability needs in older people. A variety of services are available to support those with greater need in the community or in accommodation. The voluntary sector services advocates and promotes rights and independence through holistic approaches.

The prevalence of learning disabilities in older people is set to increase significantly by 2050⁷². Services must develop so learning disability needs continue to be met holistically, including social and economic aspects. Wandsworth needs to ensure services for older people include provision for people with a learning disability. Many people with a learning disability may receive accommodation-based support for a primary need other than learning disabilities.

4. Unpaid Carers

A detailed needs assessment was carried out in 2019 and is available on [DataWand](#). This section summarizes the key points and updates some of the figures.

4.1 Introduction

“Our vision in Wandsworth 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.”

Wandsworth Market Position Statement

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 and education opportunities, as well as caring having a detrimental impact on physical and mental well-being. Carers must remain a high priority for central and local governments to ensure they feel they have choices, respect, and value.

A carer is anyone who provides care to a friend or family member who, because of a limiting long-term condition or addiction, is unable to cope independently. Nationally, it is estimated that the number of carers will increase by 60% to 3.4 million people by 2030⁷³. Wandsworth estimates are shown in section 4.3.

The Care Act 2014 and the Children’s and Families Act 2014 recognises the importance of carers and aims to promote their physical and mental well-being. All carers (including young carers and adult carers of children) have a right to a carer’s assessment and relevant support⁷⁴.

The 2010 National Carers Strategy ⁷⁵aimed that by 2018 every carer should be:

- recognised and supported as an Expert Care Partner
- enjoying a life outside caring
- not financially disadvantaged
- mentally and physically well and treated with dignity
- children will be thriving, protected from inappropriate caring roles.

The National Carers Action Plan 2018–20⁷⁶ outlines a range of cross-cutting governmental actions based on five key themes:

- services and systems that work for carers
- employment and financial well-being
- support for young carers
- recognition and support for carers in the wider community and society
- building research and evidence to improve outcomes for carers.

⁷² Emerson (2008)

⁷³ Buckner (2015) and Carers UK (2019)

⁷⁴ Care Act 2014 and Children and Families Act 2014

⁷⁵ HM Government (2010)

⁷⁶ HM Government (2018)

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 security⁷⁷.

Most of the care is provided by family, friends, and relatives. The care they provide is worth an estimated £132bn per year⁷⁸. Notably this is more than total spending on the NHS, which was 124.7 billion in 2017/18⁷⁹. This equates to an average of £20,300 contribution from each unpaid carer in the UK. If this average was applied to the Wandsworth Carers, it is estimated that they provide over £450 million of care.

Despite the significant contribution carers are making to society and the health and social care 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.

As people are living longer with health and social care needs, the gap between the number of carers and the number of people with limiting long-term conditions is increasing.

This means:

- an increasing number of people will become unpaid carers with all the increasing attendant needs
- an increasing need for social care support for people without an unpaid carer.

The number of “sandwich carers” (those looking after young children at the same time as caring for the older generation) is expected to rise as are the number of people with ageing parents increases.

4.2 Identification of the Caring Role

The number of carers in the 2011 Census⁸⁰ compared to the number of carers known to services, indicates there is a gap in identification. Carers often do not recognise their role and only associate with their primary relationship to the person. Most of us will look after an elderly relative, sick partner, or disabled family member at some point in our lives. This invaluable service undoubtedly ensures the continued health, well-being, and comfort of many cared for people. One of the reasons people require social care services is due to unpaid carers becoming unable to continue. Failure to identify carers and offer support at an early stage represents a potential future risk.

Data show three in five people will be a carer at some point in their lives. Women are more likely to be carers, often with multiple caring responsibilities such as for children and elderly relatives. Older people often become carers for their partner⁸¹.

The UK 2011⁸² census showed the proportion of the population who were carers had increased and evidence and this trend is likely to continue. The number of people aged 65+ is increasing more rapidly than the general population.

83% of carers care for one person. 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 **Table 8**. Carers of older people make up approximately three-quarters of all carers. Middle-aged carers may have dependent children whilst also caring for older parents.

