

contact *For families  
with disabled children*



**National Network of Parent Carer Forums**

**'Our Strength Is Our Shared Experience'**

contact *For families  
with disabled children*



## Welcome

Welcome to this Contact Webinar

If there is a technical hitch, please do bear with us

Those of you joining by pc, laptop, tablet or smart phone should now be able to see this introduction slide

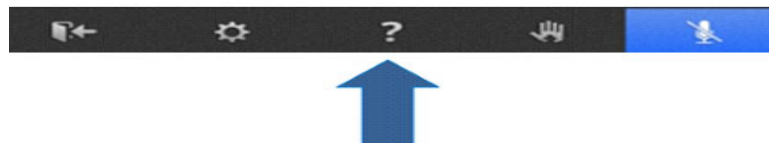


# Timings and Questions

As there are so many attendees, it is not practical for verbal questions to be taken, therefore you will all remain 'muted' throughout

If at any point you have questions, please use the question icon on your GoToWebinar tool bar on your screen

- This will allow you to type your question in to the text box and submit this to the Webinar administrator
- I will select as many relevant questions to answer as time allows, if similar questions are received I will condense these where possible



# Q & A

- Further relevant questions, not covered in the time allowed, will be answered and posted on the Contact website along with the recording of this Webinar, details of which will be circulated next week
- At the end of the Webinar a short questionnaire will launch, please take the time to complete this as this will assist with future online training events





## The NHS Long Term Plan



**A stronger national,  
regional and local  
focus on children  
and young people  
with autism, a  
learning disability or  
both and their  
families**

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26 February 2020

# Agenda

- Population data
- NHS Long Term Plan
- Building the Right Support
  - Specific commitments
  - CETR<sub>s</sub>
  - Seclusion and segregation learning
- Key working, Diagnoses, Sensory checks
- LeDeR, mandatory training & health inequalities
- Ask Listen Do and coproduction
- Local System Plans and questions for Forums

# Population



- 1.3 million pupils in England (14.9% of all pupils) have special educational needs and disabilities (SEND)
- Some primary needs are associated with complexity: on average, children with these needs are most likely to attend special schools and most likely to receive specialist support provided through an Education, Health and Care (EHC) plan. Based on this approach, a narrow estimate of the number of school children (broadly, aged 5-16 years) with complex needs is 73,000, made up of:
  - 10,900 children with profound and multiple learning difficulties
  - 32,300 children with severe learning difficulties
  - 27,500 children with autistic spectrum disorders in special schools
  - 2,300 children with multi-sensory impairments.

The equivalent figure in 2004 was 49,300. This suggests that the number of school children with complex needs in schools in England may have risen by nearly 50 per cent in just over a decade.

# Population



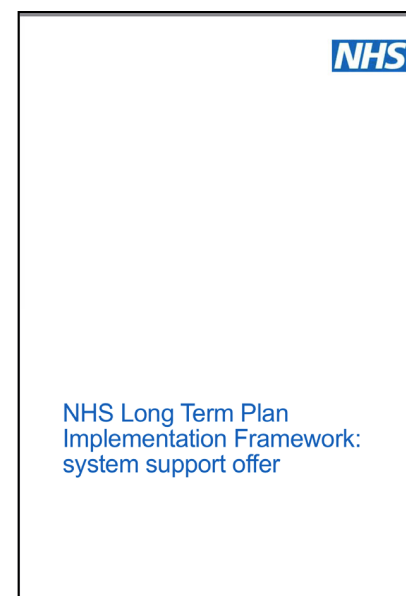
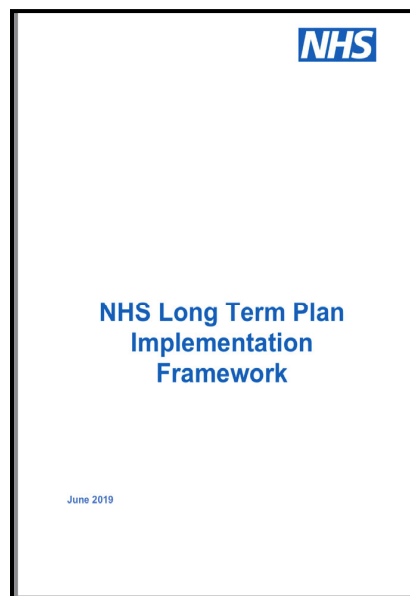
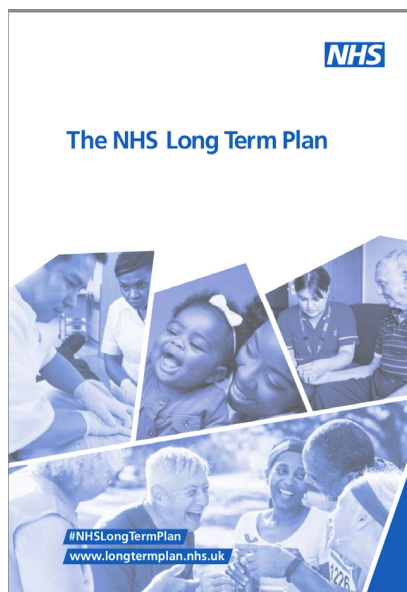
The actual number is higher, as children with other primary needs may have complex needs and because there are some important gaps in School Census data. Notably:

- 13,500 children with EHC plans placed in independent schools, which provide some of the most specialist placements
- 23,100 more young people aged 16-25 years with statements or EHC plans who are not included in School Census data, including over 1,000 aged 20-25 years.

\*Understanding the needs of disabled children with complex needs or life-limiting conditions Pinney 2017



# The NHS Long Term Plan: an integrated approach to meet the needs of children and young people



NHS England and NHS Improvement



# Long Term Plan - ambitions at a glance



This plan is structured according to the strategic commitments set out in Long Term Plan for people with a Learning Disability, Autism or both, to help local systems develop their plans. Colours relate to the four key themes: **Better Start**, **Improving Health**, **Better Care** and **Improving Quality**.

Tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people, through work on reducing health inequalities (LeDeR)

Make the necessary investment in intensive, crisis and forensic community teams to support people to live in the community and reduce

We will work with CYP services to improve access to and reduce waiting times for Autism diagnosis for children

Introduce a digital flag in summary care records to enable NHS staff to easily make adjustments for autistic people and people with a learning disability.

All services funded by the NHS will adopt the NHS Improvement Learning Disability standards.

By 2023/24 children and young people with the most complex needs will have a designated key worker.

The NHS must do more to improve the quality of care provided across the NHS and in particular reduce the use of restrictive practices.

We will work with partners to bring hearing, sight and dental checks for children and young people in special schools.

More people with a learning disability will receive an annual health check; and health checks will be piloted for autistic people.

Personalised Care

Ensuring the workforce has the right capability, skills and capacity will be fundamental in the success delivery of plans.

Working people with a learning disability, autism or both, and their families must be a key priority for planning and delivery.

Ask, Listen Do and expand STOMP and STOMP STAMP.

