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

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
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.

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“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 get choice and control about my care and support
- My care and support is well planned
- I have an enjoyable and interesting life
- I get expert health and social care support in the community if I need it
- I get help to stay out of trouble with the law if I need it
- If I need to stay in hospital because of my mental health or behaviour it is good quality
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.

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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

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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.
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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