

# Joint Strategic Needs Assessment 2023

For people with a learning disability and/or autism in Surrey



This report tells us about the lives of people with learning disabilities in Surrey. It says what needs to improve.



**Healthy lives**



**The right support**



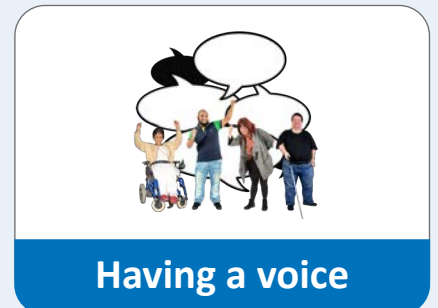
**The right home**



**Feeling safe**



**Work and learning**



**Having a voice**



**Surrey Heartlands**  
HEALTH AND CARE PARTNERSHIP





# Our vision for Surrey

## Our vision.

*By 2030, we want Surrey to be a uniquely special place where everyone has a great start to life, people live healthy and fulfilling lives, are enabled to achieve their full potential and contribute to their community and no one is left behind.*

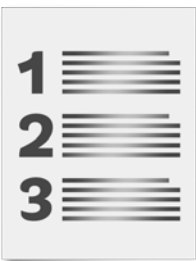
## We want people with a learning disability to:



- Feel safe and confident.
- Have good education, skills and employment support.
- Be healthy and active.
- Make good choices about their health and well-being.
- Get the health and social care information and support they need.
- Have a happy and fulfilling life.



We want communities in Surrey to be welcoming and supportive of people with a learning disability.



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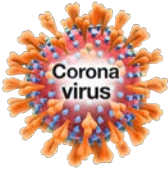
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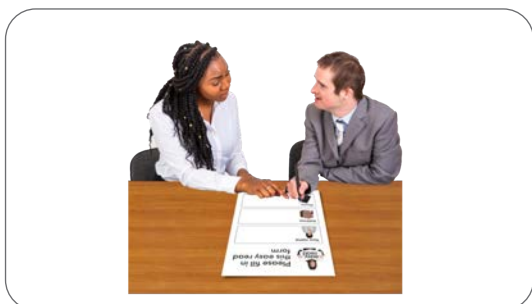
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# 1. People with a learning disability in Surrey

The number of adults with a learning disability in Surrey is likely to increase by from 21,980 in 2023 to 22,971 in 2040.

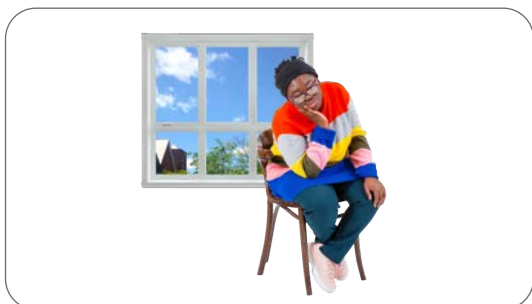
The International Classification of Disease says that a person with an IQ less than 70 has a learning disability.



People with a learning disability often find it hard to understand information. learn new skills and live fully independently.



Some people with a learning disability only need a little support and others may need a lot of support.



Not everyone who has a learning disability is diagnosed. This means those people may not get the support they need.



The Down Syndrome Act 2022 aims to make people with Down's Syndrome lives better and help them get support. We think there are around 446 adults in Surrey with Down's Syndrome.

## A learning disability is not the same as a learning difficulty.



A person with a learning difficulty will have an IQ of 70 or more but finds certain things difficult. For example, a person who has dyslexia will find reading and writing difficult.

## We think that 10% of people with a learning disability are autistic.



This is much higher than the percentage of the general population who are autistic.

Surrey has an All-Age Autism Strategy. [Click here](#) to find it.

## We think around 315 adults with a learning disability (aged 18 to 64 years) in Surrey will have challenging behaviour.



Challenging behaviours can cause harm to themselves or others. This can make it hard for people to go out in their local community.



We want to make sure people who have challenging behaviours get the right support so they can enjoy their local community.

## Making sure everyone is included.

At the moment we think that people from some communities are less likely to the support they need.



We have been talking to people from the Gypsy, Roma and Traveller (GRT) communities about how we offer support to people with a learning disability.



It is important that people with a learning disability from all ethnic backgrounds have equal access to services and support.

## Recommendations.

These are things we think needs to happen to make things better.



- To review how we diagnose people with a learning disability so that more people get the diagnosis they need.
- To think about whether people should need a learning disability diagnosis before they can get support from services.
- To make sure that education, health and care services notice and highlight that someone has a learning disability when they are young, so support can be planned for their future.
- For services in Surrey to follow the Government guidance about supporting people with Down's Syndrome.

## Recommendations continued.

- To improve the records kept about the ethnicity of people using health services in Surrey.
- To find out more information about people with a learning disability who are lesbian, gay, bisexual, transgender, queer (LGBTQ) and gender diverse to make sure they are treated equally.







