





JOINT GUIDING PRINCIPLES

How partners in **Integrated Care Systems** should work together to improve the **health** and **lives** of people with a learning disability and autistic people



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The **Integrated Care Systems**, or **ICSs**, are a new way for local health and care organisations to work together.



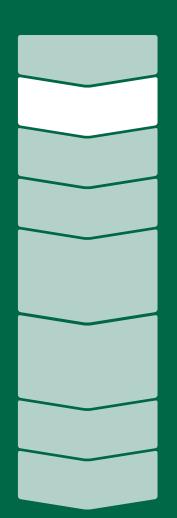
Integrated Care Systems should improve the health and lives of people with a learning disability and autistic people.



There are forty-two **Integrated Care Systems** in England.









Integrated Care Systems support the following organisations and groups to work together to offer better health and care services:



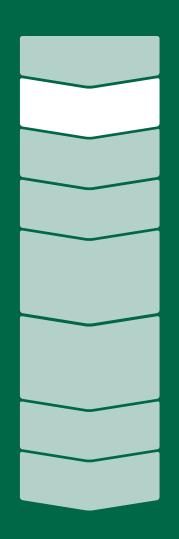
NHS organisations



primary care professionals such as GPs









local councils/local authorities



social care providers



people and families







community and voluntary organisations and social enterprises.



A **social enterprise** is a business that puts any profit it makes back into the business or the community.



This support is important work because people with a learning disability are more likely to experience poor health.







This is also known as **health inequality**, **and** here are some examples:



• six out of ten people with a learning disability die before they are 65



people with a learning disability, on average,
 die 20 years younger than people who do not have a learning disability.



This information is from NHS England's LeDeR report, which comes out every year.







Autistic people are also more likely to experience poor health. For example:



over half of all autistic adults have had depression



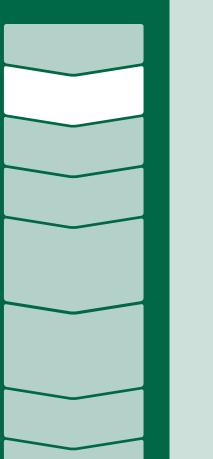
 autistic adults who do not have a learning disability are over nine times more likely to think about suicide than the general population.



Click here for data about depression and autism from the Autistica website.









So, these organisations have worked together:



NHS England



the Local Government Association or LGA.

The **LGA** is the national membership body for local authorities.







 the Association of the Directors of Adult Social Services or ADASS.

ADASS is a charity made up of all the Directors of Adult Social Services in England.



These three organisations wrote the **guiding principles** for all 42 **Integrated Care Systems** in England.







The **guiding principles** explain how health and care organisations should work together to improve the health and lives of:



people with a learning disability



autistic people.







You could read this document with these three policies, which are all in Easy Read:



Building the right support was written in 2015.

www.england.nhs.uk/wpcontent/uploads/2015/10/ld-netplan-er.pdf

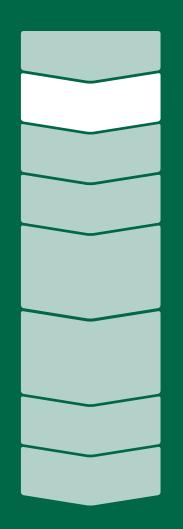


Supporting people with a learning disability and/ or autism who have a mental health condition or display behaviour that challenges was written in 2015

https://www.england.nhs.uk/wpcontent/ uploads/2015/10/ ld-servmodel-er.pdf







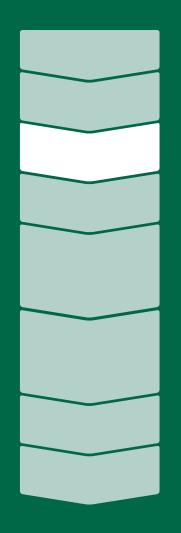


Developing support and services for children and young people with a learning disability, autism or both was written in 2017

http://www.england.nhs.uk/learning-disabilities/about/resources/er/





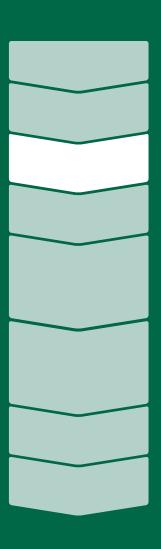




The **guiding principles** are based on the values that all **Integrated Care Systems** and health and care organisations should be working towards:









Value 1: Equality and Inclusion



This value is about supporting everyone to:

• live healthy lives at home and in their local area



be valued as people



be treated with respect.







Value 2: Having the same opportunities as everyone else



This value is about:

taking part in community life



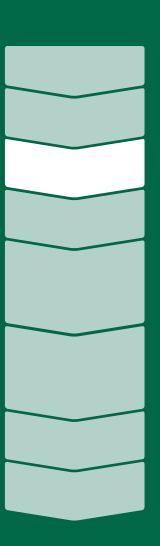
having relationships with family and friends



taking part in activities with family and friends









having an education



social and leisure activities



This value is also about having:

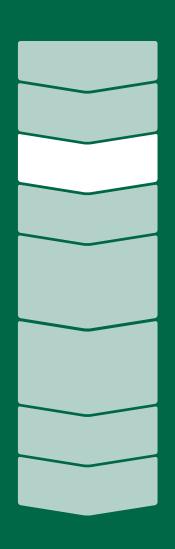
good housing



a good understanding of your finances and money









good job



good health



good transport









Value 3: Person-centred planning and support



Person-centred planning is about making sure children, young people, adults and their families are:

- listened to
- included in decisionmaking.



