



Developing support and services for children and young people with a learning disability, autism or both



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### **Document Status**

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# Developing support and services for children and young people with a learning disability, autism or both

Supplement to Supporting people with a learning disability, autism or both who display behaviour that challenges, including those with a mental health condition: Service model for commissioners of health and social care services (October 2015)

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**Equality and Health Inequalities Statement** 

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

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### Introduction

The Transforming Care programme aims to transform services and support for children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. NHS England and the Local Government Association (LGA) are committed to this transformation.

In line with the provisions of both the Children and Families Act and Care Act, which focus on outcomes, personalisation and wellbeing, this commitment focuses on strengthening support in the community by building on the provision of preventative support that will avoid crises and help support people to be active members of the community, with all the benefits that brings.

In 2015 we published our national strategy 'Building the Right Support', and a national service model setting out what good services and support look like for people with a learning disability, autism or both who display behaviour that challenges, including those with a mental health condition. The service model is all-age and takes into account the needs of children and adults from all our diverse communities.

In her review for the Department of Health of care for children and young people with complex needs (and behaviour that challenges), Dame Christine Lenehan, recommended that we issue supplementary guidance for commissioners to set out in more detail how the national service model applies to children. This document seeks to do that.

The Department for Education supports the development of the work undertaken in the Transforming Care Partnership Boards and encourages local authorities to pay regard to this guidance

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.

**Service Model Vision Statement** 

### Who this document is for

To deliver the Transforming Care agenda, 48 Transforming Care Partnerships (TCPs) have been established across the country. The national service model was aimed at supporting TCPs to formulate joint transformation plans. This supplementary document is therefore aimed at all TCP partners in order to ensure that plans are encompassing of children and young people, and that they align with related children and young people's initiatives.

### Who this document is about

This document is about children and young people with a learning disability, autism or both who display behaviour that challenges, including behaviour which is attributable to a mental health condition.

It includes those with autism (including Asperger Syndrome) who do not have a learning disability, as well as those who have both a learning disability and autism. It also includes those young people with a learning disability, autism or both whose behaviour can lead to contact with the youth justice system.

Throughout this document "children and young people" are defined as aged 0-24 to align with SEND reforms. The Children and Families Act 2014 defines a 'young person' as being over compulsory school age but under 25.

Transforming Care Partnerships are responsible for meeting the needs of a diverse group of children and young people with a learning disability, autism or both who display, or are at risk of developing behaviour that challenges, including those with mental health conditions.

TCPs should be addressing the needs of the following groups.

- 1. Children and young people with a learning disability, autism or both who have or are at risk of developing a **mental health condition** such as anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- 2. Children or young people with an (often severe) learning disability, autism or both who display or are at risk of developing self-injurious or aggressive behaviour, not related to severe mental ill health. Some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.
- 3. Children or young people with a learning disability, autism or both who display or are at risk of developing, risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).

4. Children or young people with a learning disability, autism or both, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance misuse, troubled family backgrounds) who display or are at risk of developing, behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.

This is not an exhaustive list. These groupings cannot cover the complexities of every young person, nor all the causes of certain behaviours; individuals do not 'slot neatly' into any single grouping. However, they demonstrate the range and complexity of the group of children and young people that the Transforming Care programme is about, and some common themes and needs that will require consideration and planning for by TCPs.

The main text of this document, structured around nine core principles, describes what good services and support look like for children and young people with a learning disability and/or autism who display behaviour that challenges. Annex C describes how things should change as a result of the service transformation described.

### Principle 1 - I have a good and meaningful everyday life

- 1.1 Children and young people have the right to a good and meaningful everyday life. This means being part of a well-supported loving family, having friends, trying new things and having fun. Children and young people tell us they want to go to their local school and get a paid job when they become adults. Families should expect coordinated support and the services they need to make that a reality. Ensuring access to meaningful activities and robust person-centred support is essential in preventing behaviour that challenges.
- 1.2 Children and young people should have their needs met at home or as close to home as possible. This should include an opportunity to **attend their local school**, **with the right support**, **where possible.** In line with Public Health England guidance, <sup>1</sup> School Nurses should play a key role in ensuring staff in schools and colleges have a good level of support and training to work with children and young people with a learning disability, autism or both. SEN Coordinators could play a similar role. TCPs should ensure there is a process in place to ensure the right agencies, including those delivering specialist multidisciplinary intensive support (see Principle 7 in this document) are involved in the planning and delivery of support for any individual who is close to exclusion from school or may be subject to an out of area placement.
- 1.3 Children and young people should have support in **developing and maintaining positive relationships** to reduce the risk of social isolation, enhance personal safety and to reduce the risk of socially unacceptable behaviours going unchecked. This is an essential component of a good quality of life and a protective factor against behaviours that challenge. **Reasonable adjustments must be made to enable children to access a range of universal services, including childcare settings, playgroups, playgrounds, youth clubs, sport and leisure**. The Local Offer<sup>2</sup> must be clear regarding expected reasonable adjustments for children and young people whose behaviour challenges in universal provision, and encourage inclusion and citizenship in line with Public Sector Equality Duties. The Local Offer should also clearly set out opportunities for children and young people who display behaviour that challenges.
- 1.4 TCPs should ensure high aspirations for children and young people with a learning disability, autism or both by commissioning a full range of training grounded in equality and inclusion for staff working in a wide range of universal and specialist settings; including training on the social model of disability, learning disabilities and autism, supporting children who display behaviour that challenges, and why supporting parents and carers is important. This should include the use of the Disability Matters materials which have been co-produced with parents and carers and young people including those with these this range of needs. Families and individuals with direct experience of learning disabilities, autism and challenging behaviour should be involved in the delivery of the training wherever possible.

<sup>&</sup>lt;sup>1</sup> Overview of the Six Early Years and School Aged Years High Impact Areas Public Health England 2016

<sup>&</sup>lt;sup>2</sup> Section 4.31 SEND Code of Practice Department for Education January 2015

Disability Matters is a free and flexible learning resource to help those who work, volunteer or engage with disabled children and young people and their families. Developed in co-production with parent carers and young people with disabilities and with 58 modules ranging from Learning Disability Matters and Autism Matters to Mental Capacity Act Matters and Deprivation of Liberty Matters, it is available by going to https://www.disabilitymatters.org.uk/

- 1.4 In addition, the local authority must publish a **short breaks offer**<sup>3</sup> which adequately meets the needs of children with learning disability, autism or both. Specialist short breaks provision should be made for those who display behaviours that challenge and this should be included in the Local Offer (see principle 4.5).
- 1.5 As young people grow older they should be supported to seek and secure work experience, and learn skills that will help them **get into a paid job** when they reach adulthood. To enable this, support providers and multi-disciplinary specialist health and social care teams (see principle 7) should provide training and support to mainstream service staff and/or provide support to individuals and their families/carers that enables them to participate in mainstream services, and to access education and training within local schools and colleges. Commissioners should also seek to ensure that supported employment/ training services meet the needs of this group. Under the Children and Families Act, preparation for entry into adulthood, including employment, should be considered early and form part of transition planning.