## 2. Health services and people with a learning disability

### Digital flags.

Health services can use 'digital flag' in their patient records to make sure that staff know a patient has a learning disability or is autistic and the support they need to use the service.



By March 2024 all NHS services should use a 'digital flag' in their patient records.

### The NHS learning disability improvement standards.

These standards aim to make the quality of health services better for people with a learning disability and autistic people.



#### The four standards are:

1. Giving people their rights.
2. Involving people and listening to them.
3. Making sure we have the right staff with the right training.
4. Good specialist health services for people with learning disabilities.

[Click here](#) to go to the website for the standards

## Learning Disability Registers.

Learning disability registers are lists of children, young people and adults who have a learning disability.



The register is used by GP Surgeries to make sure that people with a learning disability get the right support.

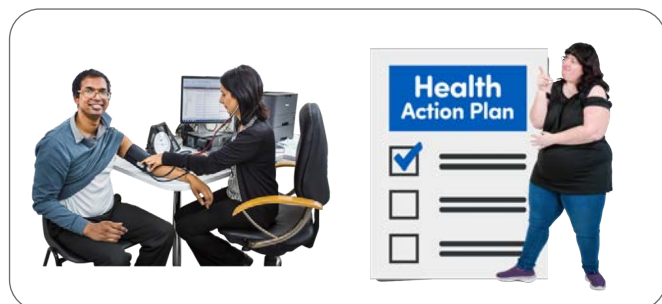


Public Health England say that only 23% of adults with learning disabilities in England are on learning disability registers.

We think there are around 22,000 adults with a learning disability in Surrey. Around 5,000 people are on our learning disability registers.

## Annual health checks and health action plans.

People aged 14 or over who are on their GP Surgery learning disability register can have an annual health check and health action plan to help them stay healthy.



In March 2022 we found that 75% of people who could have an Annual Health Check had been given one.

People with a learning disability who live at home with their family are less likely to have an annual health check.

## The Learning Disability Primary Care Liaison Service.

This service offers support to adults with a learning disability age 18 and over who are registered with a GP in Surrey.



### The nurses help people to:

- Find health information that's easy to read.
- Get the right support and treatment.
- Use the NHS cancer screening programmes.
- Have an Annual Health Check and a Health Action Plan.

## The Learning Disability Acute Hospital Liaison Service.

This service offers support to adults with a learning disability to get the right support from hospitals in Surrey.

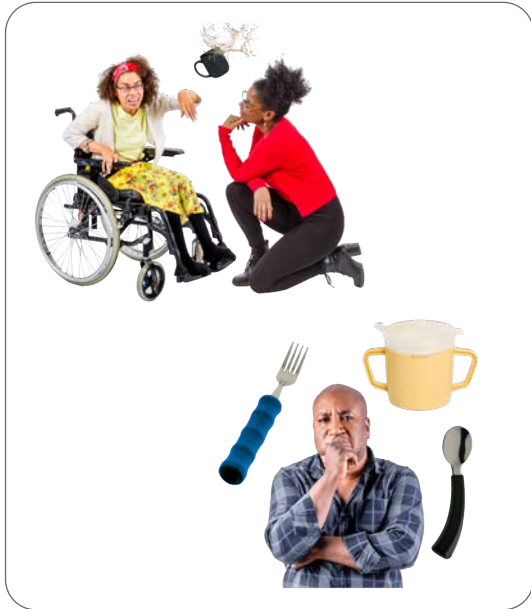


### The nurses help people to:

- Get the right care in hospital.
- Make choices about their treatment.
- Attend outpatient appointments.
- Make plans to go home from hospital when well enough.

## Community Learning Disability Teams.

These teams offer specialist health support to adults with a learning disability. The teams have staff including nurses and therapists.



They support people with a wide range of needs including:

- Challenging behaviour.
- Communication.
- Mobility.
- Eating, drinking and swallowing.

## Recommendations.

These are things we think needs to happen to make things better.



- To make sure the NHS learning disability improvement standards are applied to all NHS-funded care by 2023/24. We can use the information from progress reports to share good practice and help to make sure people in all areas of Surrey can access similar support.
- To make sure that health and social care staff receive the Oliver McGowan training on learning disability and autism.
- We will continue to increase the number of people of all ages with a learning disability on the GP Register. This will mean they could have an annual health check and a Health Action Plan.

## Recommendations continued.

- To offer support to help more people to have annual health checks and a Health Action Plan.
- To talk about whether the acute liaison service should also support younger people with a learning disability.
- To talk about whether the acute liaison service should also support autistic people who don't have a learning disability.



## Health Inequalities.

A health inequality is when one group of people are less healthy compared to other people and when this can be avoided.

Health inequalities are unfair.



People with a learning disability have health inequalities compared to people who don't have a learning disability.