New Care Models/Provider Collaboratives

Learning Disability and Autism Employment

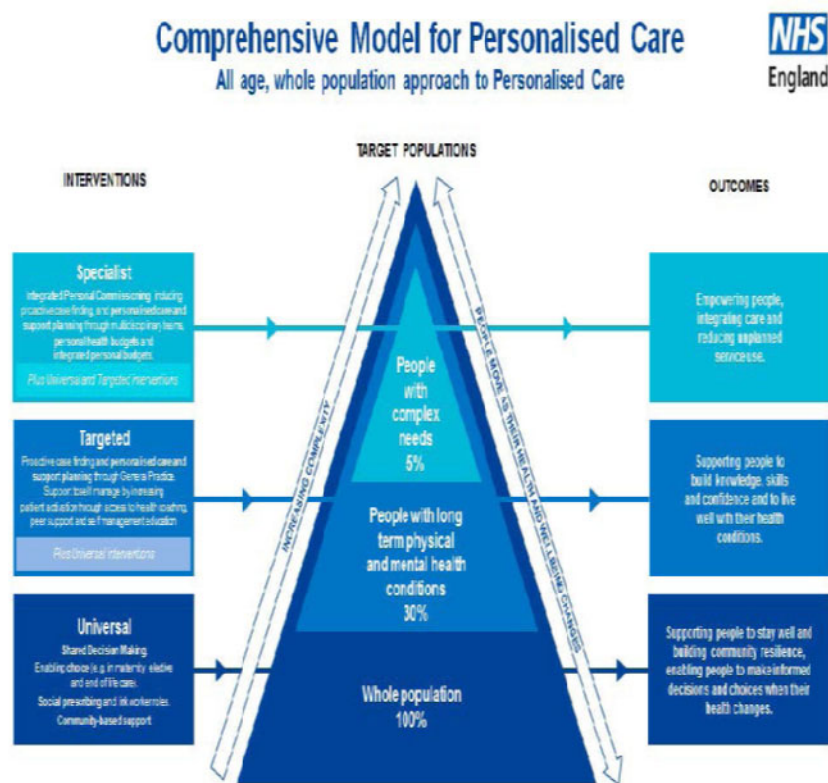
# Universal personalised care



- In the NHS Long Term Plan it says personalised care should be the main way health and care services work.

- The Personalised Care Group have written a plan to make personalised care happen.

