



Priority Areas

Research questions that the NHS needs answering

www.england.nhs.uk/ourwork/innovation

About this document



This is the easy read summary of Research Demand Signalling National Learning Disabilities and Autism Programme.



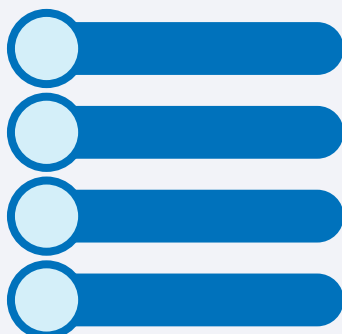
You can read the full, non-easy read document at:

www.england.nhs.uk/aac/what-we-do/how-do-we-do-this/demand-signalling/



Blue words:

When a word or phrase is difficult, it is in **blue writing**. The word is then explained below where it is first mentioned.



This booklet has been divided into sections to make it easier to understand.

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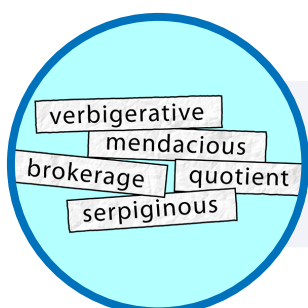
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Introduction



Demand signalling is a way to identify important health research questions that need answering.



We have worked with a lot of different people including people with a learning disability, autistic people, families, carers, researchers and health care professionals.



We have looked at what the NHS Long Term Plan said about learning disability and autism services.



We then identified some priority areas for research questions.

Introduction



Priority areas are things that people think needed to be worked on ahead of everything else.



Priority areas were identified by a range of people during workshops in 2019.



A workshop in June 2021 checked if the priority topics were still the most important.



The priority areas will be shared with researchers and **research funders** to look in to.

Research funders give money to researchers so they can do projects.

What types of services are included?



NHS services that are designed for autistic people or people with a learning disability.

For example, community health nurses.



Physical healthcare services used by everyone, including autistic people or people with a learning disability.

For example, dentists.



Mental healthcare services used by everyone, including autistic people or people with a learning disability.

For example, NHS psychological therapies service.



NHS healthcare that is provided in other public services.

For example, school nurses.

What types of services are not included?



Services looked after by local authorities or social services or private sector, such as:



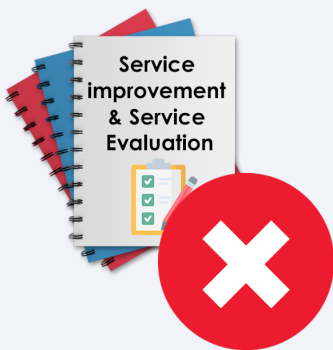
Housing



Education



Training to support employment
(Example, job coaching)



Service improvement and service evaluation (review) projects are not included.

Scientific words and terms



Research questions need to be clear and specific.



This helps researchers work out how to design studies to answer the questions.



Research questions use words which mean specific things in science, but can have a different meaning in everyday life.



Because this document is intended to help guide the drafting of research questions, it uses some scientific words or terms.

Scientific words and terms



All of the Priority Areas listed in this document apply to people with a learning disability and autistic people of all ages.



This includes children and young people and their families and carers, as early **intervention** was raised as an important aspect in the workshops.



In healthcare, the word **intervention** is used to describe any action taken with the aim to try and improve someone's life.



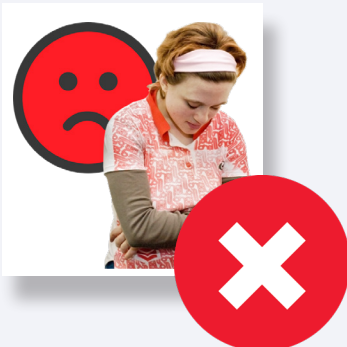
Intervention is a term that can refer to many types of action.

For example, a drug treatment, a sensory assessment or talking therapies.

Priority Area 1: Health Checks



What makes health checks work well for people with a learning disability and for autistic people?



Health checks aim to help stop the **health inequalities** experienced by autistic people and people with a learning disability.



Health inequalities are unfair and preventable differences in health.



This may include difficulties in getting support from NHS services.

Priority Area 1: Health Checks



For many people, COVID-19 made getting support from NHS services harder.



There are many things we need to understand about health checks.



We need to understand how to get more people to make use of health checks.



We need to understand how to make health checks better.

