

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

Introduction

Building the Right Support (NHS England et al., 2015) sets out 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. The plan covers children and young people as well as adults. It includes a new service model of local support arrangements to prevent admission.

This set of resources were commissioned and funded by the NHS England Transforming Care Programme. These resources have been developed by Jacqui Shurlock (The Challenging Behaviour Foundation) and Carol Robinson (National Development Team for Inclusion). They draw on previous research, guidance and best practice and were informed by visits to four local areas. We are grateful to the members of the steering group who have overseen this project and to all the children and young people, family carers, professionals and commissioners in the four local areas who participated in our focus groups and interviews.

The resources are:

1. This explanatory note. Why we need local pathways and who is responsible for them.
2. A reminder of legal duties and guidance already in place with regard to support for this group of children and young people.
3. A practical guide to help support development of local pathways.

Why do we need local pathways for children and young people with learning disabilities and autism who display behaviours that challenge?

To improve outcomes for children and families

Children displaying challenging behaviours are at greater risk of social exclusion, institutionalisation, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions (McGill et al., 2012). They are also more likely to be both perpetrators and victims of crime. Poor outcomes are experienced not just by children themselves but by their families too. Carers face an increased risk of physical and mental-ill health, physical injury, increased financial burdens, and reduced quality of life

Figures from the *Learning Disability Census* (HSCIC, 2015) show that were 165 children and young people with learning disabilities under the age of 18 living in ATUs. 36% of these children and young people are in hospitals 100km or more from home. This figure rises sharply for 18-25 year olds, with

725 living in Assessment and Treatment Units (HSCIC, 2015). Nearly two thirds of those under 18 had been given anti-psychotic medication on a regular basis. Young people were also the most likely in-patients to suffer certain types of incident in the three months leading up to the Census, notably self-harm, hands-on restraint, and seclusion.¹

Many more children with learning disabilities or autism live out of area in 52 week schools (1100 children were identified in a recent survey, based on responses from 148 local authorities²) with 75% placed more than 20 miles from home. Research shows that challenging behaviour is a key factor that leads to exclusion from mainstream schools, breakdown of placements and family breakdown. Parents have indicated that these breakdowns formed part of the reason why children were placed at a residential school that is out-of-area. For those living out of area, residential placements for children with learning disabilities and autism reduce family contact, increase young people's vulnerability, and accentuate the difficulties of transition to local adult provision (McGill, 2008).

Around a quarter of children and young people in custody have learning disabilities.³ Some children and young people who have learning disabilities and/or autistic spectrum conditions are particularly vulnerable to exploitation by people they perceive as 'mates', or by more defined gangs, and such exploitation may include persuading/coercing the young person to commit crimes. In addition, some young women are highly vulnerable to domestic violence and sexual exploitation and again may be persuaded or coerced into criminal behaviour. Difficulties with understanding cause and effect, managing anger or understanding relationships and intimacy may lead to offending behaviour yet these are potentially amenable to early intervention.

To target public funding more effectively

The Challenging Behaviour Foundation Academic Expert Group published an evidence briefing in 2014 citing the costs for those aged 17 or under in Assessment and Treatment units as over £46 million per annum with an average annual cost of almost £250,000.⁴ Young people were the most likely of any age group of inpatients with learning disabilities to be in placements costing in excess of £230,000 per annum (*Data supplement, 2014*).

The most recent robust cost estimates, updated to reflect current prices, put the average annual cost of an out of authority placement at £99,798 for a boarding place, rising to £171,176 for a 52 week residential placement. Return to the local area is very difficult to achieve. Instead young people often move to adult placements in residential care homes or colleges out of area. Annual individual service costs of between £89,335 and £358,415 have been identified for adults with severely challenging behaviour (*Data supplement, 2014*).

¹ Some caution must be attached to these figures as data quality checks raised concerns about the reporting of date of birth information, particularly for this younger age group.

² NHSE (2016) Survey of Local Authority Areas regarding Children and Young People with Learning Disabilities and / or Autism Placed in 52 Week Residential Schools- summary report

³ Foundation for People with Learning Disabilities : <http://bit.ly/29tCmtY>

⁴ Estimate reached as follows: (no. of service users for each cost band) x (mid-point in weekly charges) x 52 weeks. For placements >£6499, a charge of £7000 was assumed. For placements <£1500, a charge of £1000 was assumed.

The London School of Economics conducted an economic analysis of a local service for young people with learning disabilities who display behaviour described as challenging who were at imminent risk of residential placement and stated that it “shows that a crisis does not have to result in an unplanned admission to hospital or a move to a 52 week school. Crises can be well-managed locally in what look very cost effective ways using a positive behavioural support approach” (Iemmi et al., forthcoming).