### Relevant legislation and guidance

- Where a disabled person is substantially disadvantaged, reasonable adjustments must be made to avoid those disadvantages. Section 20 Equality Act, 2010
- The responsible bodies of schools and education providers must make reasonable adjustments to address barriers to learning, including the provision of auxiliary aids where reasonable. Section 20 of and Schedule 13 to the Equality Act 2010
- Children with medical conditions must be supported to attend school in specified circumstances. Section 100 Children and Families Act 2014
- Any decision to exclude a child from school must be lawful, reasonable and fair; when excluding a child, schools must not discriminate on the basis of disability. Schools should recognise disruptive behaviour can be an indicator of unmet needs. Section 2 Statutory guidance: Exclusion from maintained schools, Academies and Pupil Referral Units in England, Department for Education 2012

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<sup>&</sup>lt;sup>3</sup> Section 5 The Breaks for Carers of Disabled Children Regulations 2011

## Principle 2 - My care and support is person-centred, planned, proactive and coordinated.

- 2.1 Children with a learning disability, autism or both should be identified at the first opportunity. Local authorities are required by law to identify children and young people who have or may have special educational needs and who have a disability, and when a clinical commissioning group, NHS trust or NHS foundation suspect that a pre-school child has (or probably has) special educational needs or a disability, they have a responsibility to discuss this with the parents and in turn inform the appropriate local authority<sup>4</sup>. Staff working across health, education and social care (but particularly Health Visitors and School Nurses) should have the skills and knowledge to identify the signs and symptoms of learning disability and autism. TCPs should ensure that the Healthy Child Pathway plays a key role in early identification of children with a learning disability, autism or both<sup>5</sup>.
- 2.2 When a learning disability or autism is first suspected children, young people and their families should have access to timely assessment and/or diagnosis. There should be clear local assessment pathways; timescales for autism assessment should be in line with NICE guidance and formal assessments for learning disability should follow a similar process. Practical support should not be dependent on diagnosis and should be offered alongside assessment processes.
- 2.3 Commissioners should risk stratify their population of children with a learning disability or autism, and provide early support to those children more likely to develop behaviours that challenge (or their families). Challenging behaviour can be reduced through prevention strategies, including reducing risk factors (for example, improving physical health), positive reinforcement of other behaviours, promotion of alternative adaptive behaviours (for example developing communication skills). Preventative support (such as evidence-based parenting training or support from multidisciplinary teams, as described later in this document under Principles 4 and 7) could, for instance, be prioritised for children with a learning disability and/or autism who have a neurodevelopmental condition that makes behaviours that challenge more likely, have unmet physical and/ or mental health needs, face high rates of environmental adversity, or demonstrate sensory and/ or communication needs. The dynamic risk stratification process should ensure children and young people at risk of admission to specialist hospitals, (including those currently in 52-week residential schools) are included on a local register, in line with the updated CETR policy as well as other children and young people who meet the criteria.6.
- 2.4 Person Centred approaches should be promoted across all settings. TCPs must ensure early years' services, and school and further education providers are able to access training in person-centred planning and approaches. Every child with a

<sup>&</sup>lt;sup>4</sup> Section 23, Children and Families Act 2014

<sup>&</sup>lt;sup>5</sup> Guidance to support the commissioning of the Healthy Child Programme 0-19: Health Visiting and School Nursing services Public Health England 2016

<sup>&</sup>lt;sup>6</sup> The requirements of local registers are described in more detail in the Care and Treatment Review Policy published by NHS England in March 2017

learning disability, autism or both should be offered a **single person centred care and support plan**. **Education, Health and Care Plans (EHCPs) should be used** whenever a child or young person is eligible for one<sup>7</sup>. Where a child with a learning disability, autism or both who displays behaviour that challenges is not eligible for an EHCP; a locally developed person centred support plan should still be put in place.

Local areas must develop robust systems and governance to ensure that EHCPs contain:

- a. Appropriate and timely contributions from each of the partner organisations
- b. Evidence from a Positive Behaviour Support Plan and/ or functional assessment where one has taken place (and the resulting support required to access support from education, health and care)
- c. Clear and measurable outcomes based on aspirations and needs, these should include life outcomes such as having a job, independent living, community inclusion and maintaining good health.
- d. A clear plan of provision that is tailored to the child's needs.
- 2.4 Annual reviews should increasingly look forward to adulthood and be based on person centred approaches. A key element is preparing the child or young person for the meeting and making sure they have a voice. From year nine, the review should include a focus on preparing for adulthood, looking at achieving life outcomes such as employment, community inclusion, housing and achieving good health. For information on good practice in conducting a review see the good practice toolkit produced by Preparing for Adulthood<sup>8</sup>. There should be a named lead for transition and clear plans should be put in place to support the transition between child and adult services across health, education and social care. Commissioners should ensure that young people who are likely to need support from adult services, are able to have a timely transition assessment and that plans are always put in place promptly especially in relation to housing and support needs.
- 2.5 Children and young people, particularly those at potential risk of admission should have a **named local care and support navigator** (often described as a **keyworker**). The keyworker should coordinate and ensure the timely delivery of a wide range of support and services set out in the single plan. They will work closely with the child or young person and their family and ensure a consistent point of contact. A keyworker should support regular multi-agency planning meetings and reviews of provision, ideally managed as a 'Team Around the Child' package of support. There should be appropriately skilled people available to act as keyworkers for children, young people and their families when there are two or more services involved in providing support. Appropriate keyworker training should be available across all partner organisations and there should be a clear system for the allocation and support of key workers. For more information about developing effective keyworking go to:

https://councilfordisabledchildren.org.uk/help-resources/resources/developing-keyworking

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<sup>&</sup>lt;sup>7</sup> S.37, Children and Families Act 2014