# Comprehensive model for personalised care

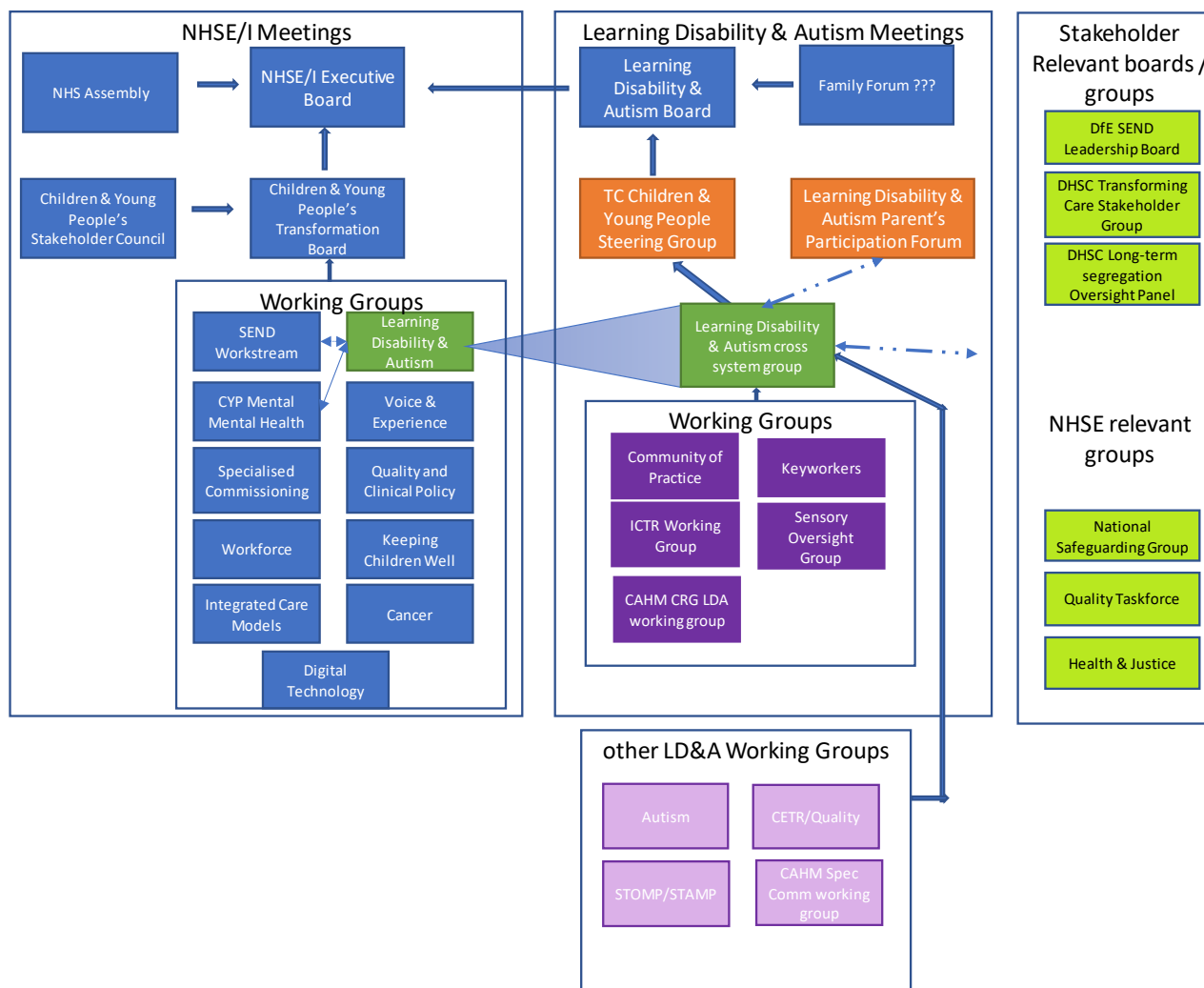


This is what the model says good personalised care should be like.

There are 6 components:

- ✓ Shared decision making
- ✓ Personalised care and support planning
- ✓ Choice
- ✓ Social Prescribing
- ✓ Supported self-management
- ✓ Personal health budgets

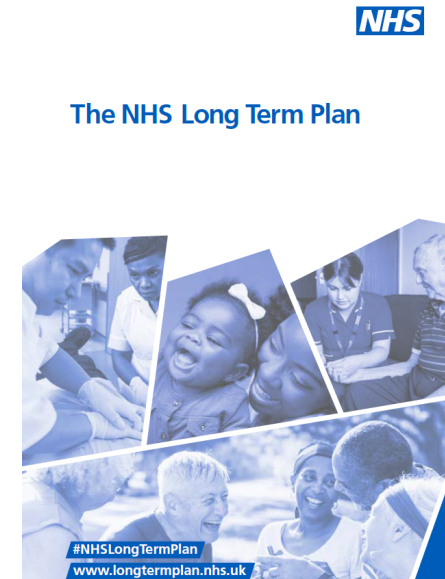
## Learning Disability & Autism Programme Planning: Better start for children and young people governance structure



# Building the Right Support (Transforming Care)



- By March 2023/24, inpatient provision will have reduced to less than half of 2015 levels (on a like for like basis and taking into account population growth) and, for every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. For children and young people, no more than **12 to 15** children with a learning disability, autism or both **per million**, will be cared for in an inpatient facility.
- We will closely monitor and – over the coming years – bring down the length of time people stay in inpatient care settings and support earlier transfers of care from inpatient settings. All areas of the country will implement and be monitored against a '12-point discharge plan' to ensure discharges are timely and effective.
- Finding the right housing and support solutions are part of this work.
- We will continue to work with partners to develop specialist community teams for children and young people, such as the Ealing Model, which has evidenced that an intensive support approach prevents children being admitted into institutional care