Two public health leads have been recruited to help to reduce the health inequalities for people with a learning disability.

## Life expectancy – based on 2018/19 research.



Males with a learning disability have a life expectancy of 66 years.

This is 14 years lower than the average for males of 80 years.



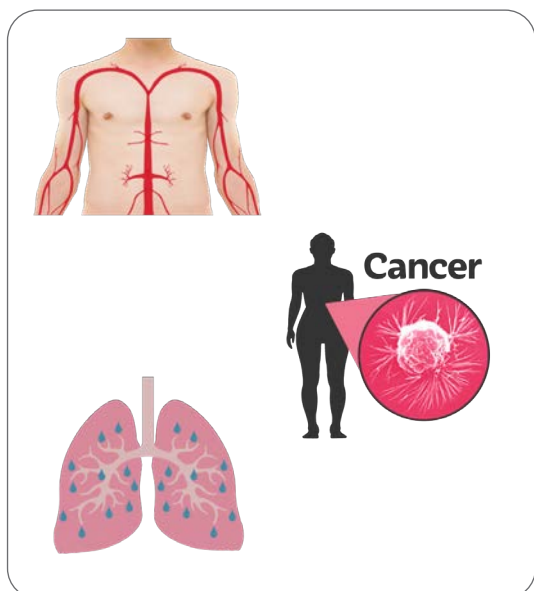
Females with a learning disability have a life expectancy of 67 years.

This is 17 years lower than the average for females of 84 years.

## Finding out why people have died.

LeDeR started in 2018 and is a project that reviews the deaths of people with learning disabilities and autism across England.

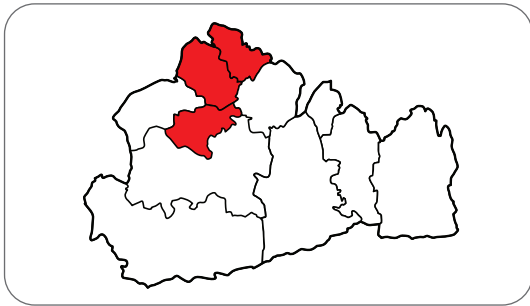
[Click here to go to our three-year LeDeR strategy that shows how we will tackle of health inequalities for people with a learning disability.](#)



In Surrey, people with learning disabilities die most commonly from respiratory, circulatory, and cancer related deaths.

LeDeR has found that people with learning disabilities are three times more likely to die from a cause that could have been avoided.

## North-West Surrey.



People with a learning disability living in North-West Surrey often have poorer health than people living in other areas of Surrey.



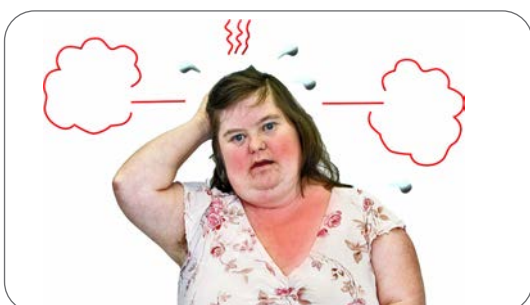
People from North-West Surrey are also less likely to have an Annual Health Check.

## Learning disability and gender.



Women with learning disabilities in Surrey are much more likely than men to be overweight.

Women who don't have a learning disability are less likely to be overweight than men.



We think that women with a learning disability may need more support with managing the effects of the menopause.

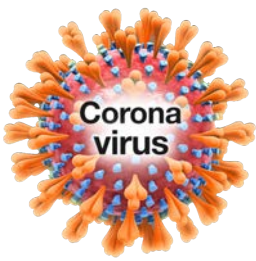
## Recommendations.

These are things we think needs to happen to make things better.



- To set up a health inequalities group to work on reducing the health inequalities for people with a learning disability and autistic people.
- To find out whether people with a learning disability find it harder to access health services than other people.
- To give more support to North-West Surrey to make sure people with a learning disability have annual health checks.
- To improve support for women with a learning disability to manage the menopause and weight gain that can happen as a result.

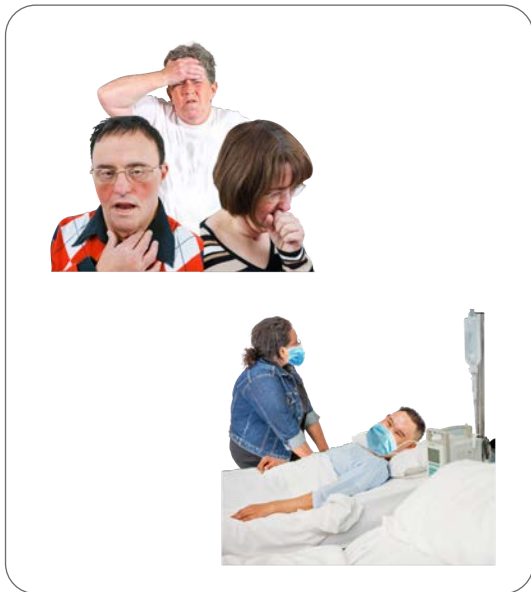




### 3. The COVID-19 pandemic and people with learning disabilities

#### Health inequalities during the pandemic.

The COVID-19 pandemic showed us examples of how people with a learning disability have health inequalities.