Every person-centred plan should support each person's:

- individual strengths
- needs
- · wishes.







Value 4: Early intervention and prevention



This value is about arranging the right care and support at the right time to:



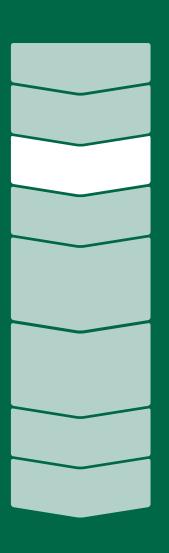
making the best use of the money that is available in local areas



improve everyone's health and lives.









Value 5: Safety and wellbeing



This value is about making everyone feel safe:

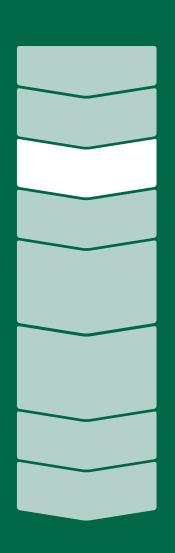
in their community



· when they get care and support.









No one should have to experience:

discrimination



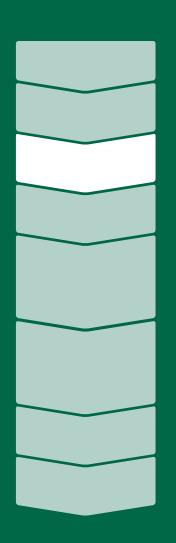
hate crime



abuse









being harmed



Everyone will know their rights and how to report a risk or problem.









Value 6: Learning new skills



This value is about making sure everyone:

• gets the right support to learn new skills



has better lives.









These are the expected **guiding principles** for all of the **Integrated Care Systems** in **England**.



Co-production should be an important part of all **guiding principles**.





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Useful resources

Useful information



Partners in **Integrated Care Systems** should use coproduction in their work at every stage with:



- people with a learning disability
- autistic people
- family carers.



People live better lives when they are treated fairly.

And their families, friends and supporters are treated fairly, too.





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Integrated Care Systems could use the Ladder of Co-production approach.

There are different levels of taking part, as explained in this 4-minute video about the Ladder of Co-production.



Website

https://www.thinklocalactpersonal.org.uk/Latest/ Coproduction-The-ladder-of-co-production/

Video

www.youtube.com/watch?v=R5PyXN8MWa4



The next part explains the best ways for **Integrated Care Systems** to work.

These are called **guiding principles**.





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Reducing health inequalities



Find out more about <u>Health inequality</u>.



Local councils and the NHS run Integrated Care Partnerships or ICPs.

ICPs are a group of partners who want health, public health and social care to improve in their local area.



ICPs should have an integrated care strategy which looks at ways to reduce health inequalities.







Partners should use a **population health management approach** to understand better why
there is poor health in different areas.



This approach should help partners in **Integrated Care Systems** to:

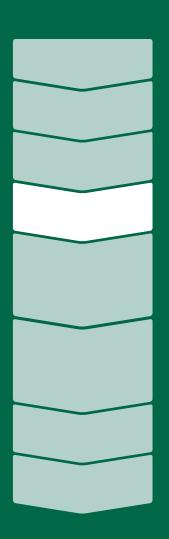
- find out who needs the most support in their local area
- make sure they get the right support.



 work together across health and local government to coproduce a clear and accessible plan for everyone.









This approach would also mean working with local health and wellbeing boards, including:



public health teams in local authorities



social care organisations







education organisations



Healthwatch – health and social care advocates.



This work will reduce <u>health inequality</u> for people with a learning disability and autistic people.









Health equality



Integrated care strategies should include intersectionality.



What is intersectionality?

Not everyone who uses NHS services has the same experience.







Many things in a person's life also affect their identity.



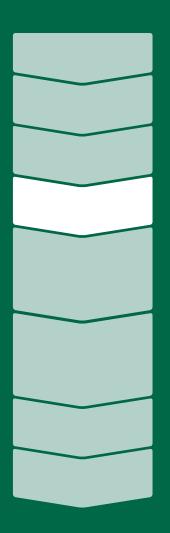
When these come together, it can result in different issues, called **intersectionality**.



The protected groups a person belongs to are part of who they are or their identity.









There are nine **protected characteristics** in the Equality Act 2010:



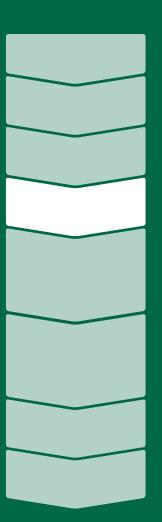
age



disability









• sex – being a man or a woman



- gender reassignment, which includes:
 - someone who wants to reassign their sex

or

someone who is making a physical change



pregnancy and maternity







 race, which includes colour, nationality, and ethnic or national origins



religion or belief



sexual orientation
 who someone is attracted to and wants to have a relationship with.



marriage and civil partnership.