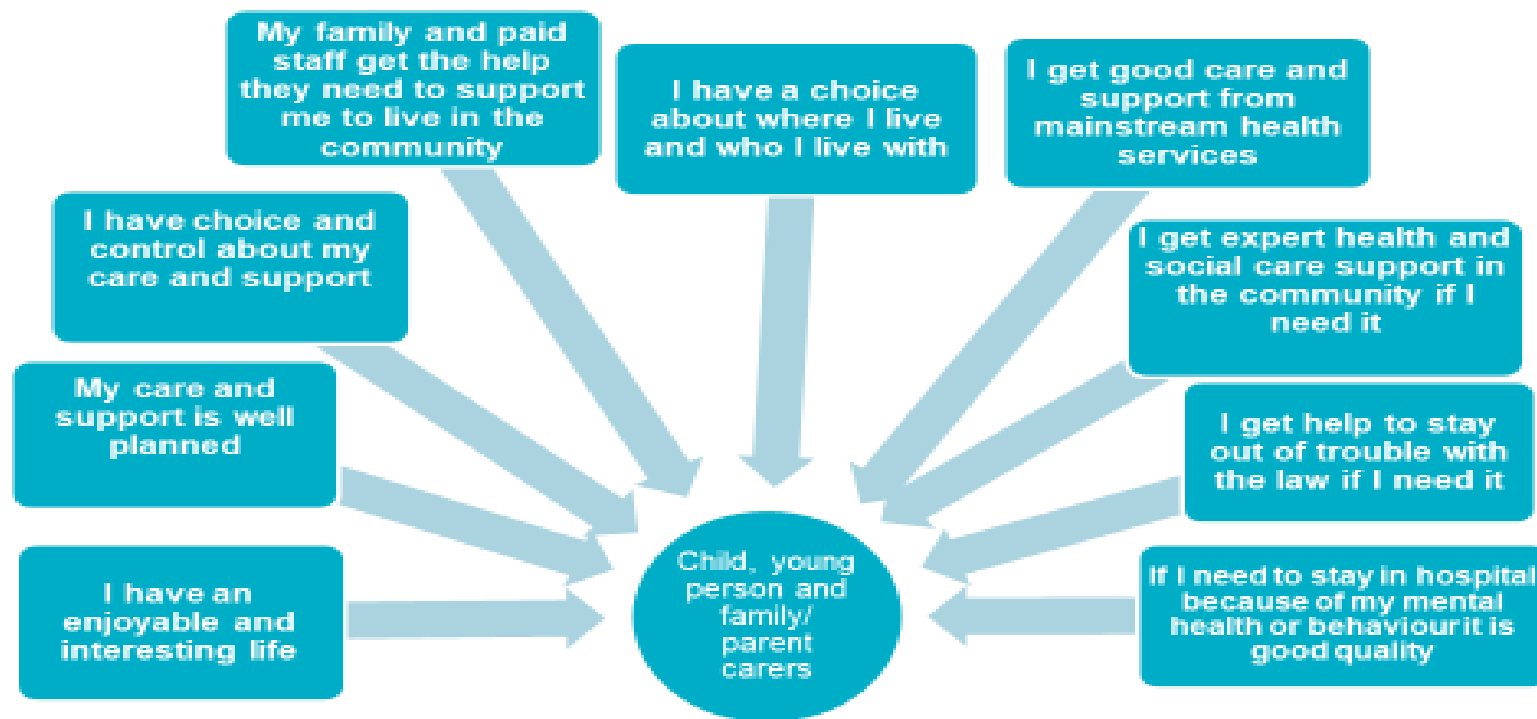


National guidance – this is what good looks like in enabling out of hospital care

# Building the right support: Person and family centred policy



## The 9 principles of the service model





# Care (Education) and Treatment Reviews



**There has been a lot of feedback about improving C(E)TRs**

- We want to make C(E)TRs easier for everyone
- And more collaborative
- And more person-centred
- They always need to be good quality
- We need to know more about how well a C(E)TR was done
- And to learn more from a C(E)TR about the quality of people's care, education and treatment
- Policy Refresh 2020



# Seclusion and segregation learning and response



# Key themes

- Disproportionate number of children and young people with a learning disability, autism or both experiencing periods of seclusion and / or long-term segregation
- Pathways of most children and young people demonstrate extreme challenges in accessing appropriate early support, mental health support, social care support, short breaks – and almost all experienced exclusion (often multiple)
- Many had significant delays in discharge
- Outcomes during care were often poor.

## **Responses include:**

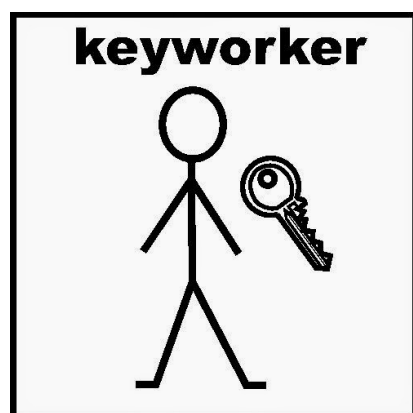
- Childrens Commissioner led Task Force into improving quality in inpatient settings
- Baroness Hollins led Independent CETRS
- 6-8 week commissioner visits and host commissioner arrangements