⁷⁷ Carers UK (2017)

⁷⁸ Carers UK, University of Sheffield, University of Leeds, 2015

⁷⁹ Carers UK and the King's Fund, 2017

⁸⁰ ONS Census 2011 data

⁸¹ George, Mike (2001), ONS (2011) and Carers UK (2019)

⁸² ONS Census 2011 data

Table 8: Cared for person by percentage of UK carers

CARING FOR	PERCENT %	Estimated numbers in Wandsworth
Parents/parents-in-law	40	9,000
Spouse/partner	26	5,900
Child	13	2,900
Friend or neighbour	9	2,000
Other Relative	7	1,600
Grandparent	4	900
Other	1	200

Source: ONS: Census 2011

Young carers

The 2011 Census identified there are 1,719 young carers under 25 years providing unpaid family care in Wandsworth. Assuming the same proportion applied to the 2020 population, an estimate 1,890 children and young adults are providing care.

All young carers identified by the Council are offered assessment and appropriate support through the Wandsworth Children's services.

Many young carers take on their role because of multiple care needs in the family. Growing up in such an environment, 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, attainment, physical and emotional health, social activities, and individual aspirations. Young adult carers' responsibilities may delay them for moving away from home, reducing employment possibilities, and accessing further education⁸³.

Transition arrangements are crucial for improving employment and higher education opportunities. Carers aged between 16 and 18 years are twice as likely not to be in education, employment, or training. Of those who are in education, 56% at college or university said they were struggling with their studies. 30% said they may have to drop out (17% because of their caring role and 13% for financial reasons). Young carers are three times more likely than their peers to have a mental health condition⁸⁴.

55% of young carers provide care to a parent whilst 25% care for a sibling. 80% of young carers are helping with practical tasks such as cooking and household chores. Responsibilities tend to increase with age⁸⁵.

Young carers risk being hidden and not receiving appropriate support because⁸⁶:

- they do not realise they are a carer or that their life is different to their peers
- their parents do not recognise their children are carers
- they do not want to be different from their peers
- one in four young carers were bullied specifically because of their caring role
- they worry 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 do not realise they need help
- no opportunity to share their story
- lack of understanding of available sources of support.

Even when young carers are known to services, some will under state their caring role and the affect it has on them. In the 2011 census, 442 children aged 0–15 years and 1,348 young people aged 16–24 years, provide unpaid care in Wandsworth.

⁸³ Dearden (2000) and Cheesebrough (2017)

⁸⁴ Buckner (2015), Hounsell (2015) Dearden (2000) and Cheesebrough (2017)

⁸⁵ Ibid

⁸⁶ Ibid

The experiences of LGBT+ young adult carers can be even more challenging. Research by the Carers Trust indicates that LGBT+ young adult carers are three times more likely to experience bullying than young adult carers. They are three times more likely to have a mental health problem than their peers⁸⁷.

Parent carers and sandwich carers

Applying national research to Wandsworth's population it is estimated there are 2,900 parent carers, approximately 13% of the carer population. Some of these will be caring for "adult children". However, there are 5,800 school pupils who have Special Educational Needs and Disabilities (SEND). Most of these children will be cared for by their parents but some may not. This suggests a discrepancy between the number of parent carers identified, and the total number of parent carers⁸⁸.

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

The number of sandwich carers is rising due to the pressures of an ageing population, combined with people starting families later. Over the last ten years the number of middle-aged (50–64) female carers has risen by 13%, to 1.2 million. This is a sharper increase than the total carer number of 11% (Carers UK, 2014). In Wandsworth 20% of women aged 50 to 64 are carers, compared to 14% of men⁸⁹.

Parents who provide care for their children often do not identify themselves as carers and may be unaware 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). The "parent" and "carer" roles are intertwined. Residents are most likely to be carers if they are between 50 & 65, 46% of carers are aged between 25 and 49 years, and 30% between 50 and 64 years⁹⁰.