ICS partners need to have plans in place that explain how they will support people to:



get screenings to find out if they have a health problem



 get vaccinated to prevent illness from viruses such as COVID-19 and flu.







The **integrated care strategy** should think ahead about health needs at different stages in everyone's life:



childhood



pubertywhen your body changes from a child to an adult



adolescence – living as a young adult







adulthood



pregnancy and one year after birth



menopausewhen women stop having periods



• older age.







The **integrated care strategy** should also explain how partners in the **Integrated Care Systems** will support:



annual health checks for people with a learning disability



health action plans, which are different to health passports



better access to health and care services for people from ethnic minority groups.







The **integrated care strategy** should also give details of how organisations would:

 check or make sure that reasonable adjustments give someone the support they need



 understand reasonable adjustments and how to plan and offer accessible services



 check and support the physical and mental health and wellbeing of everyone when they are in hospital.







The **integrated care strategy** should explain how organisations should learn from and make changes using information from:



- LeDeR learning from the lives and deaths of people with a learning disability and autistic people
- local reviews
- LeDeR reviews.





Integrated Care Systems should put an action plan inplace to stop people with a learning disability and autistic people from dying too early.









Thinking about health inequality will make sure all the health and care organisations in the **Integrated Care Systems** meet everyone's needs.





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Partners in every **Integrated Care System** should thinkabout the needs of people with a learning disability and autistic people when they put new services in place.



Partners in **Integrated Care Systems** should have a joint finance plan showing how they will use their money to support people with a learning disability and autistic people.







Partners in every **Integrated Care System** should have a plan saying how they will support people with a learning disability and autistic people who are:



at risk of going to a mental health hospital



getting care and treatment in a mental health hospital.



Over the following pages, we explain how organisations in the **Integrated Care Systems** should work together. This work will make sure that people with a learning disability and autistic people get the right support.







A plan that focuses on people



Integrated Care Partnerships should develop plans for services and plans for their **Integrated Care System**.



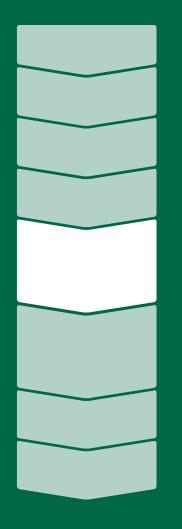
These plans should say how they will improve health and care for local people and how they should:



support human rights









be easy to update based on personal choices



- include the views of a wide group of people and organisations, such as:
 - people with lived experience



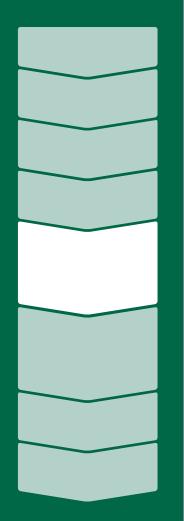
families and carers



 user-led organisations, such as local parent carer forums.









The plans should also include the views of people working in:

voluntary and community organisations



- care and support organisations
- housing organisations



- community healthcare organisations
- hospitals.







When you plan services, you should co-produce those plans with:



 experts by experience – people with a learning disability and autistic people



families and carers



 experts by profession – people who offer health and care services







A plan that includes everyone of all agesvoluntary and community organisations



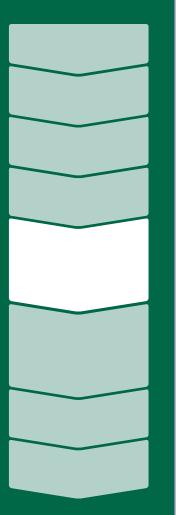
The plan should focus on each life stage:



early years









primary school



secondary school



becoming an adult.







The goal of every **plan** for services should be to give every child the best start in life.



The **plan** should also:

 focus on getting young people ready to become an adult



 make sure young people, adults and families get the right support at the right time







 make sure the support offered is based on the skills and strengths of each personevery child the best start in life.



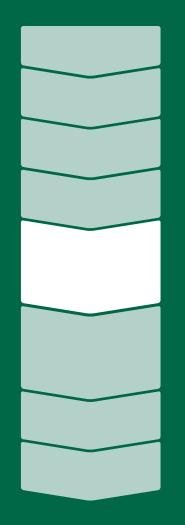
Organisations from different areas should write the plan for services together, including:



education









employment



housing



leisure







criminal justice system



emergency services.



A person does not need a medical diagnosis or condition to get support.

They should get support based on their strengths and needs.







A plan with useful information



A good plan for services should:

look at the health of everyone in the local area



 look at everyone with a learning disability and autistic people, not just people with high support needs







 understand that other organisations, not just the NHS or social care, can offer support.



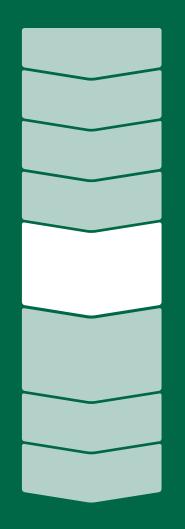
- understand that people with a learning disability and autistic people can:
 - face discrimination



have needs that are not seen but can still have poor health and wellbeing









- be updated based on the following:
 - current needs



future needs



housing needs



 use information from the local <u>dynamic support</u> register







A plan that includes care and support for all ages



A good plan for services should:



 include a joint housing plan for the housing needs of people with a learning disability and autistic people







Include the best ways to offer health and care services.