## Listening: Commissioner Oversight Visits



- Every 6 weeks for children, 8 weeks for adults
- Building better relationships with patient, also family and advocacy if patient wants this
- Friendly opportunity to meet the patient and talk about their experience of services, and see the service through the patient's eyes
- Ensure people's human rights are respected and protected
- Check on safety, current care, and involvement of patient and family in decisions about their care and treatment
- Listen to frontline care staff and spend time on the ward as part of a normal day
- Agree simple actions with patient on the day and flag up any concerns

# LTP commitments : Key working



- By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker, implementing the recommendation made by Dame Christine Lenehan. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital.
- Keyworker support will also be extended to the most vulnerable children with a learning disability and/or autism, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services
- Trials will begin in each region in 2020/21

# LTP commitments : diagnoses, STOMP STAMP



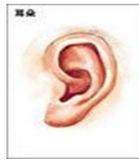
- We will expand the Stopping over medication of people with a learning disability autism or both and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes to stop the overmedication of people with a learning disability, autism or both.
- We will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.
- Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services
- Together with local authority children's social care and education services as well as expert charities, we will jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process.



# LTP commitments : Sensory checks



**eyes**



**ear**

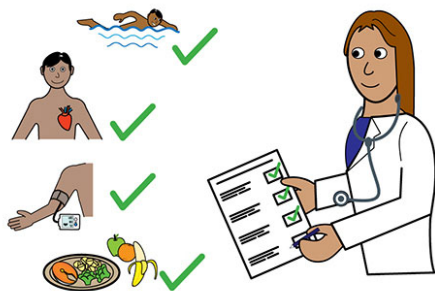


**teeth**

- Over the next five years, we will invest to ensure that children with learning disabilities have their needs met by eyesight, hearing and dental services, are included in reviews as part of general screening services and are supported by easily accessible, ongoing care.
- We will work with partners to bring hearing, sight and dental checks to children and young people with a learning disability, autism or both in special residential schools
- We have commissioned guides for parents to help them understand the importance of these areas
- Work in schools will begin in 2020/21



# LTP commitments : Annual Health Checks **NHS**



- We will improve uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, so that at least 75% of those eligible have a health check each year
  - Pan England campaign being planned now to help achieve this target including for parents, building on work by Contact and NNPCF
- We will also pilot the introduction of a specific health check for people with autism, and if successful, extend it more widely.



# Learning Disability Mortality Review (LeDeR) and Mandatory Training



- All deaths of children and adults with a learning disability must be reviewed
- CCGs are responsible for leading this work in their areas and learning from it
- Government (DHSC) response to Third LeDeR report just published:

“Recommendation three: Identifying young people at transition.....	11
Recommendation four: Identifying people from BAME groups.....	12
Recommendation five: Listening to families .....	13
Recommendation six: Priority programmes of work needed .....	14
Recommendation seven: Service and care co-ordination .....	15
Recommendations eight and nine: Transition from children's to adults' services .....	16
Recommendations ten, eleven and twelve: Addressing bias.....	18”

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/865288/government-response-to-leder-third-annual-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf)

## **Oliver McGowan Mandatory Training in Learning Disability and Autism**

In November 2019, the Government announced the introduction of mandatory training in learning disability and autism for all health and social care staff, relevant to their role. This was in response to a consultation on the proposal of mandatory training arising from LeDeR and championed by Paula McGowan.