Compared to other people, people with learning disabilities were more likely to:

- Catch COVID-19.
- Become very ill with COVID-19.
- Be admitted to hospital with COVID-19.
- To die from COVID-19.

#### (DNACPR) - Do Not Attempt Cardiopulmonary Resuscitation orders.

There were reports that some hospitals in England were deciding that people with a learning disability should not get treatment to try to keep them alive if their heart or breathing stopped.



They were not checking that this was in the person's best interest.

In Surrey we found that ‘Do not attempt cardio-pulmonary resuscitation orders’ were done correctly and followed in 77% of the LeDeR reviews.



We worked across health and social care services to improve the situation.

## COVID-19 Vaccination.

During the pandemic vulnerable people were the first people given the vaccine, but people with a learning disability were not on the list of vulnerable people at the start.



86.5% of the 5,144 people with a learning disability on the GP registers in Surrey received two COVID-19 vaccination doses and a booster jab.

This was a higher percentage of people than in the rest of the South-East Region of England.

## Recommendations.

These are things we think needs to happen to make things better.



- To find out more about the experiences of people with a learning disability during the pandemic to help us plan for any future pandemics.
- To find out if mass vaccination centres can record people with learning disabilities and use the learning disability digital flag.



## 4. Physical health and people with learning disabilities

### Smoking.

People with a learning disability are slightly less likely than other people to be smokers.



Research from 2021/22 showed that men with a learning disability were more likely to smoke than women with a learning disability.

### Exercise and diet.

The number of people with learning disabilities in Surrey having an assessment of their diet and physical activity increased from 24% in 2018/19 to 32% in 2021/22.



The number of people with a learning disability in Surrey who are overweight fell from 63% in 2018/19 to 58% in 2021/22.

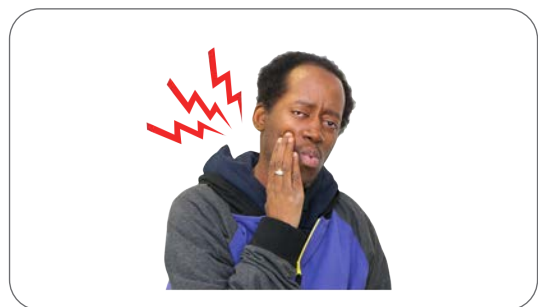
### Flu Vaccination.



More people with a learning disability are having a flu vaccination. Around 6 out of 10 people now have the vaccine each year. This has increased from less than 3 in 10 people in 2016.

## Teeth and gums.

Research shows that people with learning disabilities have more problems with their teeth and gums than other people. They also have more problems visiting a dentist.



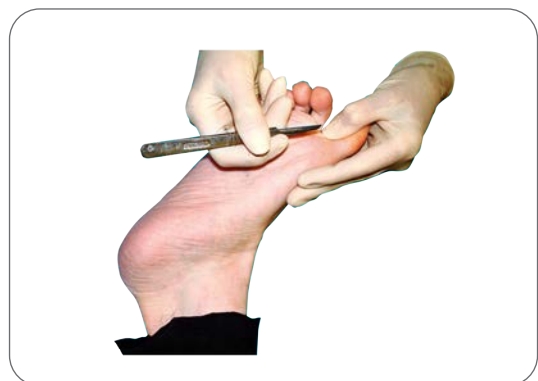
Some people with learning disabilities may not know they have problems with their teeth and gums.



They may rely on other people to notice and make dentist appointments for them. Some staff may not always see dental care as very important.

## Foot care.

More people with a learning disability have problems with their feet than other people. It is important that people have the foot care (podiatry) they need.



There are podiatry services in all parts of Surrey, but only East Surrey has a learning disability podiatrist.

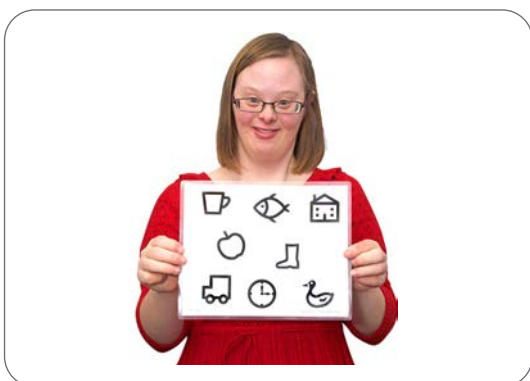
## Hearing loss.