Black, Asian, and Minority Ethnic (BAME) Carers

In Wandsworth, 2011 Census⁹¹ data revealed 47% of the population are from BAME Groups. The population of unpaid carers who are from BAME groups is similar at 45%. The lack of identification is a key barrier to recognising and managing the effects on health and well-being. Furthermore, it prevents carers from accessing support and services⁹².

4.3 Prevalence and Level of Need

Estimated Population Prevalence

The 2011 census⁹³ showed there was a total of 19,728 carers living in Wandsworth, 6.5% of the population. This varies by age with:

- 2.1% 0–24 years (1,719)
- 5.7% 25–49 years (9,015)
- 16.7% 50–64 years (5,944)
- 11.8% aged 65+ (3,050).

Carers in Wandsworth are less likely to be in good health than people who provide no care. 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**. 37% of carers in Wandsworth had an appointment with a GP in 2018–19 for an issue related to their caring duties.

⁸⁷ Traynor (2016).

⁸⁸ NHS Information Centre (2010)

⁸⁹ Holzhausen (2014)

⁹⁰ Ibid

⁹¹ ONS Census 2011

⁹² ONS (2011) and LBR (2017)

⁹³ ONS Census 2011

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

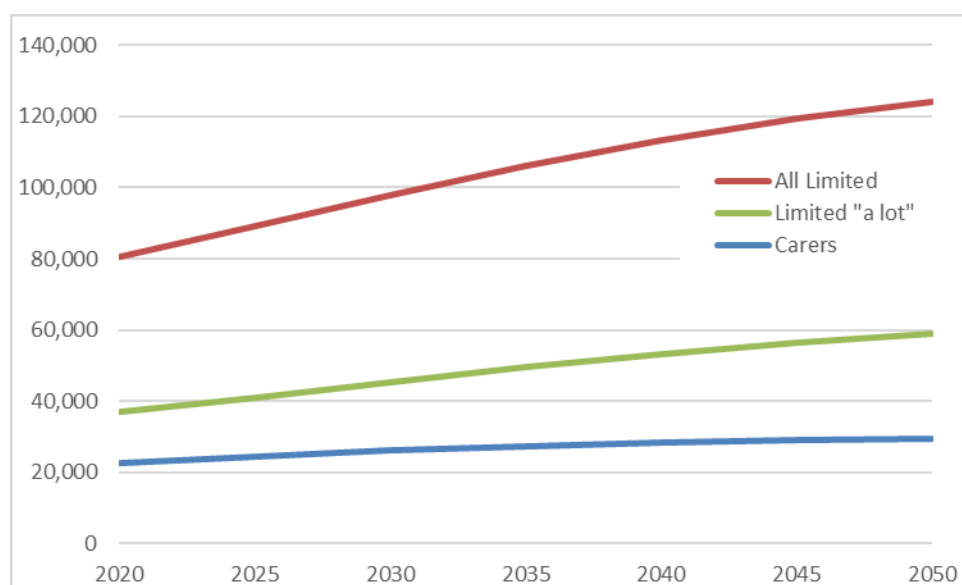
	Bad or very bad health	Fair health	Good or very good health
1–19 hrs.	547 (4.2%)	1883 (14.5%)	10544 (81.3%)
20–49 hrs.	216 (7.6%)	621 (21.9%)	2002 (70.5%)
50+ hrs.	464 (11.9%)	1127 (28.8%)	2324 (59.4%)
No care	9749 (3.5%)	22418 (8%)	249753 (88.6%)

Source: ONS: Census 2011

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

People are living longer with multiple morbidities. The population of Wandsworth is ageing with an estimated increase by 2050 of 87% of people 65+ compared with 16% of those aged 18–64. This is even higher in the 85+ age group which is expected to increase from 9,300 in 2020 to 26,500 in 2050.

Projecting the percentage of carers from the 2011 Census⁹⁴ on to the estimated population gives an estimate of 22,600 carers in 2020, expected to rise by 30% to 29,400 by 2050. 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 80,600 in 2020 by 54% to 124,000 in 2050 (**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 Wandsworth residents with limiting long term illness and residents who are carers

Source: ONS: Census 2011 & GLA population projections

The gap is likely to increase as more of the population becoming carers. This will put more pressure on social care services and the voluntary sector. It is probable some people support will not have access to their own carers.