<https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

<https://www.england.nhs.uk/blog/ask-listen-do-olivers-story/>

# We must end health inequalities

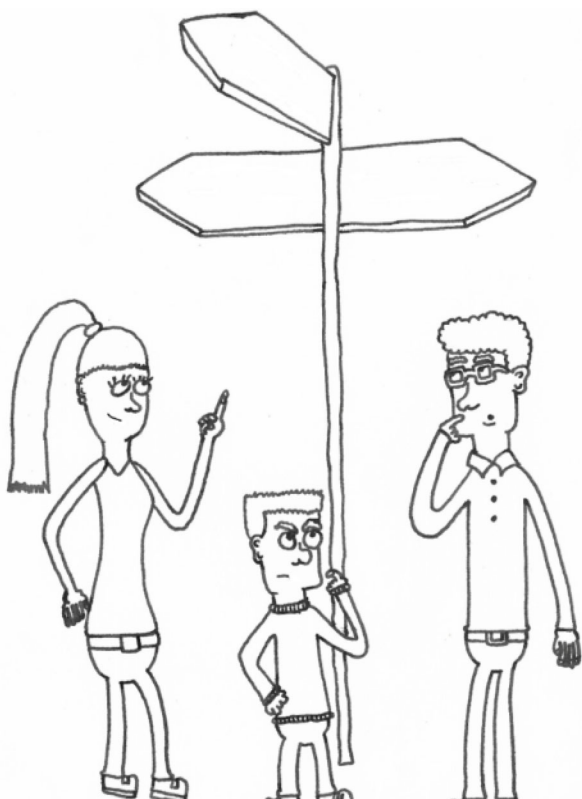


- People with a learning disability, autism or both experience more health inequalities than others
- People are still dying too young
- People with a learning disability are four times more likely to die from treatable causes
- About 70% of autistic people are said to develop mental health problems at some point and suicide is a leading cause of premature mortality
- People with autism and/or learning disability face social, educational and communication barriers
- Many people in specialist hospitals for too long
- More vulnerable to neglect and abuse e.g. Whorlton Hall, Winterbourne View
- Family carers often feel powerless and excluded

# Getting it right for people with a learning disability, autism or both; reasonable adjustments **NHS**

## Ask Listen Do

Making conversations count  
in health, social care and education



- The NHS Constitution, equality and human rights laws say everyone has the right to good quality services, person-centred care and support
- It means doing things differently for people with a learning disability, autism or both – so people of all ages have the best chance of good outcomes and equal access to services
- You can't do this if people are not understood, listened to, or able to raise a concern, complain or influence services
- This creates health and social inequalities – poorer health, shorter lives, harm or injustice leading to safeguarding risks and criminal issues
- It is your legal and moral duty to stop this from happening

# Feedback/Compliments examples for early and local resolution

Health	Education	Care
I find waiting difficult as I have autism. Can I be seen on time please?	Thank you for not making a fuss about taking our child on the school trip.	Thank you for the activities, I really like them.
I am worried you are not taking me seriously because have a learning disability.	I appreciate the feedback about the speech and language session.	I do not want to go to bed at 9pm. I want to sit up and watch TV.
I will find it hard to get to that appointment because my autism makes me afraid of public transport	The home school communication book is working really well.	I would like to have friends and go out more. I would also like a job.
Can I have a double appointment please as I need more time?	I am concerned my child is not making progress at SEN Support.	We are concerned about the lack of contact with our family member.
Thank you for listening and caring so much.	I want to go to a college that will meet my needs.	The staff are kind.

# Different types of issues in concerns and complaints

Individual	Organisational	Structural
Needs Speech and Language Therapy and cannot access	Information is not made easily available about how to access the service	Not enough NHS Speech and Language Therapists in local area
Cannot get a blood test	Times and locations are not accessible to someone with a learning disability, autism or both	Service has not been commissioned to do this
Lack of transition planning from childhood to adulthood	Lack of information and confusion about who does what	Lack of joint commissioning
Family are worried about quality of care and afraid of consequences	Families not welcome - seen as difficult. Lack of clarity about safeguarding	Provision has a good CQC rating. Paying LA different to location of care
College excludes as say they cannot meet needs	Routes of redress are unclear and/or expensive	LA do not see it as their problem and YP sits at home

# Ask Listen Do: organisations

‘They should think of it as a conversation’

‘We want to talk to someone before it becomes a complaint’

‘I want to talk to a person, not a number’

‘Sometimes it’s just about being able to give feedback or ask questions’



- Use the [resources](#) and involve people and families in training your staff
- Ask a leader in your organisation to be a champion for Ask Listen Do
- Find out about and make reasonable adjustments – each person is different
- Meet and work with people and families when designing or reviewing services – true co-production
- Give people time
- Be welcoming, sympathetic and pro-active about how you seek feedback, respond to concerns and handle complaints
- Don’t be afraid to say sorry and mean it