We think around 4 in 10 adults with a learning disability have moderate to severe hearing loss.

## Sight problems.

Adults with learning disabilities are 10 times more likely, and children are 28 times more likely to have serious sight problems than other people.



With the right support everyone can have a sight test.



People who need a lot of support are most likely to have sight problems.

They may not know they have a sight problem and may not be able to tell people.

People supporting them often think they can see very well.

## Recommendations.

These are things we think needs to happen to make things better.



- To make sure support to help people stop smoking is accessible for people with a learning disability. We need to offer more support to people living in North-West Surrey.
- To help more people with a learning disability aged 14 to 29 get support for their exercise and diet.
- To get better information about how to support people with a learning disability in Surrey to do more physical activity.
- To do more work to understand how best to make sure that everyone with a learning disability can get support to go to the dentist.
- To work with specialist dentistry to think about collecting information about the needs of people with a learning disability.
- To find out more about the support given to people with a learning disability in Surrey to look after their sight.
- To find out whether people get the help they need to have an eye test.
- To find out more about the support given to people with a learning disability in Surrey to look after their hearing.
- To find out whether people get the help they need to have a hearing test.
- To find out more about the support podiatry services give people with a learning disability in Surrey.
- To find out whether having a learning disability podiatry service makes the service better in East Surrey.

## 5. Health conditions and people with learning disabilities



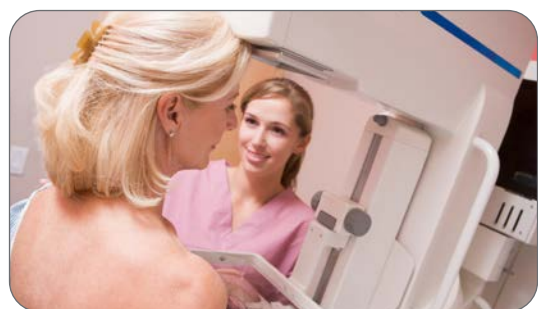
### Cancer and cancer screening.

**Fewer people with learning disabilities in Surrey died from cancer than expected in 2021/22.**

People with learning disabilities are much less likely to have cancer screening than other people. People living in some areas of Surrey are more likely to be screened than others.



The number of people with a learning disability having cervical and breast cancer screening has not increased in Surrey over the last 4 years.



36% of people with learning disabilities who were eligible in North-West Surrey had breast screening, but only 14% in East Surrey.

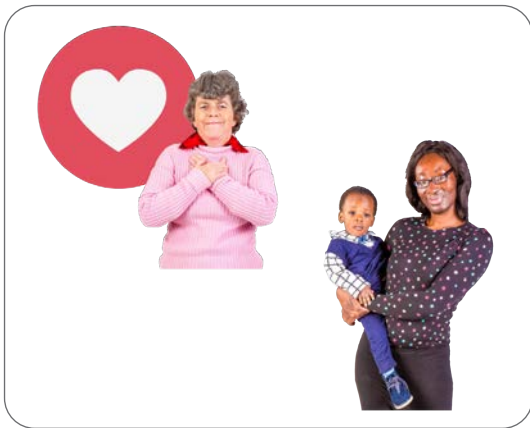
### Recommendations.

**These are things we think needs to happen to make things better.**

- To make screening easier for people.
- To increase the number of people with a learning disability being screened by sending Easy Read information that explains why it is important and what happens.



## Sexual health and pregnancy.



Having a private life, relationships and possibly having a child is important to many people with a learning disability.

The national survey of adults with learning disabilities in England (2003/04) found that 9% of women with learning disabilities had a child.

## Recommendations.

These are things we think needs to happen to make things better.



- To make sure services better understand the needs of people with a learning disability regarding sex and relationships.
- To make sure sexual health and pregnancy services are accessible for people with a learning disability.
- To find out how many people with a learning disability who have a child in Surrey and learn from their experiences.

## High Blood Pressure (Hypertension).

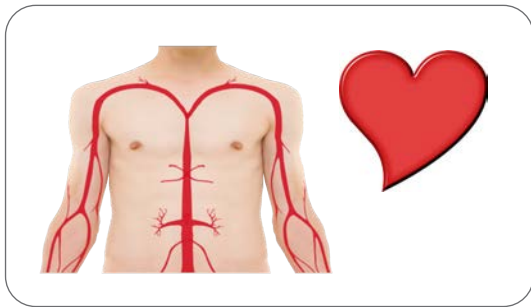
People with learning disabilities in Surrey are slightly more likely to have high blood pressure than other people.



People with a learning disability aged 35 to 54 are around twice as likely to have high blood pressure than other people in that age range.