The following should write the **joint housing plan**:



social care







housing departments at local councils



NHS commissioners who plan and buy services



leaders of Integrated Care Systems.







The plan for services should meet the changing needs of:



the local community



people with a learning disability and autistic people who want to move into their own home



people with a learning disability and autistic people as they get older.







The plan for services also needs to:



 accept there is more inequality due to intersectionality in local communities



explain how **Integrated Care System** organisations will make reasonable adjustments to make it easy for people with a learning disability and autistic people to use services







- look at everyone's needs, including:
 - the needs of people living in the community



 the needs of people who need care in the community



 the needs of people who get specialist care at hospital.







The plan should include **specialist support** at hospital that could be:

good quality



for a short time



based on need



close to someone's home or their community.







Specialist support, such as secure services, may be **offered** outside the **Integrated Care System** area.



A decision about care or treatment offered **outside** the **Integrated Care System** area would be made by:

 working closely with people who use services and their family carers



 looking at ways that care or treatment could be offered.







Local health and care organisations should offer extrasupport as early as possible to stop a crisis in the future.



Extra support could come from:

- the Dynamic Support Register
- Care (Education) and Treatment Reviews.



Link to Easy Read doc

https://www.england.nhs.uk/publication/dynamicsupportregister-and-care-education-and-treatmentreviewpolicy-and-guide/#heading-2







Planning and offering care and support in the community



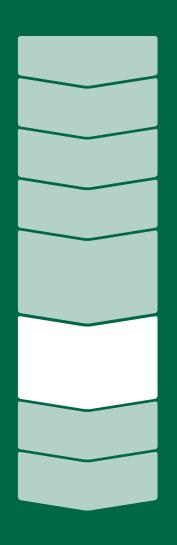
Integrated Care Systems need to work closely with people, families and carers to make sure they get the right support at the right time in the community.



Integrated Care System organisations should understand that people with lived experience, their families and carers









can help to write plans that support people to live a healthy life.



Partners in each **Integrated Care System** should understand that:



 many children and young people live at home with their families







most adults can live independently with little or no support from the NHS or social care.



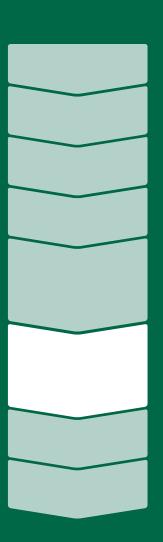
- people with extra support needs should have:
 - an assessment under the Children Act 1989 or Care Act 2014



 a personal care plan that describes the care and support they need.









A good personal care plan should include:

details of where that person will live



how their housing needs will be met



how their health, care and support needs will be met



any issues that could affect someone's support needs.







A good personal care plan:

should be written with the person and their family or carer and support staff



should have clear action points



should include dates for when those actions will take place



 should include details on the person or organisation who will take action.







The plan should include different ways to pay for support, such as **personal health budgets**.



A **personal health budget** is money to support someone's health and wellbeing needs.



It is important to offer care and support as early as possible when planning care and support for people with a learning disability and autistic people.

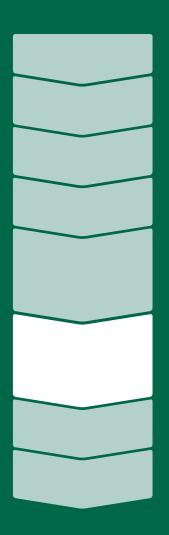


A plan and a budget are needed as early as possible so that partners in the **Integrated Care Systems** and the NHS can work together to get the best results.











Integrated Care Systems working together can:

offer the best support that is local and flexible.



- make sure the **Integrated Care System** has enough:
 - community health support
 - social care support o
 - housing to meet the needs of local people



 make sure there is enough well-trained staff to support people in the community and in hospital.









The best support for people with a learning disability and autistic people is:

- planned and paid by Integrated Care System
- organisations working together



offered by health and care services working together.



This work includes **joint assessments** using paper or online assessment forms.







Health and social care partners should work closely with:

- criminal justice service
- police and probation service
- emergency services.



A good personal plan should include information from:

Dynamic Support Registers



Care (Education) and Treatment Reviews.

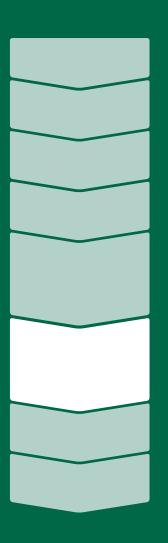


Education and Health Care Plans

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Safeguarding and quality checks for:

- people who live in the community
- people in mental health hospitals



Partners in **Integrated Care Systems** should be able to check the quality and safety of:



care and support in the community



patient care at hospital









This work includes focusing on care and support for vulnerable people.



This could also include:

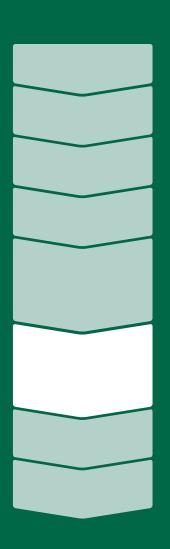
people living in a hospital or residential school that is a **long way** from their family and local community



people who are sectione under the Mental Health
 Act or lose their freedom in other ways.









