



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

contact a family
for families with disabled children

Strengthening Parent Carer Participation



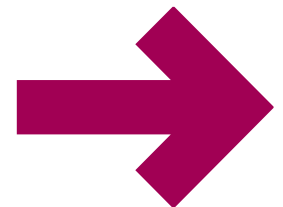
**Transforming
Care for
children and
young people**

February 2017

Transforming care for who?

- Children and young people with learning disabilities
- Children and young people with autism
- Children and young people with learning disabilities and autism

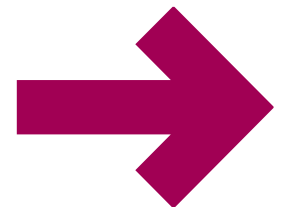
- Those with behaviours that challenge
- Those with a mental health condition



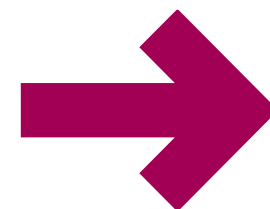
Top NHS England priority

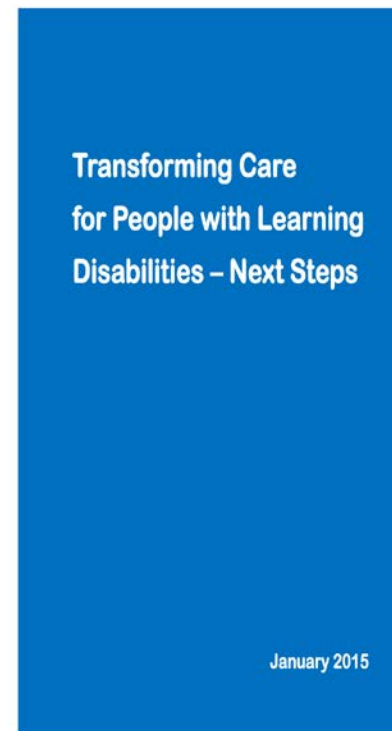
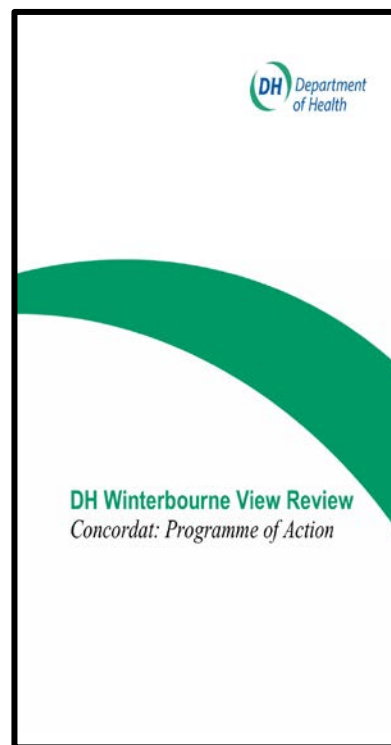
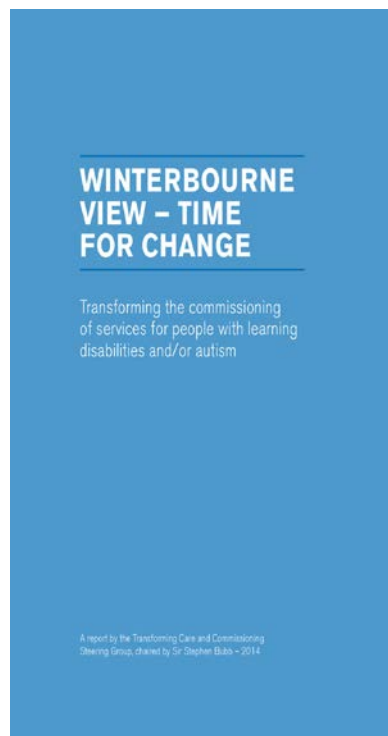


- NHS England 4 top priorities for 2015 and 2016
- These are the **big** things NHS England wants to improve
- **Improving care for people with learning disabilities is one of the top 4 priorities**
- This includes children and young people with learning disabilities



Background





Building the right support

The cover of the report 'Building the right support' features the logos of the Department of Health, adass, and NHS England at the top. The title is in large blue font. Below the title is a blue banner with white text describing the report's focus. The main image shows a group of people, including a man in a wheelchair and a young boy. The date 'October 2015' is at the bottom.

Department of Health
adass
NHS England

Building the right support

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

October 2015

The cover of the report 'Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition' features the logos of the Department of Health, adass, and NHS England at the top. The title is in blue font. Below the title is a blue banner with white text. The main image shows two people talking. The date 'October 2015' is at the bottom.

Department of Health
adass
NHS England

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

Service model for commissioners of health and social care services

Supplementary information for commissioners

October 2015

The cover of the report 'Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition' features the logos of the Department of Health, adass, and NHS England at the top. The title is in blue font. Below the title is a blue banner with white text. The main image shows a young boy and a woman. The date 'October 2015' is at the bottom.