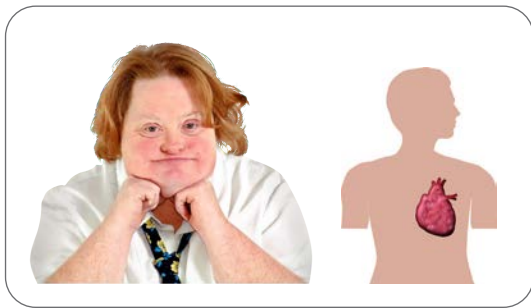


## Cardiovascular Disease (CVD).



Cardiovascular disease (CVD) is the name for conditions that affect the heart or blood vessels and is one of the main causes of death and disability in the UK.

**Adults with a learning disability may be more likely to get CVD than other people, and also get it earlier in their life.**



Having problems with how their heart works (congenital heart anomalies) is a much more common cause of death for people with Down's syndrome than for other people.

**Cardiovascular disease can be prevented by leading a healthy lifestyle.**



**Things that increase people's risk of Cardiovascular disease include:**

- High blood pressure (hypertension).
- Smoking.
- Diabetes.
- Obesity (being very overweight).

## Type 2 Diabetes.

People who have a poor diet or overweight are more likely to have Type 2 diabetes. People with learning disabilities in Surrey are more likely to have type 2 diabetes than other people.



Since 2016 the number of people with a learning disability who have Type 2 diabetes has increased from 1.8% to 2.1%.

Helping people to have healthier lifestyles is the best way to stop people getting Type 2 diabetes. North-West Surrey is where the highest proportion of people with a learning disability have diabetes, smoke and are overweight.

## Recommendation.

These are things we think needs to happen to make things better.



- To make sure diabetes services are accessible for people with a learning disability and are promoted to younger adults and people in North-West Surrey.

## Postural care.



People with profound and multiple learning disabilities often sit and lie in positions which can lead to their body shape becoming distorted.

Because of their body shape being distorted, these people are at high risk of health problems including breathing difficulties, swallowing difficulties and hip problems.



The right equipment and support helps to protect their body shape, and if they get help when younger it can prevent the need for surgery.

## Recommendations.

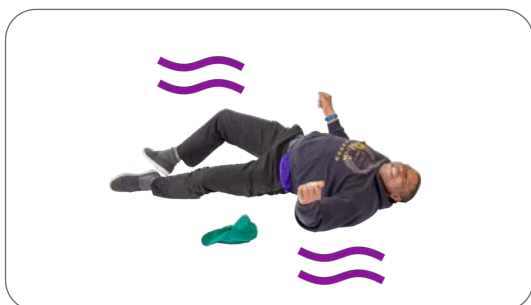
These are things we think needs to happen to make things better.



- To find out more information about the postural support that is offered to people with a learning disability in Surrey.
- To find out who may need postural care.

## Epilepsy.

Research shows that up to 22% of people with learning disabilities have epilepsy compared to 0.4 to 1% of people without a learning disability.



In Surrey around 17% to 18% of people with a learning disability have epilepsy.

## Recommendation.

- To make sure people use our guidelines on how to manage epilepsy in people with learning disabilities.

## Ageing.

People with learning disabilities are living longer.



We think that by 2030 there will be a 30% increase in the number of adults with learning disabilities aged 50 and over. Many more people aged over 80 will need social care services.

## Recommendation.

These are things we think needs to happen to make things better.



- To plan for the support more older people with a learning disability will need in the future.

## Dementia.

Dementia affects people with a learning disability at a younger age.



People with learning disabilities aged over 60 are two to three times more likely to have dementia than other people their age.

In Surrey, we think that there are around 105 people with a learning disability who have dementia, but care providers think there may be more people than this.

We think that the numbers of people with a learning disability who have dementia will increase by 28% by 2030.



Health services in Surrey offer dementia assessment, diagnostic and support service for people with Down's syndrome.

The service supports 54 adults with Down's syndrome diagnosed with dementia and a further 32 adults with a learning disability.

## Recommendation.

These are things we think needs to happen to make things better.



- To work with care providers to find out an accurate number of people with a learning disability who have dementia in Surrey.



## 6. Medication and people with learning disabilities

### Medication.

We funded a pharmacist to carry out medication reviews for adults with a learning disability in residential homes.



This was to make sure people were not being given more medication than they needed to stay well and have a good quality of life.

### Recommendations.

These are things we think needs to happen to make things better.



- To decide about funding our plan for how services can work together to make sure that all adults with a learning disability have their medication reviewed.
- To decide about funding a similar project to check the medication that is given to children and young people with a learning disability.



## 7. Mental health and people with learning disabilities

### Mental health problems.

Research suggests that more people with a learning disability may have mental health problems than other people.

Some people with a learning disability can use the same mental health services as people who don't have a learning disability.



People can also get support from the psychologists within the Community Teams for People with a Learning Disability as well as other therapies including art, drama and music therapy.



[The Green Light Toolkit](#) can help us to make mental health services more accessible for people with learning disabilities and autistic people.

### Recommendations.

These are things we think needs to happen to make things better.