<sup>&</sup>lt;sup>8</sup>Preparing for Adulthood Review – a Good Practice Toolkit NDTi/ Council for Disabled Children in partnership with Helen Sanderson Associates January 2015

### Relevant legislation and guidance

- A Local Authority must identify children and young people who have or may have special educational needs and who have a disability. Section 22 Children and Families Act 2014
- CCGs, NHS Trusts and NHS Foundation Trusts have a duty to bring to the attention of the local authority children under compulsory school age who in their opinion have or probably have a special educational need or disability. Section 23 Children and Families Act 2014
- Local commissioning bodies must secure the provision specified in an Education, Health and Care plan (EHCP). Section 42(1) Children and Families Act 2014
- Local authorities must have regard to:
  - (a) The views, wishes and feeling of the child and his or her parent or the young person;
  - (b) The importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned;
  - (c) The importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions;
  - (d) The need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes. Section 19 Children and Families Act 2014
- Everyone involved in assessment and planning should adopt Person Centred approaches. Those working with children and their families should focus on the child or young person as an individual and should enable children and young people and their parents to express their views, wishes and feelings.

Section 9.22 SEND Code of Practice, Department for Education January 2015

 Requirement for co-ordinated assessment of education, health and social care needs for children and young people with SEND.

Section 26(4) The Children and Families Act (2014)

 Alignment of other assessments with EHC assessment and plans (a number of assessments can be carried out at once e.g. an assessment under s17 of the Children Act or an assessment under the Care Act 2014)

Section 10.18 SEND Code of Practice, Department for Education January 2015

 CCGs must have mechanisms in place to ensure practitioners and clinicians will support the integrated assessment process.

Section 9.70 SEND Code of Practice, Department for Education January 2015

There must be person centred planning for the transition to adulthood, including:

- Educational transition planning from the review meeting in year 9
- Social care transition planning, involving input from CCGs, and
- Support from, for example, an independent advocate for the transition assessment process if the young person would experience substantial difficulty in being involved otherwise.

Section 8.9, 8.10, 9.25 SEND Code of Practice, Department for Education January 2015

 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

Section 66 Care Act 2014 amendment to Children Act 1989 section17ZH

# Principle 3 - I have choice and control over how my health and care needs are met

- 3.1 Children, young people and their families should be actively **involved in every** aspect of the strategic planning, development, and commissioning of the services they use, and the design, delivery and review of their own support. Commissioners should work with existing children and young people's groups, such as school councils, to establish a channel for young people's voices to be heard around policy changes that affect them. Annex A sets out more detailed support in this area.
- 3.2 When a learning disability, autism or both is suspected or diagnosed, parents should be offered **timely access to information** on how to access the support they need, including where English is not the first language. This should include information about behaviours that challenge and how to access mainstream and specialist support, if necessary. The Local Offer<sup>9</sup> should set out information about the support and services available to children, young people and their families in their local area. This should include clear information about the roles of the different professionals. Professionals should be prepared to access the information that families need if families cannot access it for themselves. It should include information about national organisations who can offer information, advice and support. The SEND local offer should be used to understand what is working and what needs to change for people and their families, and identify any gaps into the local joint commissioning strategy.
- 3.3 Personal budgets offer children, young people and their families the opportunity to have greater support over their lives. **Personal budgets should be considered the default option** for those children and young people with an Education, Health or Care Plan or receiving Continuing Care funding. TCPs should use the development of Integrated Personal Commissioning (see Annex B) to offer personal budgets to children and young people outside of these groups. For example, personal budgets can be useful for children, young people and families where existing support such as group based services may have a negative impact on the child's behaviour
- 3.4 The Government's Mandate to NHS England for 2017-18<sup>10</sup> and NHS Operational Planning and Contracting Guidance for 2017-19 reaffirm the Government and NHS England's commitment to the rollout of personal health budgets and integrated personal budgets. The Mandate sets a clear expectation that 50-100,000 people will have a personal health budget or integrated personal budget by 2020. The NHS Operational Planning and Contracting Guidance for 2017-19 require commissioners and providers to submit trajectories for achieving key mandate objectives, including trajectories for personal health budgets. Children in receipt of Continuing Care and young people aged 18-25 receiving Continuing Health Care already have a right to

<sup>&</sup>lt;sup>9</sup> Section 30 Children and Families Act 2014 and regulation 53 and Schedule 2 of the Special Educational Needs and Disability Regulations 2014

<sup>&</sup>lt;sup>10</sup> The Government's mandate to NHS England for 2017-18 https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/601188/NHS\_Mandate\_2017-18\_A.pdf

have a personal health budget and CCGs are required to consider the extension of PHBs to a wider group of children and young people who have complex health needs

3.5 The SEND Code of Practice sets out what local authorities and health partners must do in relation to personal budgets and joint commissioning. Young people and parents of children who have EHC plans have the right to request a personal budget when the local authority has completed an EHC needs assessment and confirmed that it will prepare an EHC plan. Personal budgets should reflect the holistic nature of an EHC plan and can include funding for special educational, health and social care provision. Local authorities must provide information on personal budgets as part of the Local Offer. This should include a policy on personal budgets that sets out a description of the services across education, health and social care that currently lend themselves to the use of Personal Budgets, how that funding will be made available, and clear and simple statements of eligibility criteria and the decision-making processes.

Systems should be put in place to enable young people and families to take a personal budget as a direct payment where suitable, or a notional budget or have it held by a third party. This includes the option of individual service funds which can be an effective way of personalising support from a provider. Partners must set out in their joint commissioning arrangements their processes for agreeing personal budgets. They should develop and agree a formal approach to making fair and equitable allocations of funding and should set out a local policy for personal budgets. The SEND Code of Practice specifies what should be covered. <sup>15</sup>

3.5 Independent **advocacy** should be available in addition to access to peer support or advocacy from someone with direct experience of or living with someone who displays behaviour that challenges. Local areas should consider commissioning independent advocacy for families to enable them to exercise choice and control not just to meet statutory requirements under the Mental Health Act or Mental Capacity Act 2005. The provision of advocacy is particularly key for children in hospital settings.