Impact of Caring on Health

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, three in five carers have a long-term

⁹⁴ Ibid

health condition. This is frequently exacerbated by carers being unable to find time to attend medical appointments due to their ongoing caring responsibilities. It is essential that services and systems are flexible to allow carers to balance their own needs with their caring role. Arrangements should be in place for providing increased assistance as carers age or become less able to care. Social and health care services should synchronise their support in order to improve carers well-being⁹⁵.

- National data shows that 72% of carers live with mental ill health. 61% experience physical ill health associated with their caring responsibilities. 23% of carers reported refusing health and care support due to concerns over the quality and appropriateness of the services. In addition, carers are more likely to postpone their own medical treatments because they prioritise the needs of others⁹⁶.
- Older carers often have their own disabilities or long-term health conditions. Some older people become visible to social care and hospitals at the point of crisis – i.e., when their unpaid carer can no longer cope with their needs⁹⁷.
- The Wandsworth 2011 Census shows 24.6% of carers say their health is fair, bad, or very bad compared to 11.4% who are not providers of care⁹⁸.
- The risk of poor health increases with the number of hours of unpaid caring, 18.7% of those who do 1–19 hours per week, and 40.6% of those who do 50+ hours per week⁹⁹
- The risk of poor health also increases with age
- 48% of carers aged 65+ reported having fair, bad or very bad health compared to 22% of carers aged 25 to 64¹⁰⁰
- 37% of carers in Wandsworth have had to see a GP for health issues relating to their caring duties in the past 12 months¹⁰¹.
- 4.7% of carers in Wandsworth reported their caring responsibilities had no effect on their health. This is slightly lower than other South London Boroughs, an average of 5.9%¹⁰².
- 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.

Employment / Income / Cost of Living

Work has an important role in promoting and protecting mental well-being. It is an important determinant of self-esteem and identity. It also provides a sense of fulfilment and opportunities for social interaction, and income. However, without adequate support, working and caring together can have a considerable detrimental impact on 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'¹⁰³.

There are 4.27 million carers of working age living in the UK. The employment rate for carers is 67% and over half of those who are not working say they would like to do so. One in eight workers is a carer. One in three carers gives up employment because of their caring responsibilities. 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 unemployment¹⁰⁴.

Over half of carers have had to borrow money due to their caring responsibilities. Of these, three out of five have borrowed from friends or family, others 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 property¹⁰⁵.

⁹⁵ ONS (2011)

⁹⁶ Carers UK (2019), Equality and Human rights Commission (2010), NHS Digital (2016) and Pinquit (2007)

⁹⁷ ONS (2011)

⁹⁸ *ibid*

⁹⁹ *ibid*

¹⁰⁰ *ibid*

¹⁰¹ NHS Information Centre (2019).

¹⁰² NHS Information Centre (2019).

¹⁰³ ONS (2011)

¹⁰⁴ Carers UK (2019)

¹⁰⁵ *ibid*

Social cohesion

Social cohesion refers to the strength of community relationships, levels of participation in community activities, and public affairs. It also refers to social contacts and networks (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.

Carers often experience feelings of isolation and resentment. They can become disconnected from friends and families, and carers are unlikely to have the time to socialize or enjoy their own hobbies. Research also suggests being a carer can influence the ability to participate in social activities. In Wandsworth 17% of carers in contact with social services report having as much social contact as they want, while 28% report they have little social contact and feel socially isolated¹⁰⁶.

Carers receiving services and support

There were over 1,100 carers known to Wandsworth Adult Social Care Services in December 2019, and over 4,700 known to the Carers Centre, **Table 10**.

Table 10: Known Wandsworth carers

	Number of adult carers
Carers known to Wandsworth Adult Social Care Services Dec 2019	1,105
Carers known to the Carers Centre Dec 2019	4,742
Carers on the GPO register Dec 2019	2,737
Carers receiving assessments Apr-Dec 2019	389
Carers receiving assessments 2018–19	691
Carers receiving GP Carer consultation Apr-Dec 2019	1,394
Carers Centre referrals Apr-Dec 2019	501

Source: internal figures

An increasing number of residents with caring responsibilities are choosing not to register with the services. In preference, they “dip in and out” when support is required. 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.

