

Developing local pathways for children with learning disabilities and/or autism whose behaviours challenge (including those with a mental health condition)

Legal duties and guidance

Introduction

This document summarises the key elements of Transforming Care guidance relevant for commissioners of children's services and the legal duties in England that **must** be implemented for children with special educational needs and disabilities (SEND). Although recent legislation refers to SEND, in order to avoid confusion about whom we mean and to be consistent with wording in other documents produced for Transforming Care partnerships, we are using the term phrase children and young people with learning disabilities and/or autism whose behaviours challenge. The phrase 'children and young people whose behaviour challenges' is used throughout the remainder of the document to refer to the group of people on whom we are focussing.

The guidance and legal duties (in the boxes) are organised under the 9 principles of *Building the Right Support* (2015)¹. For more detail about the legal requirements please refer to Broach, Clements and Read (2016)².

This document will be relevant for commissioners across health, education and social care who are involved in commissioning services for children with SEND whose behaviours challenge (age 0-25).

Commissioning Arrangements

Under the Children and Families Act (2014) there is a duty to put in place joint commissioning arrangements for children with SEND. These arrangements should have a specific focus on effective commissioning, as set out in *Ensuring Quality Services* (2014)³ to improve outcomes for children and young people whose behaviours challenge in order to fulfil the commitments set out in *Building the Right Support* (2015). This includes the role of CAMHS in increasing capacity and capability to improve the wellbeing of children with learning disabilities and autism as set out in *Future in Mind* (2015)⁴.

Section 14Q of the NHS Act (2006) states that each Clinical Commissioning Group (CCG) must exercise its functions effectively, efficiently and economically. Section 14R NHS Act 2006 states each CCG must exercise its functions with a view to securing continuous improvement in the quality of services provided to individuals for, or in connection with, the prevention, diagnosis or treatment of illness.

¹ NHSE (2015) *Building the Right Support*. Available at : www.england.nhs.uk/learningdisabilities/natplan

² Broach, S., Clements, L. and Read, J., (2015) *Disabled children: a legal handbook 2nd Edition*. Legal Action Group. Available at: <http://bit.ly/1XHomL5>

³ LGA & NHSE (2013) *Ensuring quality services*. Available at: <http://bit.ly/NfkVwS>

⁴ NHSE (2015) *Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing* <http://bit.ly/1CONHTj>

There should be agreement across those responsible for joint commissioning for disabled children, and the relevant Transforming Care Partnership, about the content of the Transforming Care Plan in relation to children, young people and their families. Families of children and young people whose behaviour challenges should be consulted as part of the development of the plan (in line with the SEN Code of Practice and Section 14Z2 of the NHS Act 2006). The Designated Medical Officer or Dedicated Clinical Officer role (introduced by the Children and Families Act 2014) is likely to be critical in ensuring effective communication and planning between health and education. For effective commissioning to occur, there is a need to collect relevant data about children and young people whose behaviours challenge. (See statement 10 of the benchmarking questionnaire)

Principle 1: A good and meaningful life

The Transforming Care service model states that:

- Children and young people should have access **to activities/services (such as early years services, education, employment, social, sports/leisure) that enable them to lead a fulfilling and purposeful everyday life**
- Children and young people should have access to **education, training and employment which addresses their needs** and which they can access within their local area. To enable this, mainstream service staff may need training from specialists.

Legal duties:

- Disabled children have a right to access to almost every area of public life (Equality Act, 2010)
- School/education must make reasonable adjustments to address barriers to learning (Equality Act, 2010)
- Local authority has a duty to identify and assess SEN and ensure that children with SEN get the level of support which helps them achieve the best possible education outcomes (Children and Families, Act 2014)
- Children must be supported at school for medical conditions (Children and Families Act, 2014)
- Children have a right not to be excluded from school. Any decision to exclude must be lawful, reasonable and fair and (in excluding a child) schools have a duty not to discriminate on the basis of their disability. In particular, schools should pay due regard to the fact that disruptive behaviour can be an indicator of unmet need. (DfE Guidance: Exclusion from maintained schools, Academies and Pupil Referral Units in England, 2012)
- Local Authorities must provide all the special education provision specified in Education, Health and Care (Children and Families Act, 2014)
- Any health provision identified in the EHC plan to support the child's special educational needs must be provided by the local health provider (usually the CCG)
- Social care provision under the Chronically Sick and Disabled Persons Act (CSDPA) 1970, which has been assessed as necessary to support a child or young person's special educational needs and which is specified in their education, health and care plan must also be provided by the Local Authority
- Under the Care Act, (2014) local authorities must continue to provide children's services until adult provision has started or a decision is made that the young person's needs do not meet the eligibility criteria for adult care.