### **Relevant Legislation**

 Children have a right to be involved in all decisions about them even if they lack competence or capacity

> Section 19.5 Mental Health Act 1983 Code of Practice, Department of Health 2015

 If a child or young person is detained under the Mental Health Act, a comprehensive assessment of their needs should be undertaken to ensure that reasonable adjustments required by the Equality Act are made, which should include communication support

Section 20.31 Mental Health Act 1983 Code of Practice, Department of Health 2015

<sup>&</sup>lt;sup>11</sup> Section 9.98 SEND Code of Practice, Department for Education, January 2015

<sup>&</sup>lt;sup>12</sup> Section 9.99 SEND Code of Practice, Department for Education January 2015

 $<sup>^{13}</sup>$  Para 19 of Schedule 2 to the Special Educational Needs and Disability Regulations 2014

<sup>&</sup>lt;sup>14</sup> Section 3.38 SEND Code of Practice, Department for Education January 2015

<sup>&</sup>lt;sup>15</sup> Section 3.38 SEND Code of Practice, Department for Education, January 2015

 Local authorities must ascertain and give due consideration to the wishes and feelings of "looked after" children, their parents and others whose wishes and feelings are relevant.

Section 22(4) Children Act 1989

Education, Health and Care plans must include the views, interests, aspirations
of the child and his or her parents, or the young person.

Section 9.62 SEND Code of Practice, Department for Education January 2015

 Local authorities must ensure that children, young people and parents are provided with the information, advice and support necessary to enable them to participate in discussions and decisions about their support

Section 1.9 SEND Code of Practice, Department for Education January 2015

• Children who receive Continuing Care and young people who receive NHS Continuing Healthcare have a "right to have" a personal health budget.

Regulation 32B, National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

• All Clinical Commissioning Groups (CCGs) have been required to develop Sustainability and Transformation Plans that demonstrate how personal health budgets and integrated budgets would be included as a way of handing more power to patients, in line with the mandate commitment. To improve the lives of children with special educational needs, CCGs will need to continue to work alongside local authorities and schools on the implementation of integrated education health and care plans and the offer of personal budgets.

Forward View into action: Planning for 2015/16 NHS England

 Local authorities must promote the efficient and effective operation of a market in services for meeting care and support needs to promote variety, quality and by providing sufficient information to enable choice.

Section 5(1) Care Act 2014

# Principle 4 - My family and paid support and care staff get the help they need to support me to live in the community.

- 4.1 The Local Offer 16 should include direct support for the families of children and young people with a learning disability, autism or both who display behaviour that challenges. This should include support from children's centres, child development units and health visiting services. Early advice should be available to parents from relevant services such as children and young people's mental health services or specialist multidisciplinary teams to specifically aimed at supporting this group (see Principle 7).
- 4.2 Parents should be aware of how to access early support through the Healthy Child Programme<sup>17</sup> which at Universal Plus level will include timely, expert advice from a Health Visitor when they need it on specific issues such as postnatal depression, weaning or sleepless children. At the level of Universal Partnership Plus, families can expect ongoing support, with Health Visitors playing a key role in bringing together relevant local services, to help families with continuing complex needs. TCPs should ensure that the Healthy Child Programme in their area supports children and young people with a learning disability, autism or both who display behavior that challenges, and their families.
- 4.3 NICE guidance on challenging behaviour and learning disabilities<sup>18</sup> emphasises the importance of **evidence-based parenting training.** There should be good availability of appropriate, evidence-based parental training to help prevent the onset of behaviour that challenges or to help families manage their child's behaviour; where appropriate these should be specifically adapted for parents of children and young people who have a learning disability, autism or both. Other approaches that are based on the contribution of lived experience should also be considered, potentially planned with the support of local parent carer forums.
- 4.4 Other **practical family support**, which will help to prevent behaviour that challenges, includes access to child care, social care, and practical support including communication aids, benefits, adaptations and equipment. There should be support to make living an ordinary life at home possible, including practical support with sleeping, feeding or toileting. Brothers and sisters should be able to access a full range of support from young carers groups.
- 4.5 **Short breaks must be available**, flexible and able to cater for the needs of this group of children, with appropriately trained staff. TCPs, via responsible commissioners, should commission a full range of specialist respite services and short break opportunities. These should be publicised via the Local Offer. These should include residential and non-residential options and be appropriate for children and young people who display behaviour that challenges.

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 $<sup>^{16}</sup>$  Section 30 Children and Families Act 2014 and regulation 53 and Schedule 2 of the Special Educational Needs and Disability Regulations 2014

<sup>&</sup>lt;sup>17</sup> Healthy Child Programme Department of Health 2009

<sup>&</sup>lt;sup>18</sup> Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges NICE May 2015

4.6 Links with other families going through similar experiences is useful and **peer** support should be promoted and available to families.

### Relevant legislation and guidance

Care Act 2014

 Local Authorities must provide services (for adults) that help prevent people developing needs for care and support

Section 1 (3c) The Care Act 2014

 CCGs must co-operate with Local Authorities in the development and review of the Local Offer

Section 4.14 SEND Code of Practice, Department for Education January 2015

 Parent carers have the right to request a Carers' assessment, to determine support required to enable them to continue in their caring role, to access work, education and leisure

Section17ZD Children Act 1989, Section 1 Carers (Recognition and Services) Act 1995, Section10 of the

 Local authorities have a duty to safeguard and promote the welfare of children within there are who are in need. Children considered to be in need include disabled children.

Section 17 Children Act 1989

- Local authorities may assess a child's need for the purposes of the Children Act at the same time as any assessment of his needs is made under
  - (a) The Chronically Sick and Disabled Persons Act 1970
  - (b) Part IV of the Education Act 1996
  - (c) Part 3 of the Children and Families Act 2014
  - (d) The Disabled Persons (Services, Consultation and Representation)

    Act 2016
  - (e) Any other enactment

Schedule 2 (3) Children Act 1989

- Families of disabled children have the right to childcare, up to the age of 18.
   Section 6(2) Childcare Act 2006
- A local authority must assess whether a young carer within their area has needs for support, and if so what those needs are.

Section 17ZA Children Act 1989

- Local authorities must provide, as appropriate, a range of short breaks including
  - (a) Day-time care in the home of disabled children or elsewhere
  - (b) Overnight care in the homes of disabled children or elsewhere
  - (c) Educational or leisure activities for disabled children outside their homes and
  - (d) Services available to assist carers in the evenings, at weekends and during school holidays.

Regulation 4(2) The Breaks for Carers of Disabled Children Regulations 2011.

 A local authority must prepare a statement for carers in their area setting out details of the range of short breaks services available, the criteria by which eligibility for those services shall be assessed, and how the range of services is designed to meet the needs of carers in the area.