Priority Area 1: Health Checks



We need to understand how to make sure the quality of health checks are always good.



We need to understand how to make health checks easier for all people to access (for example, people in prison people in residential care, homeless people, people from ethnic minorities, and people living in poverty).



We need to understand what is the best way to carry out health checks (for example, face to face or over the phone).



We need make sure everyone has free access to health checks and everyone has a healthcare plan.

People with a Learning Disability



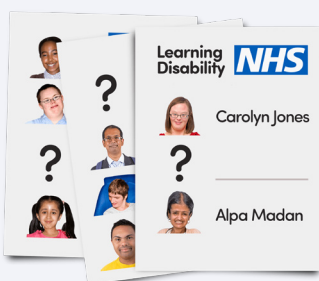
Health checks are effective for people with a learning disability.



It is recommended that people with a learning disability, aged 14 years old and over, are offered health checks every year.



Due to COVID-19, GPs offered annual health checks a lot more people with a learning disability in 2021.



There are concerns that many people with a learning disability are not known to their GP.

Autistic People



In 2017, it was agreed a health check for autistic people was needed.



That health check is now being developed with autistic people and health care professionals.



A trial of the health check for autistic people was started in 2021.



This trial will find out what works best for autistic people'

Priority Area 2: Improving Quality of Life



How can we improve the quality of life of autistic people and people with a learning disability?



We need to find out what helps autistic people or people with a learning disability to live happier, healthier and longer lives.



We can do this by putting support in place for autistic people and people with a learning disability.

We sometimes call the support we give people a support package.



The support packages should be evidence-based.

This means the right thing to do according to research.

What interventions are we interested in?



Interventions should focus on improving things that autistic people, people with a learning disability, and families/carers say are important to them.

Examples could include:



Improving life skills



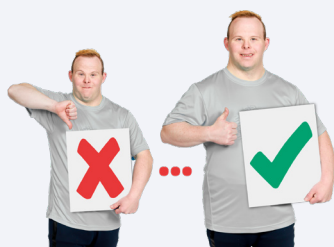
Helping to cope with uncertainty



Developing communication skills



Developing safe eating



Interventions do not 'treat' being autistic or having a learning disability.

Interventions are there to improve the quality of life for autistic people and people with a learning disability.

What interventions are we interested in?



**Sleeping or
exercise habits**



**Being more
independent**



**Support coping
with Sensory
issues**



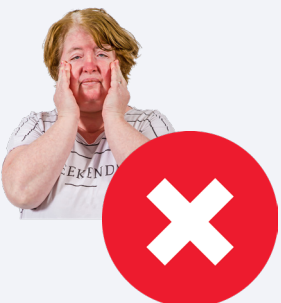
**Building on
strengths**



**Reducing
stigma from
others**



**Helping people
break down
overwhelming
tasks**



**Preventing
burnout**

Priority Area 3: Support for mental health for people who are not in hospital



What support for mental health issues do people need to stop them needing to go to hospital and to stop them having to stay for a long time?

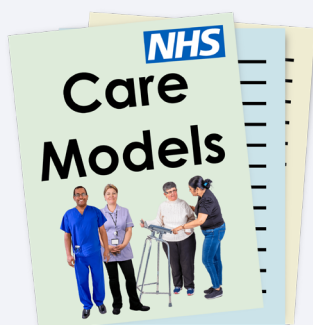


Mental health support provided outside of hospital settings could be in the local area.



The support available for autistic people and people with a learning disability in the community receives mixed feedback.

(Support is not always widely available and when it is, it is not always based on evidence of it working)



The research may also be about **care models**.

Care models are the way that health services work and what people should expect if they use them.

Priority Area 3: Support for mental health for people who are not in hospital



The research could include the training of staff who provide care.



More health professional's are using technology to keep people safe and healthy.

For example, doing video appointments.



There should be more research about using technology in the future.



The work during COVID-19 has highlighted how well using digital ways to provide care has worked.

People with a Learning Disability



Community services support adults and children with a learning disability.



When we say community services, we are talking about any organisation that people use when they are not staying in a hospital for a long time



Research is needed into different ways to support people with mental health care within the community.



Different ways may work better for looking after people's health and wellbeing and quality of life.

Autistic People without a learning disability



Autistic people have said that joint working between GP surgeries, hospitals where people stay for a long time and social care could be better.



Research is needed into different ways to support people to stop them becoming very unwell and going into hospital.