Co-production is key

# Co-production - Long Term Plan language

- Services for children and young people

“Establish local leadership – including named clinical and management leaders, coproduction with children, young people, families and carers and bringing together local leaders from across the NHS, local government, education and other partners to design and deliver transformation of the system.” (IF 5.5)

- Learning Disability and Autism

“Systems should involve people with lived experience and their families in checking the quality of care, support and treatment and set out how they will ensure that all local services make reasonable adjustments...” (IF 5.9)



# Measuring you are getting it right **NHS**



## At a strategic level

1. **Commit to co-production** – named people at a senior level
2. **Make sure it happens across all you do** to help you achieve every priority
3. **Decide on and check quality together** – how?
4. **Co-produce with the right people, with the right experience** – the people who are most affected
5. **Make reasonable adjustments in all you do** – don't see people as 'difficult'



# Local System Plans

- Learning disability and autism
  - Named senior responsible officer to oversee local implementation of LTP for Learning Disability and Autism (IF5.8)
  - Set out how proposals align with plans for mental health, SEND, CYP services and health and justice (IF 5.10)
  - Set out the local offer for Learning Disability and Autism (IF 5.10)
  - Capital investment for the development of new housing options and suitable accommodation in the community (IF 5.13)



# Questions for Parent Carer Forums

- Have you seen your Local System Plans?
- If not, check with your CCG, Local Authority, Health and Wellbeing Board and Scrutiny Committees
- Ask about coproduction and engagement with stakeholders: how can parents and families get involved, if not already?
- An example of one System Plan that is published for comment:

<https://www.wyhpартnership.co.uk/publications/our-five-year-plan>

# Questions for Parent Carer Forums

- Are you aware of or involved in the health inequalities or LeDeR work in your area?
- Are you aware of good practice in coproduction about learning disability and autism that you could share?
- Are there any other questions about our work or specific areas you would like to know more about?
- What more can we do to help you in your work?

# Resources

## LeDeR

<https://www.hqip.org.uk/clinical-outcome-review-programmes/learning-disability-mortality-review-programme/#.XlQ1jC2cZUM>

<https://www.england.nhs.uk/publication/leder-action-from-learning/>

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/865288/government-response-to-leder-third-annual-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf)

## Ask Listen Do

This is an NHS England led piece of work looking at the journey through these complex systems of education, health and social care for children and families and how to make the experiences better, parents and people more empowered and organisations more willing to listen and develop the skills to do that:

<https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

Top Tips for Families <https://www.england.nhs.uk/publication/ask-listen-do-top-tips-for-families-and-carers/>

Schools/families guide <https://www.sendgateway.org.uk/r/makingconversationswithschools.html>

Simon Knight WSS blog <https://www.england.nhs.uk/blog/working-together-to-help-children/>

Ofsted blog <https://educationinspection.blog.gov.uk/2019/05/21/ask-listen-do/>

PHSO blog <https://www.ombudsman.org.uk/news-and-blog/blog/ask-listen-do-putting-our-commitment-action>

# Resources

## **Annual health Checks**

<https://contact.org.uk/news-and-blogs/annual-health-checks-for-young-people-with-learning-disabilities/>

## **Inpatient Task Force**

<https://www.england.nhs.uk/2019/10/nhs-taskforce-to-drive-improvements-in-young-peoples-hospital-mental-health-learning-disability-and-autism-care/>

<https://www.england.nhs.uk/publication/taskforce-charter-children-young-peoples-mental-health/>

## **Inpatient Reviews**

<https://www.gov.uk/government/news/all-inpatients-with-learning-disability-or-autism-to-be-given-case-reviews>

## **Oliver McGowan Mandatory Training in Learning Disability and Autism**

<https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

<https://procontract.due-north.com/Advert?advertId=20578028-ca3d-ea11-80fc-005056b64545>

## **Blog**

<https://www.england.nhs.uk/author/mary-busk/>

# Thank You!

- Thank you for attending with us today
- A short questionnaire will launch at the end of this webinar
- Please take the time to complete this it will help us plan future online training events including other topics you would like to see
- The recording of this Webinar, presentation and questions will be on the parent participation Resources page of Contact's website next week – an email confirming this will be sent to you once this is available