Partners in **Integrated Care Systems** should make sure the right quality checks are in place.



If someone is placed in a hospital or a community service a long way from their:



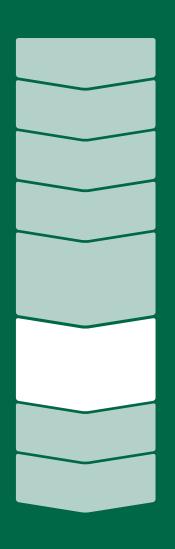
- home
- family
- community



People and their families should also be involved in making choices and decisions.









Integrated Care System organisations should also make sure that:

the person is offered support from an advocate



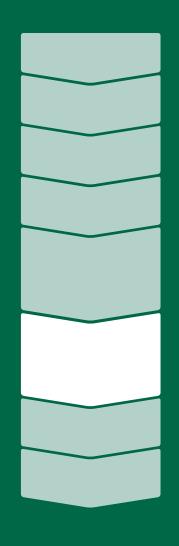
 the person is supported to keep in touch with their family, friends and local community.



If anyone is worried about the quality and safety of the support offered, organisations should listen to these concerns and work together to improve the support.









Information from these areas and organisations should be checked:



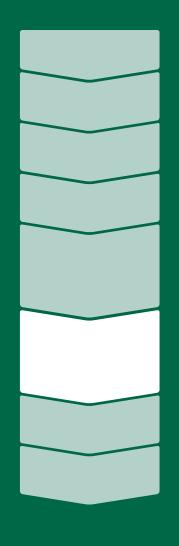
health



social care









housing



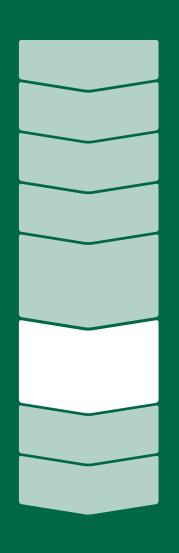
Healthwatch



Care Quality Commission









Ofsted



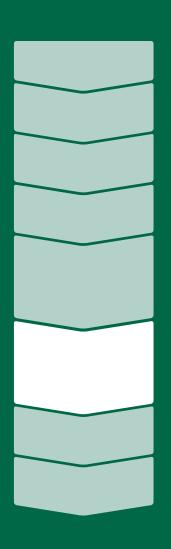
other organisations that check services.



It should be easy to raise a safeguarding concern about quality and safety.









Local areas should learn from and take action after checking local and national reviews.



These reviews could include:

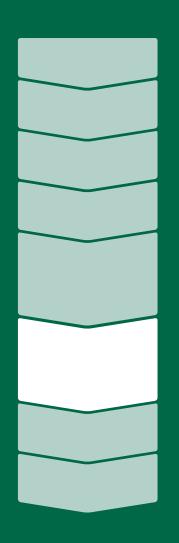
safeguarding children and adult reviews



serious incident reviews.









These boards play a big part in listening to concerns and taking action:

- Safeguarding adult boards
- Children's Safeguarding Partnership Boards



It should be clear which organisation suggests and reports on safety and quality issues.







Education and children's social care



Children and young people should get:

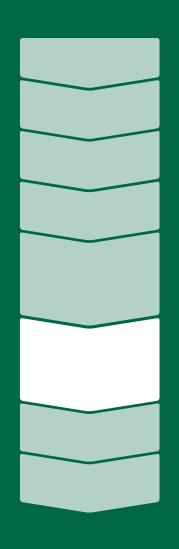
the right education



extra support if they need it.









It is a good idea if each **Integrated Care System** works closely with other leaders in:



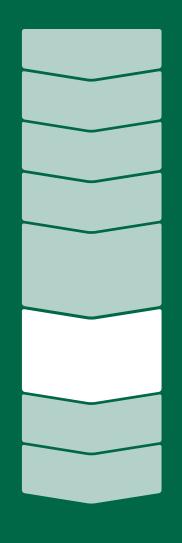
health



education









social care



parent carer forum



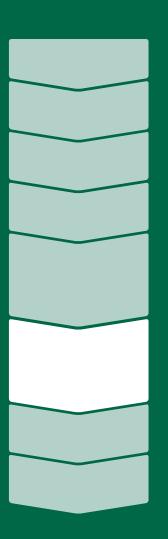
the NHS



local councils









• charities and social enterprises.



This work should mean children and young people with special educational needs and disabilities or SEND, and their families get better support.



It will also make sure everyone knows what kind of support is available from local schools and colleges.









Transition planning

Many children with a learning disability and autistic children living away from home cannot study because a school or college:

has excluded them



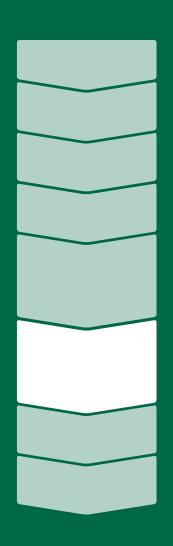
has refused to accept them.



There may be problems with the support offered to young people aged 18 to 25 years old.