There is consensus among academics in this field that, as well as averting crisis situations, local support services should be identifying difficulties early in childhood and using evidence-based approaches to address those difficulties. This approach has the potential to deliver significant social and economic benefits. This is particularly true where problems are likely to escalate over time, limit the life chances of the individual, and result in significant costs to society (*Briefing Paper*, 2014).

To fulfil the duties under the Children and Families Act 2014

The Children and Families Act (2014) brought in a requirement for formal Joint Commissioning Arrangements between local authorities, relevant CCGs and NHS England specialist services for children and young people with SEN and disabilities. In order to fulfil the commitments of the Transforming Care programme and the requirements under the Children and Families Act (2014) for this cohort of children and young people, these joint commissioning arrangements should work with local families to review the support in place locally for children with learning disabilities and/or autism whose behaviours challenge (including those with a mental health condition) in order to identify changes required. This should include a focus on how well other local plans (including Future in Mind Implementation plans) are addressing the needs of this group.

NHS England is currently piloting the use of Integrated Personalised Commissioning for a number of vulnerable groups, including children with learning disabilities. A widespread adoption of this approach would be a significant step forward in ensuring a responsive approach to commissioning effective local support for this group.

Ofsted CQC joint area inspections will be focussing on how well the requirements of the Children and Families Act are being fulfilled for vulnerable groups and those with low incidence needs, including children with learning disabilities and/or autism whose behaviours are described as challenging.

Who is accountable for development and delivery of local pathways?

Transforming Care Partnerships are responsible for driving service re-design for people with learning disabilities and/or autism, with behaviour that challenges – including those with a mental health condition. This includes improving the way local services are commissioned and provided for children. There is no one agency responsible for commissioning services for this cohort of children and young people, who will generally need a wide range of input from different services.

Local authorities have responsibility for children’s services (including early years services, Health Visiting, family information, SEND reforms, social care, short break provision, direct payments/personal budgets, advocacy)

The Children and Young People’s Partnership Board is a strategic partnership of statutory and non-statutory agencies and services that provide services for children, young people and families. The board oversees the planning and commissioning of services. It has a role in bringing partners together to identify and meet areas of specific need to improve the life outcomes for all children and young people.

CCGs and NHS England Specialised Commissioning have responsibility for health services (including GPs, the Healthy Child Programme, Child Development Centres, therapies, children’s continuing health care, school nurses, CAMHs, Future in Mind, personal health budgets, advocacy)

Local Authorities, Academies, Special schools, FE colleges, the Department for Education and the Department for Business, Innovation and Skills are responsible for education for children and young people age 0-25.

In some areas, **behaviour support** is provided by CAMHs learning disability teams (health funding), while in other areas it is provided by specialist teachers (education funding). Some areas have positive behaviour support teams (funded through a range of routes, examples include health funding, joint education and health funding and funding from children and adults social care and sometimes with several local authorities sharing costs and resources). More often, evidence-based behaviour support for this group of children and young people is simply missing. The impact of this gap has been well-documented and is likely to lead to poor outcomes for this group of children, as well as significant costs (for example through out of area placements). Historically, the system has meant that health, education and social care have looked to pass these costs onto another agency, rather than working together to meet a child’s identified needs in their local community.

The Children and Families Act 2014 brought in a requirement for formal **Joint Commissioning Arrangements** between local authorities, relevant CCGs and NHS England specialist services for children and young people with SEN and disabilities. These joint commissioning arrangements are likely to be the most effective way to review and commission improved local services for children with learning disabilities whose behaviours challenge. **Designated Medical Officers** will have a particularly key role in ensuring provision is made for those who have education, health and care plans bearing in mind the clear links between health and behaviours that challenge among this group of children and young people.

Transforming Care Partnerships should ensure that local SEND joint commissioning boards have the information they need about the best evidenced ways to support this group of children and young people, in order to:

- Ensure that children and young people currently living in inpatients units are able to return home. This will usually require individualised commissioning of a support package designed around the needs of the individual child.
- Develop local challenging behaviour pathways with an emphasis on early intervention and prevention.

Transforming Care Partnerships and Children and Young People’s Partnership Boards should clarify who is accountable for delivery of each element of the pathway as well as who is responsible for providing strategic oversight and co-ordination.

Local pathways should be included within the “**local offer**” of services for children with SEND and regularly reviewed as part of the commissioning cycle.

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