Regulation 5 The 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.

Section 17A Children Act 1989, Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009

 Those working with children and young people should ensure that they are cared for in the least restrictive environment possible

Section 1.4 and 1.5 Mental Health Act 1983 Code of Practice 2015

### Principle 5 - I have a choice about where I live and who I live with.

5.1 The right home and environment can improve independence and quality of life, and can help reduce behaviours that challenge. A comfortable, well adapted home reduces the risk of children developing behaviours that challenge and the risk of them having to move out of the family home. Housing considerations should take into account the whole family and may include for example, a separate bedroom for a child who is very active at night, or space outside for a child to play safely; this should be implemented at the earliest opportunity to avoid potential crises where determined necessary by the appropriate professionals.

TCPs should ensure occupational therapy services, or other appropriately trained professionals, are available to assess the housing needs of families with children or young people with a learning disability, autism or both who display behaviour that challenges (or are identified as being at risk of developing behaviour that challenges)

5.2 Accessible information about housing options must be available to families and housing support should be clearly outlined in the Local Offer. It is important that housing is included in **annual review processes** and appropriate signposting or referrals happen when required. Commissioners should establish processes/governance of EHCPs to ensure housing needs are covered and that planning for future housing is always included for young people from year nine onwards. Social workers, School Nurses, GPs and other health professionals should be prepared to discuss housing with families particularly where there is a child or young person who displays behaviour that challenges.

You can find out more information by reviewing the Life Begins at home – guide to housing for families and children with learning disability, autism or both and a training and development resource for housing, health and social care staff. These resources and learning materials funded by NHS England and produced by Learning Disability England can be found here <a href="https://www.housingandsupport.org.uk/life-begins-at-home">www.housingandsupport.org.uk/life-begins-at-home</a>

- 5.3 For young people not able to continue to live at home (or who are already living away from their family), housing must be discussed sufficiently early that different options can be investigated and carefully planned. Young people returning from out of area placements rarely return to their family home, so a transition assessment under the Care Act 2014 will often need to be started well before the young person's 16<sup>th</sup> birthday as putting appropriate housing and support options in place can take several years. Local areas should produce information for housing providers that outlines the needs of this group of children, young people and their families; and agree plans to increase suitable local housing provision.
- 5.4 For **children and young people who live away from home** every effort should be made to support contact between them and their families; their accommodation must meet their needs and the placement must be reviewed regularly. There should be quality checking of children's placements, and this should include the use of

experts by experience (children, young people or parent carers) as quality checkers, especially when these are outside of the local area.

Please note: Children and young people with a learning disability, autism or both should, wherever possible, receive the support and services they need to continue to live with their family, in their own home or close to home; out of area placements should ordinarily be avoided.

The Challenging Behaviour Foundation and Mencap have published a report based on research with families whose children are in residential placements. Included in the report is guidance on how residential settings should ensure parents can keep in touch with children with a learning disability, autism or both who may be living many miles away from home and their local community. The report includes learning from families, learning from local practice, and the legal framework. You can download the report here www.pavingtheway.works/whats-new/keeping-touch-home/

### **Relevant Legislation**

 Local housing authorities must pay regard to the special needs of disabled people

Section 3 Chronically Sick and Disabled Persons Act 1970

- Local authorities responsible for housing are required to ensure that accommodation provided is suitable to the particular needs of a child Section 22C (8)(d) Children Act 1989
- Every local authority shall provide accommodation for any child in need within their area who appears to them to require accommodation as a result of –
  - (c)The person who has been caring for him being prevented (whether or not permanently, and for whatever reason) from providing him with suitable accommodation or care

Section 20 (1)(c) 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 a
disabled child's needs

Section 22 (3) & section 22C(8) 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 live with family and enjoy stable relationships, where this is not possible there is a clear right to regular contact.

### Principle 6 - I get good care from mainstream health services

- 6.1 Families should expect health visitors and school nurses to have the capacity and skill to play a significant role in supporting children and young people with a learning disability and/or autism who display or are at risk of developing behaviour that challenge. They are responsible for the delivery of the Healthy Child Programme, which should identify unmet health and well-being needs, for example poor communication, speech and language skills, mental health problems, learning disabilities, autistic spectrum disorders, and risk of self-harm and harm to others.
- 6.2 There should be **regular health checks** for children with a learning disability, autism or both who display behaviour that challenges (for general health, and to prevent or treat any health issue that may cause pain or discomfort, which can result in challenging behaviours). Annual health checks for people with a learning disability can be accessed in primary care from the age of 14 years.
- 6.3 Children displaying behaviour that challenges should have a comprehensive paediatric assessment to identify and treat any health conditions that are contributing to their behaviours, for example pain, constipation, eating difficulties, reflux, spasticity or dystonia.
- 6.4 All children with a learning disability, autism or both, particularly those whose behaviours are described as challenging should have a **hospital passport and a clear plan for medical visits**. This should include reasonable adjustments, (for example appointment at a quiet time of the day, or multiple surgeries under one anaesthetic).
- 6.5 For this group of children it is particularly important that **mainstream mental health services are accessible**. Close links should be made between TCPs, CCGs and other local bodies refreshing children and young people's mental health Local Transformation Plans, and TCPs should ensure that their area benefits from the programme of work to improve access to psychological therapies for children and young people, particularly through the training being made available to therapists in evidence-based Psychological Therapies for Children and Young People with Autism and/or a Learning Disability.
- 6.6 When any health or care professional (Health Visitors, School Nurses, GPs, hospital staff) have a concern about behaviour related to learning disability and/ or autism, they need to have clear information about where to go for additional support. Commissioners should ensure they can get that support by funding liaison functions (e.g. acute liaison nurses in hospitals) and specialist multidisciplinary teams (see Principles 7 and 8 below).

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<sup>&</sup>lt;sup>19</sup> Healthy Child Programme, Pregnancy and the first five years of life (Department of Health / DCSF 2009\_

### Relevant legislation and guidance:

 Regular developmental checks are mandated under the Healthy Child Programme

Universal Health Visitor Reviews Advice for local authorities, Department of Health, 2015

 CCGs, NHS Trusts and NHS Foundation Trusts have a duty to bring to the attention of the local authority children under compulsory school age who in their opinion have or probably have a special educational need or disability

Section 23 Children and Families Act 2014

 Where a disabled person is substantially disadvantaged, reasonable adjustments must be made to avoid those disadvantages.

Section 20 Equality Act 2010.