Young people should get the right support if **Integrated Care System** organisations work together, including:



health organisations



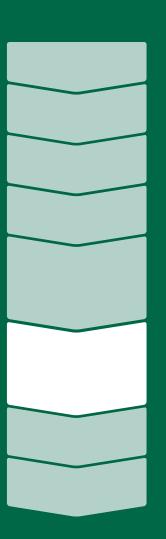
local councils.



This work should stop children from living far from home in a social care or health setting.









Checking the quality of support



Integrated Care System organisations should make sure quality checks lead to good support for children with special educational needs.



Part 3 of the Children and Families Act 2014 says quality checks should take place.







The checks should include:

a timetable for Education, Health and Care Plan



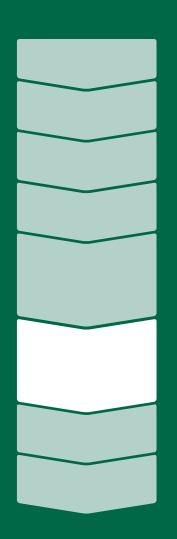
- quality reviews
- annual reviews.



The **SEND** inspection framework and handbook is a guide about area SEND inspections.









It explains how Ofsted and the Care Quality

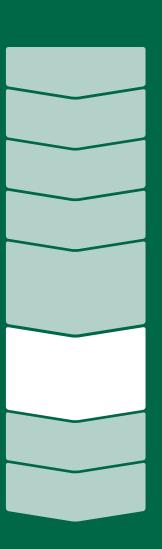
Commission will check the health requirements of:



- Integrated Care Board leaders
- Integrated Care System organisations.









Employment



People with a learning disability and autistic people should get the chance to be employed by:

the Integrated Care System



 organisations that plan and offer services for the Integrated Care System.

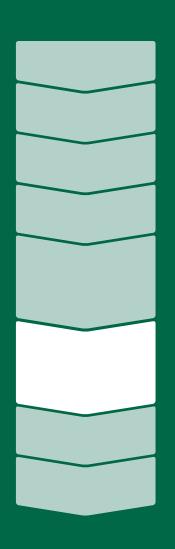


This could include:

Integrated Care System organisations working together to offer more local apprenticeships









• telling more people about jobs at voluntary organisations or charities.



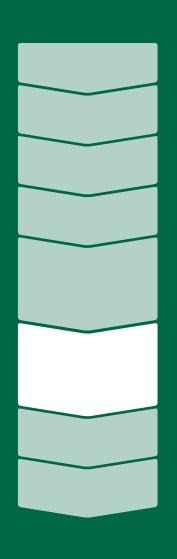
Employers should make sure their workplaces are inclusive and accessible.



Then, more people with a learning disability and autistic people can work there.









Workforce skills



Each Integrated Care Board should describe its workforce actions in the **joint workforce plan**.



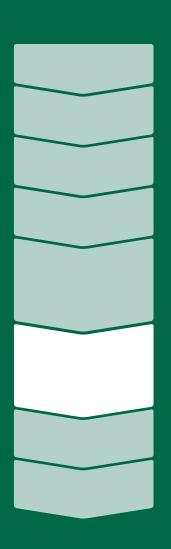
The plan for services should include information about:



current staff









the views of people who get care and support



the needs of the local community in the future.



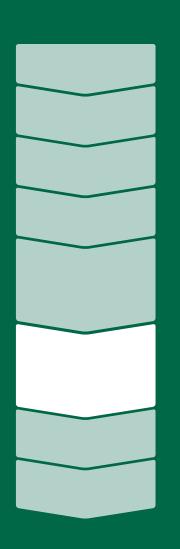
A good workforce plan should explain how **Integrated Care System** organisations will offer highquality care
and support for people with a learning disability and
autistic people by:



- employing people
- helping people to stay in their jobs









• training the right people with the right skills.



This could happen by:

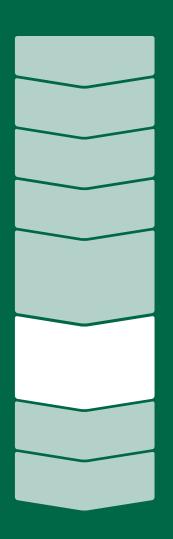
setting up more health and care teams



telling more people about apprenticeships.









This work will make sure that:

everyone gets paid fairly for the work they do.



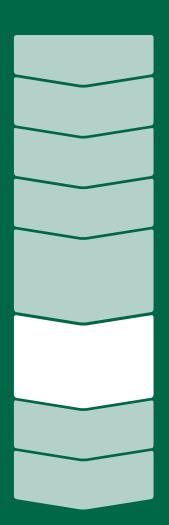
- training courses are offered to:
 - staff who support people with a learning disability and autistic people.



staff in all health and care organisations









Then, it should be easier for people with a learning disability and autistic people to work for **Integrated**Care System organisations.



It is a good idea if **training plans** include:

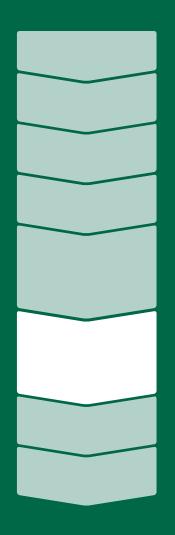
- agency staff
- staff who work for private or independent organisations



Go to Useful Information for links about staff skills and training.