Department of Health
adass
NHS England

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

Service model for commissioners of health and social care services

October 2015

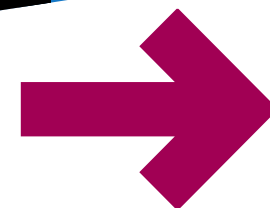
Service Model

Service model vision statement

Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life

Local
Government
Association

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



“Golden threads”



Children, young people and families are supported to have a **good quality of life**. They are treated with **respect** and have an expectation of a **home in their local community**



Children and young people should be **kept safe** but at the same time supported to take positive risks



Children and young people should have **choice and control** over their lives



Children and young people’s support should be provided in the **least restrictive way**

Children and young people should get **equal health outcomes** to the rest of the population

The 9 principles of the service model

My family and paid staff get the help they need to support me to live in the community

I have a choice about where I live and who I live with

I get good care and support from mainstream health services

I have choice and control about my care and support

I get expert health and social care support in the community if I need it

My care and support is well planned

I get help to stay out of trouble with the law if I need it

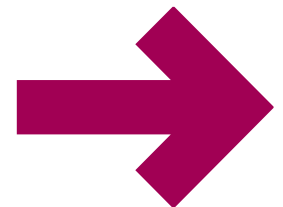
I have an enjoyable and interesting life

If I need to stay in hospital because of my mental health or behaviour it is good quality

Child, young person and family/parent carers

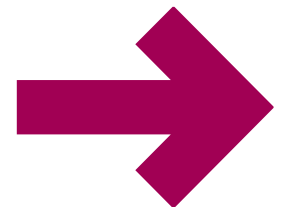
Care and treatment reviews

- Multi agency person centred reviews attended by independent clinical expert and expert by experience to consider if there is a community alternative that would prevent admission to hospital or support discharge from hospital.
- Convened and chaired by the commissioner and the individual and family members are central to the review and any decision making and outcomes.
- Panel is made up of commissioner, an independent clinical expert and an expert by experience

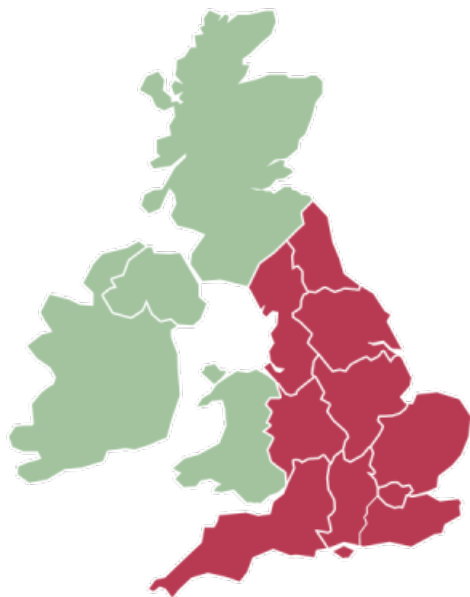


Dynamic register

- CCG's responsibility identify children, young people and adults who may be at risk of admission.
- Must include children and young people in 52 week residential schools
- Part of a dynamic register
- Voluntary register
- Should be used to plan and commission appropriately to help avoid crisis and admission
- Local areas should be thinking how it links to their Disabled Children's Register



Regional footprints



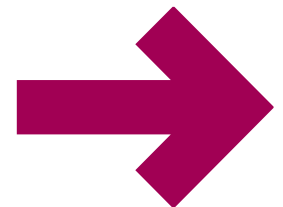
- 48 new Transforming Care Partnerships
- 48 sets of plans to transform local services for local people and families



- 48 sets of milestone plans that will enable us to tell the story of change

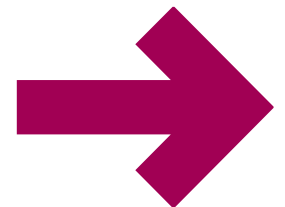
Partnership Boards

- Co-production is a cornerstone of the Transforming Care Programme
- Should include family carers and those with a learning disability, autism or both
- In most instances are cross LA / CCGs
- Opportunity to participate with the implementation of Transforming Care
- Initially adult focused (discharge) but the requirement is all age
- Local areas need to join up their work across SEND / Transforming Care / Futures in Mind



Transforming Care for children and young people

- Transforming care is an all age programme, but there are specific elements for children and young people.
- January 2016, a new team at NHSE developed to support the delivery of Transforming Care for children and young people.
- Strong links with SEND principles and agenda



Aims of the children and young people work stream

- To prevent unnecessary admission to hospital and avoid lengthy stays, ensuring treatment has clearly defined outcomes, planning for discharge from admission (Care and Treatment Review policy)
- To identify specific pathways that will enable children and young people to remain with or near to family and get the support they need
- To ensure that children and young people with LD and/or autism leave school with a good education, health and care plan that supports their transition to adulthood leading to better outcomes for them and their families.
- To encourage innovative ideas to be tested/evaluated of supporting children, young people and families through a grants process
- To ensure children, young people and their parent carers participate and co-produce their local Transforming Care plans.