Principles 2 and 3: Child and family carers at the centre

The Transforming Care service model states that:

- Children and young people should have a **person centred care and support plan**, for those eligible this should take the form of an Education, Health and Care (EHC) plan
- Children and young people should be offered a named **local care coordinator** or keyworker to coordinate and ensure timely delivery of a wide range of services.
- Increasingly, children and young people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges should expect to be offered a **personal budget, personal health budget, or integrated personal budget** across health and social care.

Legal duties:

- Children have a right to be involved in all decisions about them even if they lack competence or capacity (Mental Health Act Code, 2015)
- Children and young people have a right to support to assist them with decision making, including communication appropriate to a child's needs and seeking the views of those close to them. (Mental Capacity Act, 2005; Care Act, 2014)
- Local authorities must ascertain and give due consideration to the wishes and feelings of "looked after" children. (Children Act, 1989)
- Education, Health and Care plans must reflect the views, interests and aspirations of children, young people, and their parents/carers (Children and Families Act, 2014)
- In the drafting of an Education, Health and Care plan, Local Authorities must have regard to the:
 1. Views, wishes and feelings of child and their parent
 2. Child and parent participating as far as possible in decision making
 3. Child and parent being provided with sufficient information and support to be able to participate
 4. Supporting the child and parent to facilitate their development and help them achieve the best possible educational and other outcomes (Children and Families Act, 2014)

Principle 4: Support to my family and paid staff

The Transforming Care service model states that:

- Children with a learning disability and/or autism who have a mental health condition or display behaviour that challenges should be offered non-statutory **advocacy**, which should be available to them either at key transition points and/or for as long as they require at other times in their lives.
- Parents should be offered practical and emotional support and **evidence-based parenting training**, in line with NICE guidance, which are targeted to their specific challenges and needs.
- Families should have **access to short breaks** suitable for people whose behaviour challenges, and support to care for their child from specialist multidisciplinary teams.
- Children should be supported by **staff trained and experienced in supporting people with behaviours that challenge**, mental health conditions and those who may have come into contact with or are at risk of coming into contact with the criminal justice system. These

staff should be able to deliver proactive and reactive strategies to reduce the risk of behaviour that challenges, in line with NICE guidelines.

- Local authorities should use **Market Position Statements** and “strategic provider”/ “preferred provider” frameworks with specific service specifications including requirements for staff training in Positive Behaviour Support (PBS) to develop a market of providers with these skilled staff.

Legal duties:

- Families of disabled children have the right to childcare, up to the age of 18. (Childcare Act 2006)
- Assessment by a Social Worker to determine whether a child is “in need” and to assess social care needs as part of the education, health and care assessment (Children Act 1989, Children and Families Act 2014, Working Together Guidance 2015)
- Development of a children in need plan which forms a realistic plan of action (Framework for the Assessment of Children in need and their families, 2000)
- Family carers have the right to a Carers’ assessment, to determine support required to enable them to continue in their caring role, to access work, education and leisure (Children Act 1989, Care Act 2014)
- Young Carers have the right to have their needs assessed and to have their caring role removed (Children Act 1989, Care Act 2014)
- A range of short break services must be provided to families of disabled children by local authorities (Breaks for Carers of Disabled Children Regulations 2011)
- Local authorities are under a duty to provide families the choice of receiving a direct payment in lieu of the support they would have been provided with under section 17 of the Children Act. 1989.
- At key points in their interaction with health and care services, people should have access to different types of independent advocacy. (MCA 2005; MHA 2007; The Care Act 2014)

Principle 5: Where I live and who I live with

The Transforming Care service model states that:

- Young people should be offered a **choice of housing, including small-scale supported living**. Choice about housing should be offered early in planning processes for the transition from childhood to adulthood.
- Young people should be offered **settled accommodation**. This should include exploring shared or single home ownership, or ensuring security of tenure.
- Commissioners need to work closely with housing strategy colleagues to ensure that the future needs of this cohort are understood, considered and planned for strategically and form part of the **local housing strategies**.

Legal duties:

- Housing Authorities are obliged to have specific regard to disabled children (Chronically Sick and Disabled Persons Act 1970)
- Housing Authorities have a duty to provide adaptations through the Disabled Facilities Grant (DFG)
- Housing authorities must provide suitable accommodation if the family is homeless (Housing Act 1996)
- Children’s services must provide suitable accommodation if parents are prevented (for whatever reason) from providing their child with suitable accommodation or care. (Children Act 1989)
- Local Authorities must safeguard and promote the welfare of disabled children who are “looked after” and ensure, so far as is reasonably practicable, that the placement is close to home, does not disrupt education and is suitable to the child’s needs as a disabled child (Children Act 1989)
- Article 8 of the Human Rights Act covers the right to respect for private and family life. This includes the right to enjoy family relationships and the right to live with family and, where this is not possible, the right to regular contact.