A good joint workplace plan should mean Integrated Care System organisations:



 can employ people with a learning disability and autistic people with different needs



can offer different types of support.







How Integrated Care Systems plan their finances



A good **finance plan** should support different ways to pay for new services and support.



It is a good idea if each **Integrated Care System** has a **joint finance plan** that includes:

all funding

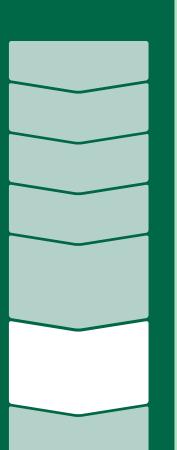


how funding will pay for services in the **Integrated Care System** area

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 how funding will pay for services outside the Integrated Care System area



The **joint finance plan** would support the commissioning plan and include housing and workforce.



Partners in **Integrated Care Systems** should tell each other when extra funding is available.



Extra funding could include

For example, NHS Learning Disability and Autism Programme funding.









When this funding is available, partners in **Integrated Care Systems** should work out the best ways to
support people with a learning disability and autistic
people by working with these groups:

charities



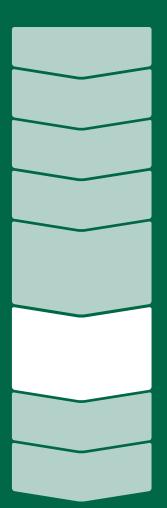
people and families



providers









· commissioners.



This support is worked out by looking at:

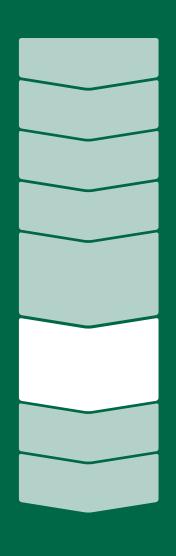
support needs across the **Integrated Care System** agreed in the plan for services



NHS England's Pathway Fund guidance.









There are different ways to spend money, including:



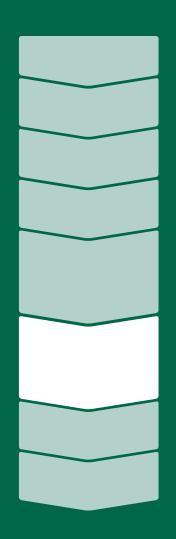
 Micro-commissioning - working out the support needs of one person and finding the right funding for them



 Personal and flexible funding, such as personal health budgets.









 Support for someone in crisis to stop them from going to hospital.



Extra support costs - for example, when home care and hospital care can support someone to leave hospital.









Running Integrated Care System organisations



Integrated Care Systems should represent:

- all health and care organisations
- · local councils.



Integrated Care Systems should include:

people with lived experience



community organisations









hospital services



specialist housing organisations.



Integrated Care Systems should manage:

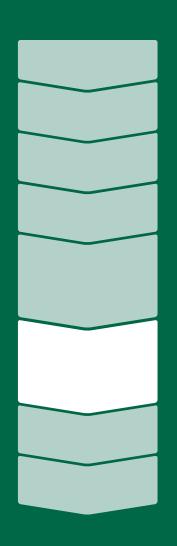
'Building The Right Support' action plan



 the goals about people with a learning disability and autistic people in the NHS Long Term Plan









Each Integrated Care Board should have an executive lead for:



learning disability and autism



down syndrome



LeDeR









· mental health



children and young people



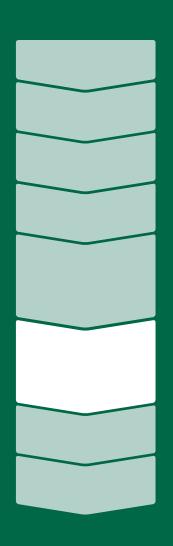
Special Educational Needs and Disabilities or SEND.



Some **executive leads** may be the same person, or the leads should work closely together to make sure the **Integrated Care Board** runs well.









Partners in every **Integrated Care System** should:



 report on learning disability and autism services to the Integrated Care Boards and regional teams



 give local people with a learning disability and autistic people the chance to work for Integrated
 Care System organisations



 work out how any transforming care partnerships can work with the new Integrated Care System organisations







 make sure the plans of Integrated Care System organisations include the support needs of people with a learning disability and autistic people



- follow new laws that affect:
 - people with a learning disability



autistic people



their families and carers

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These laws include:

 the Down Syndrome Act <u>www.legislation.gov.uk/ukpga/2022/18/enacted</u>



Liberty Protection Safeguards on gov.uk



Mental Health Act Reform
 Mental Health Act Reform on the MIND website



Mental Capacity Act on the NHS website







Plans and strategies



Building the Right Support Action Plan

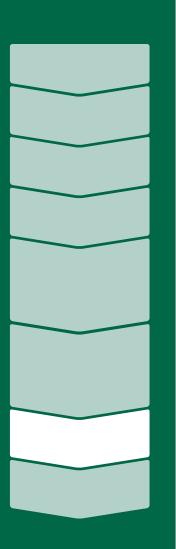
An action plan to make sure people with a learning disability and autistic people get better community support.