# Principle 7 - I can access specialist health and social care support in the community.

7.1 Children and young people who require additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and social care support** at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be culturally sensitive and be delivered by members of highly-skilled and experienced multi-disciplinary/agency teams with specialist knowledge in managing behaviours that challenge. The functions of this intensive 24/7 support, described in more detail in the model service specification published by NHS England and the LGA, should include:

- assessment, treatment and support for children and young people who display behaviour that challenges
- provision of support, and person specific training for other agencies supporting those individuals
- coordination of transitions from inpatient and other settings (e.g. 52-week residential schools)
- crisis response.

7.2 Specialist support might be provided by a range of services, and often across services (e.g. children's services, Child and Adult Mental Health Services (CAMHS), learning disability CAMHS teams, specialist community learning disability teams, extending eligibility criteria for learning disability intensive support teams). Support should be built around the needs of the individual through a 'Collaborative Care' model, or by combined teams (e.g. all age, learning disability and autism). Children and their families should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services.

### Relevant legislation and guidance

 Local authorities and CCG's must make joint commissioning arrangements for education, health and care provision for children and young people with SEN or disabilities.

Section 26 Children and Families Act 2014.

 For health care provision specified in an EHCP, the CCG (or where relevant NHS England) must ensure that it is made available to the child or young person.

Section 9.141 SEND Code of Practice, Department for Education January 2015

### Principle 8 - If I need it, I get support to stay out of trouble

8.1 Young people who have come into contact with or are at risk of coming into contact with the youth justice system should have access to the same early intervention and prevention services or initiatives aimed at preventing or reducing behaviours that may lead to contact with the law as the rest of the population. They should expect services such as parenting programmes, liaison and diversion, troubled family schemes, gangs services, youth offending teams and other youth services to identify young people with a learning disability and/or autism (or their families) amongst the young people they support, and to make reasonable adjustments so they can effectively support these young people.

This should be achieved through collaboration with and support from specialist multidisciplinary health and social care services for children and young people with a learning disability and/or autism (see principle 7 and 8.3 below). Children and young people with a learning disability, autism or both who are known to Youth Justice Services should be identified as part of TCP's dynamic risk stratification process (see principle 2), enhancing understanding of the population, enabling proactive service coordination across agencies and ensuring clear pathways for young people from and to different services. In some instances, where there is greatest risk, individuals may be included on the local register to ensure they get the appropriate support.

- 8.2 Staff in key mainstream services should be trained or commissioned to provide these children with the right support. For instance, school nurses should be commissioned to work with children and young people with a learning disability or autism who are showing signs of developing behaviour that might put them at greater risk of coming into contact with the criminal justice system, identifying any underlying health or care issues and if necessary referring them to other services. Youth Justice staff should be trained to recognise learning disability and/ or autism and to support this cohort appropriately.
- 8.3 When required, children and young people should have access to specialist multi-disciplinary health and social care support for children and young people who have come into contact with, or are at risk of coming into contact with the youth justice system. The key functions of such support are described in the national model service specification for community forensic support, and include:
  - forensic risk assessment and management of risk in the community to ensure public safety and safety of the individual
  - delivery of offence-specific therapeutic interventions (e.g. to prevent sexual/violent offences)
  - case management of the most complex cases
  - support and training to other agencies providing day to day support to this group
  - consultancy and advice to system partners
  - in-reach support to ensure safe and timely discharge from hospital.
- 8.4 This specialist support function might be provided by a range of services, and often across services (e.g. children's services, Child and Adult Mental Health Services

(CAMHS), learning disability CAMHS teams, specialist community learning disability teams). NHS England plans to commission Forensic CAMHS Outreach services, whose offer would include support for children and young people with a learning disability or autism, and these services are likely to play a key role in providing these specialist support functions in partnership with other agencies. Support should be built around the needs of the individual through a 'Collaborative Care' model. Children, young people and their families should expect continuity of care and support through close collaboration between services/agencies, including between specialist and mainstream services.

8.5 **Liaison and diversion** schemes should seek to support children and young people through the youth justice system, enabling appropriate support from health and social care services. Such schemes should seek to identify people with a learning disability, autism or both from their first engagement with the criminal justice system and should work with specialist multi-disciplinary health and social care services for children and young people with a learning disability, autism or both to improve screening and identification. Clear pathways for diversion to health and social care services should be established through local multi-agency protocols.

### Relevant legislation and guidance

 The Crime and Disorder Act 1998 requires the co-operation of the named statutory partners to form a Youth Offending Team and places a duty upon these partners (LA, police, probation service and health) to co-operate in order to secure youth justice services appropriate to their area.

Sections 38 and 39 of the Crime and Disorder Act 1998

- Under the Crime and Disorder Act 1998, Youth Offending Teams shall include (among others) a person nominated by a CCG or Local Health Board.
   Section 39 (5)(d) Crime and Disorder Act 1998
- All local authorities in England have responsibility for the 'troubled families' programme established by Government in 2012. The aim being to help families turn their lives around and achieve better outcomes for children.

Troubled Families Programme, Communities and Local Government 2012

 NHS England has commissioning responsibility for all age liaison and diversion services that exist to identify offenders who have mental health, learning disability or substance misuse vulnerabilities when they first come into contact with the criminal justice system.

www.england.nhs.uk/commissioning/health-just/liaison-and-diversion/

Principle 9 – If I am admitted for assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to.

- 9.1 Children and young people with a learning disability, autism or both should, wherever possible, receive the support and services they need to continue to live with their family, in their own home or as close to home as possible. **Prior to any hospital admission children and young people should have a community/ pre-admission Care, Education and Treatment Review (CETR)** as defined in the Care and Treatment Review policy 2017, which actively explores all possible alternatives to admission. If there are urgent reasons for admission which has meant a CETR has not been completed prior to admission, the CETR must be undertaken within two weeks of admission.
- 9.2 There must be a **clear rationale for admission to any specialist provision**; there should be a clear assessment and treatment plan. When children and young people are admitted to hospital they should expect treatment to proactively encourage independence and recovery, and their **discharge planning must start at the point of admission.** Children and young people in hospital should be subject to regular review in line with the Care, Education and Treatment Review policy guidance
- 9.3 Any assessment and treatment should be incorporated into the child or young person's broader care and support pathway, education and family life. Hospital providers should work closely with the keyworker and community specialists (e.g. multidisciplinary support services described in principles 7 and 8 above) to support recovery and reintegration into the community as quickly as possible. Children in hospital should have access to education. Children and young people should expect close relationships with friends and families to be supported and maintained. Local commissioners should provide practical and/ or financial support to family members so that they can maintain contact with their child whilst living away from home. Local authorities also have a duty to promote contact between children in need and their families. For more details see the Care and Treatment Review policy 2017 (Annex for children and young people page 49 onwards) and the Care, Education and Treatment Reviews for children and young people Code and Toolkit.<sup>20</sup>
- 9.4 Children and young people who are inpatients should expect their rights to be protected and **independent advocacy should be available** to children and young people admitted to specialist hospitals.
- 9.5 Children and young people admitted to hospital must be placed in the least restrictive setting possible. There must be an active commitment from the provider to reduce any restrictive practices including all forms of restraint (including chemical) and seclusion. The placement must be age appropriate.