COVID-19

The pandemic is on-going, the full impact is not yet known. However, there is some evidence unpaid carers have been affected significantly by COVID-19.

There has been an 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%¹⁰⁷.

During the pandemic, day and evening services have been closed and other services have been reduced. This has meant that many unpaid carers have been left without support channels, having to take on more caring responsibilities. On average carers have had to undertake an additional 10 hours of caring activity a week¹⁰⁸.

¹⁰⁶ Brodaty (2009) and Cabinet Office (2006)

¹⁰⁷ Carers Week (2020), ONS (2020) and The Young Foundation (2020)

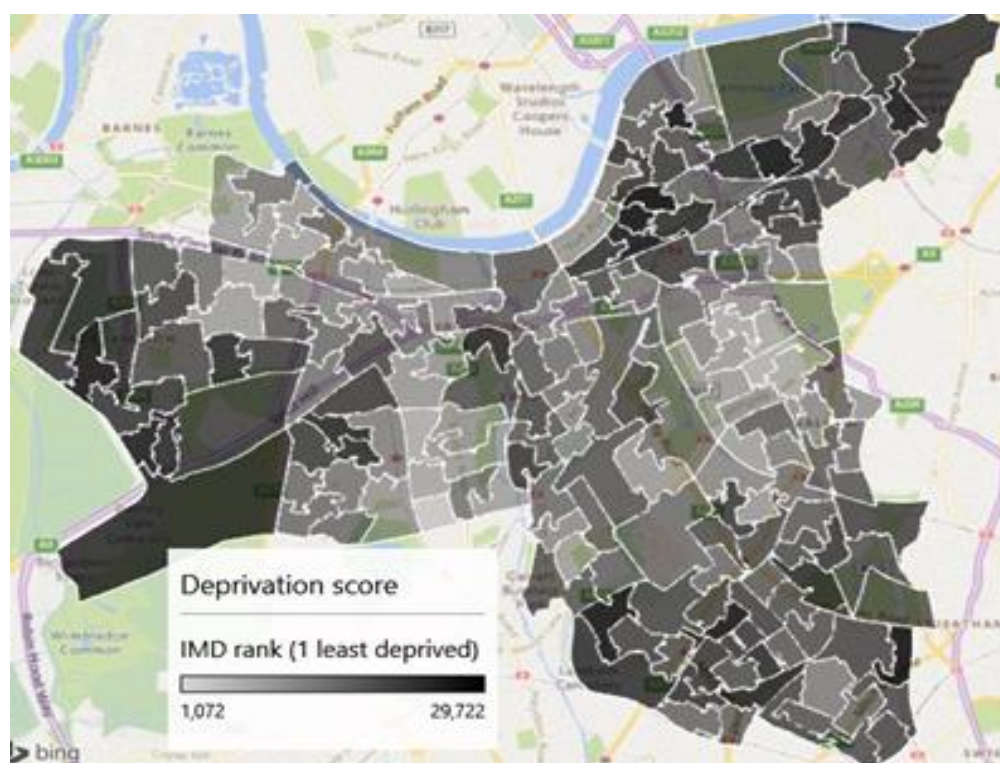
¹⁰⁸ Ibid

Deprivation

The percentage of residents who provide unpaid care is associated with deprivation. Wandsworth has pockets of deprivation and pockets of affluence. Some areas are amongst the least and most deprived in the country¹⁰⁹ (Figure 5).

Southfields, Thamesfield and Northcote, have areas counted in the least deprived (20%) of the country. Latchmere has areas that are amongst the most deprived. Level of carer need is, therefore, likely to be higher in these more deprived areas compared with more affluent areas. There are carers living throughout the Borough but the highest proportion of the population who are carers are living in West Putney and Furzedown. There are also families and individuals throughout other parts of the Borough who are experiencing above average levels of deprivation and greater needs¹¹⁰.