Better community support would mean less need for mental health hospital care.









Building the right support (transforming care) peer reviews

The Local Government Association offers peer reviews in partnership with the NHS.



National strategy for autistic children, young people and adults

The government's national strategy for improving the lives of autistic people and their families from 2021 to 2026.

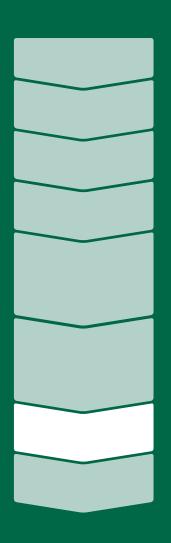


Supporting people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges

A guide for NHS staff who plan and buy health and social care services.









Learning from the lives and deaths of people with a learning disability and autistic people or LeDeR

Action from learning reports



Learning disability and autism capability frameworks

A guide on skills, knowledge and behaviours written by organisation Skills for Health.







Community support and resources



Care, Education and Treatment Reviews or CETRs

CETR policy and additional material to support CETRs



Oliver McGowan Mandatory Training

A training course on people with a learning disability and autistic people that all staff must take.









Building the right home (2016)

National guide on different housing choices for people with a learning disability and autistic people



Dynamic support register

Information on dynamic support registers for people with a learning disability and autistic people.



Reasonable adjustments

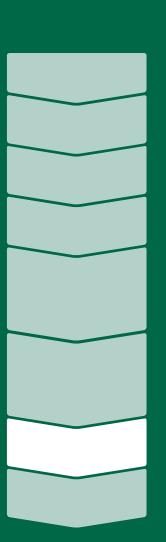
NHS information on what reasonable adjustments are and their importance



Watch this video about reasonable adjustments.









The Local Government Association Must Know Guides for Elected Councillors.



These four **Must Know Guides** about different topics might be useful for NHS board members, too:

Transforming Care



Autism





- Personalisation
- Making it real







Sector support offer

Association of Directors of Adult Social Services or ADASS

and

Local Government Association or LGA



Partners in Care and Health (PCH) programme.

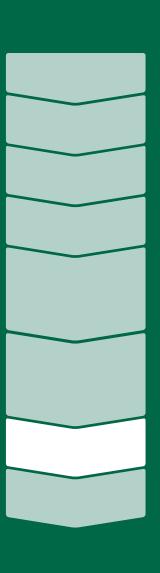


Strengths-based approaches

Information from the Social Care Institute for Excellence (SCIE).









New ideas about community centred support

Information about community centred approaches from Think Local Act Personal.



Co-production tool

Made in 2017 to support local partnerships with co-production



<u>Integrated commissioning for better outcomes</u>

A template from the Local Government Association.

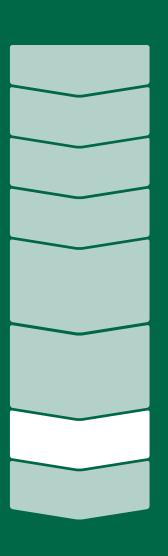


Level 5 commissioning for wellbeing

Principles of commissioning for wellbeing level 5 qualification by www.skillsforcare.org.uk









Generic Level 5 commissioning for wellbeing

Has a learning disability and autism focus by www.skillsforcare.org.uk



Small supports - small is beautiful

Local Government Association Partners in Care and Health and the National Development Team for Inclusion or NDTi run the small support programme.

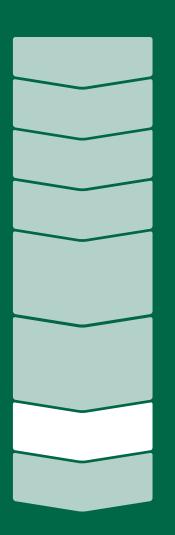


Think Local Act Personal

Useful person-centred resources about how to support people in the community.







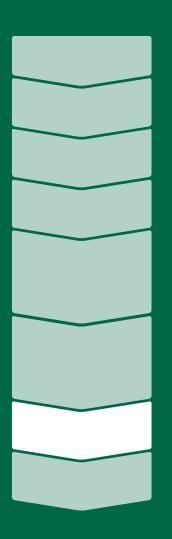


Housing for people with a learning disability or autistic people

Information on housing for people with a learning disability from the Local Government Association.









Important laws



Autism Act 2009 Down Syndrome Act 2022

www.legislation.gov.uk/ukpga/2022/18/enacted



Mental Health Act 1983

Mental Health Act on the NHS website







Mental Capacity Act 2005

Mental Capacity Act on the NHS website



Draft Mental Health Act Reform Bill 2022

Mental Health Act Reform on the MIND website



Equality Act 2010 plan

https://www.legislation.gov.uk/ukpga/2010/15/contents







Care Act 2014

https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted



Health and Care Act 2022

https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted



Children Act 1989

https://www.legislation.gov.uk/ukpga/1989/41/contents





Useful information



Population health management



ASCOF

Measures from the Adult social care outcomes framework.



Adult Carers in England Survey

Survey of adult carers in England by NHS Digital





Useful information





Information about learning disability and autism by NHS Digital



<u>Deprivation of liberty safeguards</u>

Information for England by NHS Digital



LG Inform

Local area benchmarking tool from the Local Government Association.