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<sup>&</sup>lt;sup>20</sup> Care and Treatment Review Policy *and* Care, Education and Treatment Reviews for children and young people Code and Toolkit 2017 NHS England https://www.england.nhs.uk/learning-disabilities/ctr/

### Relevant legislation and guidance

 Any child admitted to hospital for the treatment of mental disorder should be accommodated in an environment that is suitable for their age, whether or not they are detained under the Act.

### Section 131A Mental Health Act 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,

Section 20.29 Mental Health Act 1983 Code of Practice 2015

- Those admitted are eligible for support from an Independent Mental Health Advocate (IMHA) irrespective of their age, if they are:
  - detained under the Mental Health Act
  - liable to be detained under the Act, even if not actually detained, including those who are currently on leave of absence without leave, or those for whom an application or court order for admission has been completed
  - conditionally discharged restricted patients
  - subject to guardianship, or
  - patients subject to community treatment orders.

Mental Health Act 1983 Code of Practice 2013 section 6.8

- Local authorities have a duty to make arrangements for the provision of advocacy services for looked after children, children in need and care givers making, or intending to make representations under section 26 of the Children Act 1989 and for relevant children or young people making or intending to make a representations under section 24A of the Children Act 1989
- Local authorities have a duty in the Children Act 1989 to promote contact between children and young people who are children in need or who are looked after, and their families, if they live away from home, and to help them get back together if in their opinion, it is necessary to do so in order to safeguard or promote his welfare. The provision of financial support to cover the travel cost of visiting might be essential for those children placed out of area.

Paragraphs 8A, 10, 15 and 16, Schedule 2 to the Children Act 1989

For children, secure settings need to reflect the Children's Act 1989 section 25 arrangements and the Home Office Guidance for Children under 13 years.

### **Annex A – Working in partnership with families**

Local pathways, support and services should be developed in partnership with local children, young people and their families. Families offer a wealth of experience and can offer practical examples of how to make the system work better. Developing a pathway in partnership with families from the outset is key, but it should not be underestimated as a task. Families of children who display behaviour that challenges are likely, due to the difficulties they face, to find it more difficult to attend meetings, especially where they need to find replacement care for their children.

Children and young people have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This can only be done through meaningful engagement with them about their experiences. The views and wishes of this group of children have been historically overlooked. It is not acceptable to use lack of capacity or limited communication skills as an excuse not to seek understanding of the child or young person's perspective. The role of family carers in advocating for children is a key component of effective engagement, as is consultation with families about their own needs.

As well as a direct conversation, other methods of consultation with children and young people might include video diaries, use of photos or picture cues or seeking views of family carers or advocates on behalf of the child or young person. This should be an ongoing process, especially at key decision points; not a one off event. Effective engagement with parents or carers is key. Parents should be involved in discussions about:

- how best to facilitate direct participation with the child/young person
- their understanding of their child's views, wishes and aspirations,
- their own views, wishes and aspirations for their child
- their child's SEN, disability and challenging behaviour and
- information/support/training required by family members in order to provide the best care and support for their child.

	What works	Try to avoid
Identifying the right children, young people and families	Advertising the opportunity as widely as possible, through Parent Carer Forums, (www.nnpcf.org.uk) other networks, services people are likely to access and social media of organisations they are likely to follow.  Being specific about the client group in the invite.  The use of incentives to encourage participation and engagement.  Commission Parent Carer Forums	Inviting only existing forums to participate where young people/families of this cohort may not be represented  Only engaging the same few families each time and missing the harder to reach families.
	to include wider representation	
Engaging directly with young people	Using well planned, creative methods to include a range of young people, including those who are harder to reach, have no spoken communication or display more severe levels of behaviours that challenge.	Excluding those with the most severe learning disabilities or behaviours that challenge.
	Commission disabled children and young people's forums – ensure support for children and young people displaying behaviours that challenge	
Arranging meetings with families	Meetings should be well planned with a clear purpose; Give plenty of notice.	Short notice or meetings in school holidays.
	Timed during the school day or during the evening for working parents.	
	Fund travel costs/ replacement care and other expenses that may preclude some families from participating.	
	Meetings may not suit some people, find out what families think as part of other visits/ appointments.	

	Consider the use of social or multi-media options to enable those to participate who may not be able to attend meetings.	
Timing of engagement	Involving families early and throughout development, so they have a stake in the pathway and will help to make it work	Presenting a fait accompli for comments towards the end of the process.

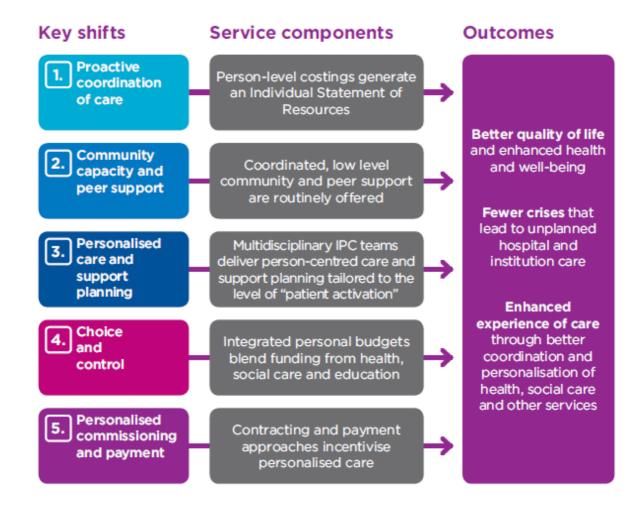
### **Appendix B - Integrated Personal Commissioning**

Integrated Personal Commissioning (IPC) is a new approach to joining up health, social care and other services at the level of each individual. It enables people, carers and families to control the resources available and to 'commission' their own care. It also supports them to develop their knowledge, skills and confidence for self-management through targeted peer support, community capacity building and an expanded role for the Voluntary Community and Social Enterprise (VCSE) sector in preventing, reducing or delaying the need for crisis intervention and acute care. IPC involves 5 key shifts (see diagram).