Figure 5: Deprivation in Wandsworth



Source: IMD, 2019

4.4 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 include¹¹¹:

- physical disability (58%),
- sight or hearing loss (20%),
- mental health problems (13%),
- learning disability (11%)
- dementia (10%).

The conditions of cared for people often dictate the types and duration of caring activities.

¹⁰⁹ Wilkinson (1996) and DCLG (2019)

¹¹⁰ Ibid

¹¹¹ NHS Information Centre (2010)

This breakdown does not fully represent all the care requirements. 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 no category for those with multiple long-term conditions, they would be included in 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 the commissioning and delivery of services tailored to individuals' requirements.

Most carers provide care for older people. In 2020, 10% of Wandsworth residents were aged over 65 years. A vast majority of older people live in the community, (96.6% were aged 65 years, 93.7% aged 75 years and over, ONS, 2011). The percentage of people over 65 years in Wandsworth is projected to increase to 14% in 2050¹¹².

4.5 Limitations to the Data

The true prevalence of caring can only be estimated due to the invisibility of some carers within communities. A proportion of carers will not identify themselves as a carer as they see themselves as simply completing their duties. Groups where identification is low includes parents and sandwich carers. Young carers may be reluctant to identify themselves for fear of repercussions.

There are gaps in the understanding of the needs of carers of autistic people and co-morbidities, and those carers who are in employment. Further development of the assessment process should include how to manage expectations and how to improve access to universal support services.

4.6 Current Services

Carers Partnership Wandsworth is the main provider of local carer support services. It is made up of four partners who work together, and with other agencies, to provide high quality services.

The four partners are:

- Wandsworth Carers Centre
- Alzheimer's Society (SW London Branch)
- Bluebird Care Wandsworth
- Carer Representatives.

The services provided include:

- Information, advice, and advocacy
- Peer support
- Carer's respite
- Back care and therapies
- Health and social care liaison and training.

Young carers (children and young adults) have the same right as other children to enjoy life as fully as possible. Young carers may have different needs to other carers. Specific services for this group in Wandsworth include:

- Carers Trust
- Children's Society
- Youth Legal.

In addition, other services that can benefit carers, especially those struggling to balance their own needs with their caring role, include:

- GP surgeries
 - annual carers consultation
 - a register of all patients identified as carer
 - referrals to Wandsworth Carers Centre

¹¹² GLA, (2019) and ONS, (2011)

annual flu vaccinations for all registered carers

- Community pharmacies
- Dental practices
 - Special Care Dental Service is available for adults and children with complex needs who have difficulty in getting treatments in a local dental practice for reasons other than cost
- Community health services
 - complex case management
 - facilitating independence
 - scheduled and ongoing care
 - specialist input
- Wandsworth Well-being Hub
 - Advice and support for ongoing conditions.

The Carer Assessment Process enables people to move between services. A personal improvement plan is created to increase the number assessments, address key requirements, manage expectations, and record objectives and outcomes. In addition, training on best practice and legal requirements relating to carer assessments is available.

Current young carer recording mechanisms are not synchronised and fail to indicate the total number of young carers through the Single Point of Access (SPA) scheme. Therefore, a review of the systems and pathways for young carers is being conducted to improve the identification of young carers.

Planning for the expected increase in carers will be a Wandsworth priority.

Acronyms

ABI	Acquired Brain Injury
ADD	Attention Deficit Disorder
3Di	Developmental, Dimensional and Diagnostic Interview
ADHD	Attention Deficit and Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview-Revisited
ADOS	Autism Diagnostic Observation Schedule
APMS	Adult Psychiatry Morbidity Survey
AQ	The Autism-Spectrum Quotient Test
AQ	Autistic-spectrum Questionnaire
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
DISCO	Diagnostic Interview for Social and Communication Disorders
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
MDT	Multidisciplinary Diagnostic Team
OCD	Obsessive, Compulsive Behaviour
PDA	Pathological Demand Avoidance
PSR	Primary Support Services
SEND	Special Educational Needs and Disabilities
WAAS	Wandsworth Autism Auditory Service

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