- To urgently decide whether to start using the Green Light Toolkit in Surrey.
- To make sure that services in Surrey understand and make plans for the proposed changes to the Mental Health Act.

## Mental health inpatient services and people with a learning disability.

People with mental health problems can be at risk of admission to inpatient services for treatment.



Some people may show challenging behaviour because of the mental health problems they have.



In Surrey we have met the NHS target for reducing the numbers of people with a learning disability and/or autism being cared for in inpatient services.

## How we plan to prevent people being admitted into inpatient services.

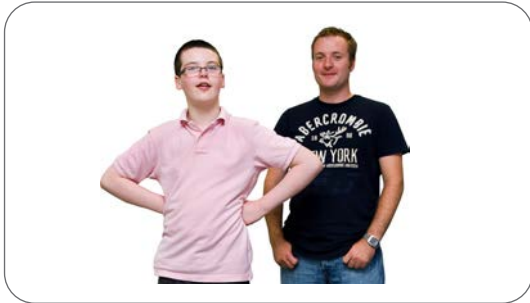


We want to make sure that people get the support they need in the community so they do not need to be admitted to an inpatient service.





We have a register of children and adults with a learning disability and/or autism who might be at risk of being admitted to an inpatient service because of challenging behaviours or mental health problems.



Children and young people aged 0 to 25 who have a learning disability and / or autism with the most complex needs will have a keyworker to make sure they have the right support.



We set up the Integrated Intensive Support Service (ISS) in 2016 to give people extra support in the community to prevent them being admitted to inpatient services.

## Recommendations.

These are things we think needs to happen to make things better.



- To agree whether the ISS Service needs to be supporting people at weekends as well as Monday to Friday.
- To regularly review our register of people at risk of being admitted to an inpatient service.

## How we are supporting people in inpatient services.



**We have an inpatient service in Surrey called The Deacon unit.**

It has 10 beds for people with a learning disability who need crisis mental health support.



We visit inpatient services regularly to check they are offering good quality care.



If someone is admitted to an inpatient service we review their support very quickly to make sure they are getting the treatment they need to get better.

We help people to be able to move back into the community as soon as possible.



## 8. Social care and people with a learning disability

**Social care is the support people need with things including:**



- Eating and drinking.
- Washing and dressing.
- Taking part in activities.
- Learning new skills.

**Social care for children.**



In 2022 there were 550 Surrey children with a learning disability who have social care support.

This has increased from 378 in 2018.



In January 2022 there were 11,747 young people who had an Education, Health and Care Plan (EHCP) which gives them extra support at school or college.

## Social care for adults.

In 2022 there were 4,156 Surrey adults with a learning disability who have social care support.



Most people get the support they need in Surrey, though around 586 people live outside of Surrey.



Between 2018 and 2022 the number of people with a learning disability needing adult social care from Pakistani and Bangladeshi communities increased by 39.1%.

## Recommendations.

These are things we think needs to happen to make things better.



- To find out why there has been an increase the numbers of people needing support from Pakistani and Bangladeshi communities.
- To make sure we understand their cultural needs and provide the right services.

## Advocacy support.

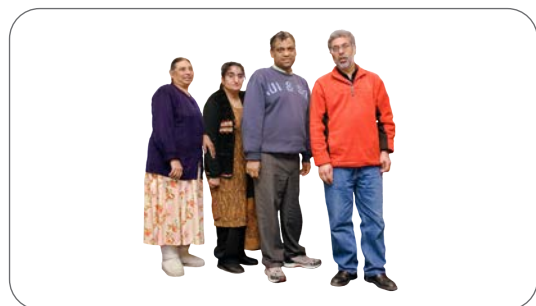
The Care Act 2014 says that people must be involved in decisions made about them and their care and support.



Some people need an independent advocate to help make sure their voice is heard.

There are independent advocacy services for both children and adults in Surrey.

## Safeguarding.



Referrals to adult safeguarding more than doubled for adults with learning disabilities between 2015 and 2019.

## Recommendation.

These are things we think needs to happen to make things better.



- To find out why safeguarding referral have increased and plan what we need to do to make sure we keep people safe.

## Domestic abuse.



People with learning disabilities and autistic people are thought to be three times more likely to suffer domestic abuse than other people.

## Recommendation.

These are things we think needs to happen to make things better.



- To find out more information about people with learning disabilities who suffer domestic in Surrey to help us make sure they get the right support.

## Hate crime and mate crime.

People with learning disabilities can be victims of crime because they have a learning disability.



Mate crime is when someone pretends to be a friend but commits a crime such as stealing their money.

Out of all the Safeguarding investigations carried out between September 2021 and August 2022, eight crimes against people with a learning disability were a recorded as a mate crime.



## 9. Other issues for people with a learning disability

### Where people with a learning disability live in Surrey can affect their health.

People who live in poorer areas of Surrey are more likely to have worse health.