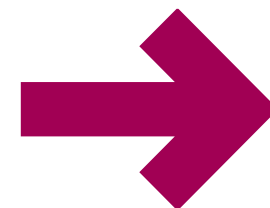


Governance



Over the last year, Steering Group has parent carer representation, and also consists of Department for Education, Department of Health, parent carer representatives, Association of Directors of Children's Services, Council for Disabled Children, Association of Director of Adult Services

New multi-agency Sub Group has just been established at a more senior level – parent carer representation at the sub group.

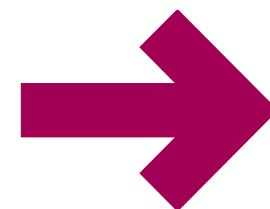


Children and young people in hospital



Making sure children and young people at risk of admission or in a specialist hospital have a Care and Treatment Review

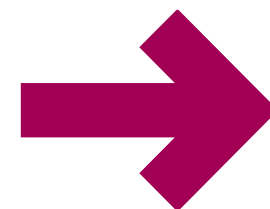
Children's Strategic Case Managers can assist with this



Children and young people in 52 week residential schools



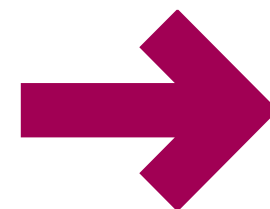
Local authority survey undertaken to determine how many children and young people with learning disability and / or autism are currently in 52 week residential schools



Responses



- We have had 151 responses to the survey
- There are currently 1120 children and young people with learning disabilities and / or autism currently placed in residential schools for 52 week placements.
- This ranged from a 0 - 36 children and young people per local authority area.
- 75% were placed at distance (more than 20 miles from home)

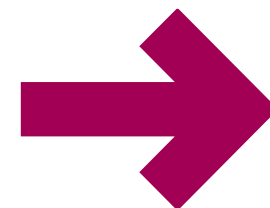


Supplementary guidance for children and young people



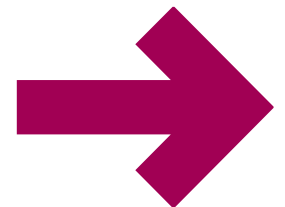
This clarifies how Transforming Care Partnership Boards and local areas should be implementing Transforming care for children and young people.

Due to be published shortly



STOMP

- Stop the over medication of people with learning disabilities
- Part of the agenda to improve the lives of children, young people and adults with learning disabilities
- Supported by Royal College of General Practitioners, the Royal Pharmaceutical Society, the Royal College of Nursing, the Royal College of Psychiatrists and the Challenging Behaviour Foundation.



The Goals of STOMP

1. Improve the quality of life of children, young people and adults with a learning disability, autism or both, who are prescribed **psychotropic** drugs.
2. Make sure people only receive these drugs for the right reasons.
3. And in the right amount.
4. Improve understanding of these drugs and when they should, or should not.
5. Improve understanding of non-drug treatments and support which may help.
6. Make sure that people work with their doctor and the people who support them in making any changes to treatment.

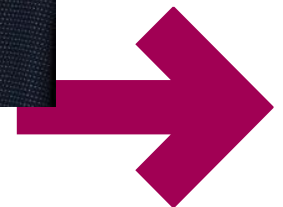


Lenehan Review(s)

The review, called *These Are Our Children*, is calling for urgent action at a national level to prevent these children being institutionalised at an early age, at huge cost to the taxpayer and with low ambitions for improving their lives.

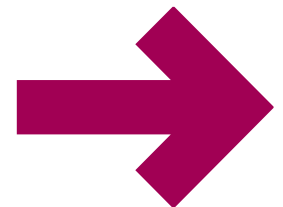
Further Independent review looking at the outcomes and experiences of children and young people attending residential special schools and colleges.

Forums have received emails about these.



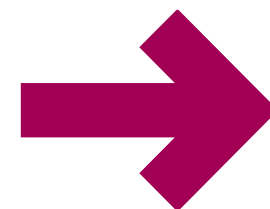
What does this mean for parent carers and families?

- Important to know this is a priority nationally and locally
- Important to think about how this links to the Special Educational Needs agenda and Children and Families Act
- The aim of both is to ensure children and young people have a good life and the support they need to do this
- Find your Transforming Care Partnership Board – they should want to learn from your experience



What does this mean for parent carer forums?

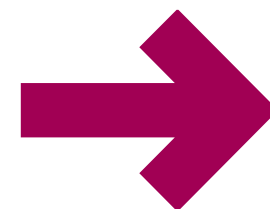
- We are encouraging all Transforming Care Partnership Boards to link with and work with the local parent carer forums.
- If during your other participatory work on SEND or with health, you ask about what is happening on Transforming Care. The children and young people are part of the SEND group of children
- Could ask how the dynamic register is linking with your Disabled Children's Register to support identification and commissioning in local areas



Thank you for listening
Any Questions?



- Mary Busk is the parent carer representative from the NNPCF working with the Transforming Care Programme
- You can contact her with any queries or comments of info@nnpcf.org.uk



Contact details

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