Through IPC, adults and children with a personalised care and support plans may have the option of a personal budget for all or part of their care. Nine sites are testing out these new models, five of which are including people with a learning disability (Cheshire West and Chester, Lincolnshire, Luton, Hampshire and the South West); others will involve this group as their programmes develop. We anticipate that more sites will be joining the programme later this year. The IPC personal budget may include health, social care or education funding. The IPC Emerging Framework<sup>21</sup> published in May 2016 is based on learning so far from the demonstrator sites and provides an initial blueprint for how the model can be implemented. The detail of the model is being co-produced with demonstrator sites and others including people with lived experience through a collaborative development process, supported by rapid cycle implementation and evaluation. Sites are demonstrating how the IPC operating model can help them to deliver Transforming Care, Future in Mind and the SEND reforms.

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<sup>&</sup>lt;sup>21</sup> https://www.england.nhs.uk/commissioning/ipc



## Annex C – Common Needs and Common Shifts in Service Responses

Children and young people with a learning disability, autism or both, who have a mental health condition such as anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.

### Now:

Too often children and young people fall between mental health and learning disability services and receive little or no support with their mental health; mental health problems may not be picked up or appropriately treated at an early stage. Difficulties with common mental health issues such as anxiety or depression are seen as part of a child or young person's learning disability or autism and appropriate support is not offered.

Some services claim they are not commissioned to work with children and young people with learning disabilities and/ or autism; or don't have the necessary skills or capacity.

Care and support is too often provided in reaction to a crisis and is fragmented, with the young person and their family having little choice or control. The child or young person is often excluded from mainstream school, services or activities.

### **Future:**

Better identification and treatment of mental health problems amongst children and young people with a learning disability, autism or both in the community.

Care and support is more proactive, planned and coordinated, and the individual and their families have more choice and control over what this looks like.

Support and services will be dependent on need rather than diagnosis. Services will actively engage with this population, they are flexible and offer reasonable adjustments. There are people trained in evidence based interventions, such as Positive Behaviour Support.

The child or young person is supported by all agencies to stay in their local school. Access to mainstream services / activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

Where a hospital admission is needed it is as short as possible, part of an integrated care pathway and based on a clear treatment plan; according to individual need and as close to home as possible.

Children or young people with an (often severe) learning disability, autism or both who display self-injurious or aggressive behaviour, not related to severe mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.

#### Now

Too often a lack of early support including delayed assessment and diagnosis can result in behaviours that can challenge services, sometimes leading to family breakdown, with the individual ending up in hospital or another specialist placement.

Specialist services do not anticipate problems or make proactive support readily available to children, young people and their families

Children and young people with a learning disability, autism or both are not always identified early and children and young people with autism have to wait unacceptable periods of time for assessment.

Care and support is too often provided in reaction to a crisis and is fragmented, with the individual, and their families, having little choice or control. The individual is often excluded from mainstream school, services and activities.

### **Future**

Learning disability and autism is identified at the earliest possible opportunity, usually in early years' services. Whenever learning disability and/ or autism is suspected assessment will be timely and always within NICE guidelines

There are highly-personalised, life-long person-centred plans and care and support packages, with highly skilled and resilient families/ staff able to deliver proactive/ reactive strategies based closely on the principles of Positive Behaviour Support for managing behaviours that challenge in the community.

Proactive identification/ treatment of physical and mental health problems, and the individual's day-to-day support in the community is informed by the expertise provided from multi-disciplinary specialist health/ social care teams (stepped up in intensity at times of crisis).

Care and support is more proactive, planned and coordinated, and the individual and their families have more choice and control over what this looks like. Increased access to local schools, services/ activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

Children or young people with a learning disability, autism or both who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).

### Now

Children and young people who may go on to get into trouble are not always identified early. They often have milder learning disabilities or autism and are not eligible for specialist support.

Too often, evidence-based interventions to minimise/ reduce risky behaviour from a young age are not made available; school or social care staff struggle to manage the behaviour, individuals may get involved with a youth justice system which then struggles to deal with needs associated with their learning disability, autism or both; the individual can end up in the youth justice system or a specialist hospital.

Care and support is too often provided in reaction to a crisis and is fragmented, with the individual and their families having little choice or control. The individual is often excluded from mainstream school, services and activities.

### **Future**

There is better early identification and risk stratification of children and young people likely to go on to get into trouble. They, alongside their families, are offered a full range of support.

Evidence-based interventions from a young age, to minimise risky behaviours; care and support packages with the right skills to manage behaviours and risk to others in the community (including through support from multi-disciplinary specialist health/social care teams and specialist forensic health services); liaison and diversion schemes to divert individuals (where appropriate) away from the criminal justice system to appropriate health and social care support or provide support throughout the youth justice pathway; working in collaboration with health and social care partners.

Care and support is more proactive, planned and coordinated, and the child, young person and their family have more choice and control over what this looks like. Access to mainstream school, services and activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life.

Children or young people with a learning disability, autism or both, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance misuse, troubled family backgrounds) who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system

#### Now

Too often, a child or young person displays behaviours that challenge, but their learning disability, autism or mental health problems are not diagnosed (possibly masked by the multiple nature of the child/ family's difficulties). They are unlikely to be eligible for support from a Community Learning Disability Team or social care services; they may also struggle to access or maintain within mainstream school or services.

Care and support is too often provided in reaction to a crisis and is fragmented, with the individual having little choice or control.

### **Future**

Those at risk are identified earlier, mainstream services working to prevent antisocial/ or 'offending' behaviours are better supported to work with children and young people with a learning disability, autism or both; health and social care needs are identified earlier and addressed in the community; care and support packages manage risk to others in the community with support from multi-disciplinary specialist health / social care teams and specialist forensic health services.

Care is more proactive, planned and coordinated, and the individual and their family have more choice and control over what this looks like. Access to mainstream schools, services and activities (taking into account, where relevant, risks posed to others) means the individual lives a purposeful and fulfilling life and avoids getting into trouble in the future.