Principle 6: Mainstream health services

The Transforming Care service model states that:

- **Children and young people should have a Health Action Plan.** Where appropriate it should include a ‘**Hospital Passport**’ to help staff in mainstream NHS services make the reasonable adjustments for the individual (including to accommodate behaviour that challenges) that are required by law.
- Everyone with a learning disability over the age of 14 should have an **Annual Health Check**. This is particularly important for those with communication difficulties.
- Children and families should expect universal NHS services to employ clearly identified and readily accessible ‘**liaison**’ staff who have specific skills in working with people with a learning disability and/or autism, and are able to advise those services on reasonable adjustments.
- Children and families should expect ‘**quality checker**’ schemes to be in place ensuring that mainstream services serve them appropriately.
- In **mainstream mental health services**, children and families should be able to expect services regularly to audit how they serve people with a learning disability and make improvements as a result, using the Green Light Toolkit. New initiatives and investment in mainstream mental health services (such as new investment in CAMHS, IAPT and the Crisis Concordat) should improve access to those services.

Legal duties:

- Regular developmental checks mandated under the Healthy Child Programme (Universal Health Visitor Reviews Guidance, Department of Health, 2015)
- Duty to make reasonable adjustments – anticipating needs and taking steps to meet them. (Equality Act 2010) so that children with SEN have an equal right of access to healthcare services
- Duty on health bodies to bring children who have SEN or probably have SEN or disability to the attention of the appropriate Local Authority (Children and Families Act 2014)

Principles 7 and 8: Specialist multi-disciplinary health and social care support in the community

The Transforming Care service model states that:

- Local areas should maintain an **'at risk' register** to provide those most at risk of admission to hospital (or 52 week school) with proactive, preventative support.
- Children and young people should have access to **integrated specialist multidisciplinary health and care support in their community**. This needs to include those children who may have come into contact with or be at risk of coming into contact with the criminal justice system, including people with lower level social care and/or health needs.
- Children and young people with a learning disability and/or autism may require additional support to **prevent or manage a crisis**. This support should be provided by a highly-skilled and experienced multi-disciplinary/agency team with specialist knowledge in managing behaviours that challenge.
- Children and young people with a learning disability and/or autism, who have come into contact with or may be at risk of coming into contact with the criminal justice system, should have **access to the same services aimed at preventing or reducing anti-social or offending behaviour as the rest of the population**. (Including those provided by youth offending teams, liaison and diversion schemes, as well as troubled family schemes and programmes such as those for drug and alcohol misuse).

Legal duties:

- The Children Act 2004 placed a statutory duty on local authorities (LA) to establish Local Safeguarding Children Boards (LSCBs). They are responsible for ensuring effective local arrangements are in place and having oversight of early help arrangements, clarifying thresholds, and developing a local framework for learning and development.
- Co-ordinated assessment of education, health and social care (EHC) needs for children and young people with SEND (Children and Families Act 2014) Provision required under section 2 of the Chronically Sick and Disabled Persons Act 1970 must be included within the EHC plan.
- The Children and Families Act allows for further integration so that a number of assessments can be carried out at once (for example, an assessment under s17 of the Children Act or an assessment under the Care Act 2014)
- Local Authorities, CCGs and NHS Specialised commissioning must make available the provision specified in the education and health sections of the EHC plan. This may include input from Positive Behaviour Support Specialists for challenging behaviour, (Children and Families Act 2014)
- Young people and parents of children who have EHC plans have the right to request a personal budget which may contain elements of education, social care and health funding. (Children and Families Act 2014)
- Challenging behaviour is now a specific domain under NHS children's continuing care guidance and those in receipt of continuing care funding have a right to a personal health budget (NHS Commissioning Board and Clinical Commissioning groups Regulations 2013)
- Health bodies and local authorities must ensure that children and young people with learning disabilities receive equal access to all tiers of CAMHs, including adequately staffed learning disability specialist CAMHs. (Equality Act 2010 and NSF standard 9)

- There must be person centred planning for the transition to adulthood, including educational transition planning from the review meeting in year 9 (SEND regulations 2014), social care transition planning, involving input from CCGs (Children Act 1989), and support from an independent advocate for the transition assessment process if the young person would experience substantial difficulty in being involved otherwise (Care Act 2014).
- All reviews taking place from Year 9 at the latest and onwards must include a focus on preparing for adulthood, including employment, independent living and participation in society (SEN Code of Practice)

Principle 9: Hospital

The Transforming Care service model states that:

- For all inpatient provision (secure or not) **children** admitted to hospital should be placed in an environment suitable for their age and must have access to education, and provision of **single-sex accommodation** is essential.
- Community Care and Treatment reviews (CTRs) should be used to prevent admissions, as set out in the CTR pathway.

Legal duties:

- Any hospital environment must be age appropriate (MHA 1983)
- Children and young people who lack capacity must have support from an independent mental health advocate if family carers are not able to advocate for them and when significant decisions about their care are being made, they are in hospital for longer than 28 days or in a social care residential placement for longer than 8 weeks.