Research is needed to show how best to support autistic people going from child to adult services or community to inpatient services.



Research is needed to test the safety and usefulness of community mental health interventions.

Autistic People without a learning disability



Research is needed to find out what works well when autistic people come out of long term hospitals.



For example, learning skills about daily living like cooking and cleaning.

Priority Area 4: Preventing and treating common illnesses



What are the best ways of preventing or treating illnesses that people with a learning disability or autistic people often get?



Autistic people and people with a learning disability often get these conditions:



Anxiety



Dementia
(affects memory)



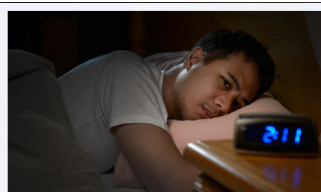
Depression



Eating disorders



Psychosis
(loose sense of reality)



Sleeping disorders



Asthma

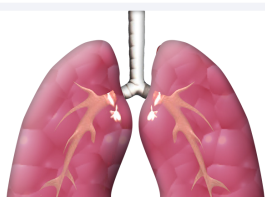


Diabetes

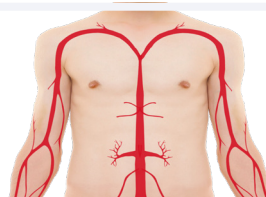
Priority Area 4: Preventing and treating common illnesses



Heart disease



Lung infections



Sepsis
(Blood infections)



Swallowing problems



Many research studies for these conditions do not include people with learning disabilities or autistic people.

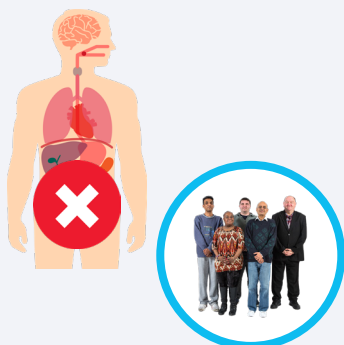


This means we do not always know if something is safe and works well for people with learning disabilities and autistic people.



More work is needed to make changes to research so that people with learning disabilities and autistic people are included.

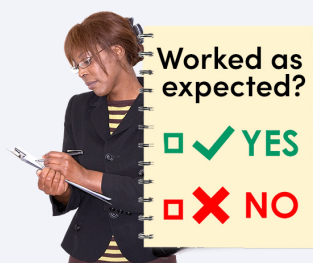
Priority Area 4: Preventing and treating common illnesses



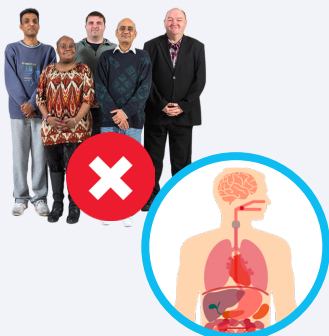
Research is needed to look at whether other health conditions are not spotted due to a focus on the **learning disability or autism diagnosis**.



A **learning disability or autism diagnosis** means someone had been seen by a health professional and been told they have a learning disability or they are autistic.



An aim raised in about testing if interventions worked as expected.



Research is also needed to look at the opposite, where a learning disability or autism diagnosis is overlooked due to a focus on other physical or mental health diagnoses.

Priority Area 5: Outcomes that matter



How do we know what works well for autistic people and people with learning disability, so they live happy, healthy and long lives?

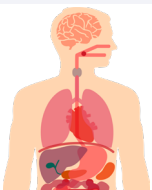


Research is needed to understand what what works well for people with learning disabilities, autistic people and families and carers.



Researchers need to find out what is important to people with learning disabilities and autistic people.

For example:



Health



Quality of life



Reducing anxiety



Being in control of own health care

Priority Area 6: Information Received



How can we make better use of information to meet the needs of autistic people and people with a learning disability?



The NHS collects information on the care people receive.



This information can be used to tell staff what works well for services they provide to people.



This could be shared across the NHS.

Priority Area 6: Information Received



It can also be used to show differences in access to care, the care provided, or what happened because of the care.



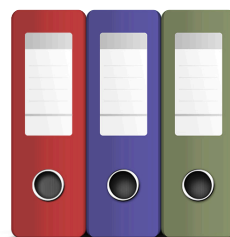
We are interested in understanding what the difficulties are to collecting high-quality information in the NHS.



Research is needed into how we **collect**, **store**, and use information.



Collect
Bring or gather together a number of things.



Store
keep something for future use.

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