People with a learning disability who live further away from a town are less likely to be overweight.



People living in residential care are more likely to have an annual health check and less likely to smoke.

### Recommendation.

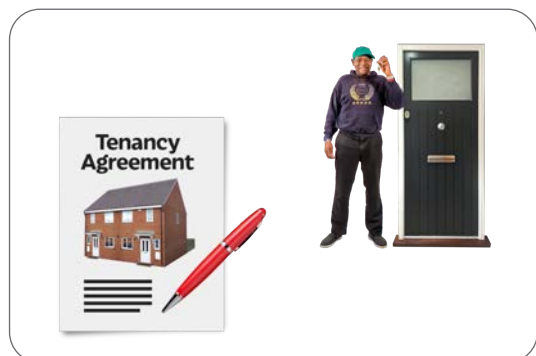
These are things we think needs to happen to make things better.



- We need more information to understand the impact of deprivation including food and fuel poverty.

## Housing.

Surrey County Council aims to reduce the numbers of people with learning disability and/or autism living in residential care by 40-50% over the next 5 years.



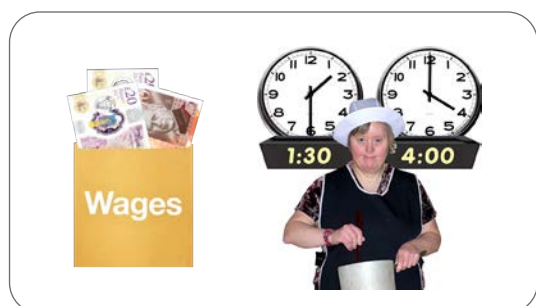
More people will have the chance to live in supported living services. Supported living is a better choice for some people with a learning disability as they have more rights and choice.



Between October 2019 and December 2022 the number of people with a learning disability living in residential care reduced from 987 to 867.

## Employment.

We have a target to help 19% of people with learning disabilities into employment or volunteering.



The number of people with a learning disability in paid employment has increased from 7.7% to 13.4% since 2014.



We have services to help people into employment as well as supported internships and apprenticeships for younger people.



## Day opportunities.

We have a commissioning manager to work on Community Inclusion.



We are reviewing the day opportunities available for people with a learning disability.

We want to offer more choice and help increase people's independence.

## Crime, the Police and the courts.

Across the Criminal Justice System (police, courts, prison and probation) work needs to be done to make sure we identify people with learning disabilities and/or autism and support them.



We don't know enough about people with a learning disabilities experience of the police and court system in Surrey.

It is not clear if people with learning disabilities and/or autism are always identified and supported.



Some people with a learning disability and/or autism who commit crimes are placed in secure inpatient services.

The numbers screened for learning difficulties and/or disabilities in prisons in Surrey is unknown.



Research tells us that 7% of people in prison have a learning disability.

From April 2019 prisoners should be screened for learning difficulties and/or disabilities when they arrive in prison and be given extra support.

## Recommendations.

These are things we think needs to happen to make things better.



- To get better information about how people with learning disabilities get support from the Police.
- To get better information about people with a learning disability in prison and make sure they have the support they need.

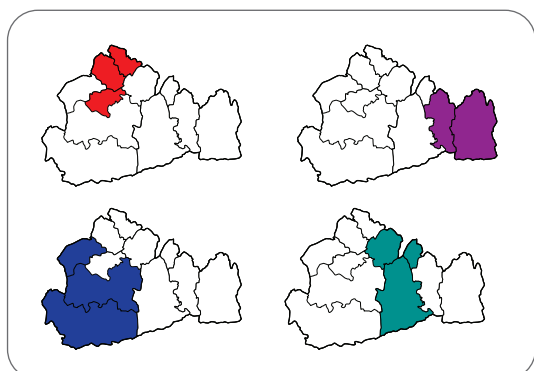
## Having your say.

People with a learning disability, autistic people and carers in Surrey must have a say in how services and their local communities develop.



### Surrey People's Group.

Is a self-advocacy group for people with a learning disability in Surrey where people can talk about issues that are important to them.



### Local Valuing People Groups.

Surrey has four Local Valuing People Groups which involve service providers, people with a learning disability and family carers. The groups talk about issues in their local areas.



### The Learning Disability Partnership Board in Surrey.

The board involves managers from health, social care and community organisations as well as people with a learning disability and family carers to talk about surrey wide issues.



### **The Surrey Autism Partnership Board.**

The board involves managers from health, social care and community organisations as well as autistic people and family carers to talk about Surrey wide issues. The board also has a reference group for autistic adults.



### **Carer voice.**

The Carers Partnership Board was changed in April 2022 and a Disabilities Sub Group is planned.



### **Provider voice.**

There is a learning disability and autism Network of Surrey Carers Association (SCA). Members explore how they can offer the best possible services to the people they care for and support.