

## Developing local pathways for children and young people with learning disabilities and/or autism whose behaviours challenge (including those with mental health conditions)

### Tools to develop local pathways

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## 1. Definitions

A child or young person with a **learning disability** will find it harder than other children to understand, learn and remember new things. He/she may need more support with everyday activities such as communicating, keeping safe and managing everyday tasks. The term learning disability refers to a range including mild, moderate, severe and profound/multiple learning disabilities. Although the terms sound similar, a learning *disability* is not the same as a learning *difficulty* such as dyslexia. Learning *difficulties* will generally have less impact on a child's ability to manage everyday life.

Someone who has a severe learning disability will have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe, have difficulties with social skills and need life-long support.

Someone with a mild learning disability may only need extra help in particular areas, for example at school and with social activities. He/she may be able to manage with less support than someone with a severe learning disability as an adult. Some children with a learning disability also have autism.

**Autism** is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. A term sometimes used to cover the range of conditions on the autistic spectrum is Autistic Spectrum Conditions (ASC).

Other terms sometimes used where children may have a learning disability are "special educational needs", "developmental delay", or "complex needs" (where a child also has significant physical or health needs.)

Learning disabilities and autism are not the same as mental health conditions. **Mental health problems** can affect anyone and may be overcome with treatment, which is not true of learning disability or autism. However, children and young people with learning disabilities are more likely than their peers to experience mental health problems.

It is harder for children with learning disabilities or autism to develop the communication and social skills which other children use to get them what they want and need. This may mean that their behaviours are much more challenging and they are unlikely to "grow out" of those behaviours on their own without skilled support to get their needs met in a different way.

Behaviours might be things like:

- Hurting others (e.g. hair pulling, hitting, head-butting)

- Self-injury (e.g. head banging, eye poking, hand biting)
- Destructive behaviours (e.g. throwing things, breaking furniture, tearing things up)
- Eating inedible objects (e.g. cigarette butts, pen lids, bedding)
- Other behaviours (e.g. spitting, smearing, repetitive rocking stripping off , running away)

The terms “behaviours that challenge” or “challenging behaviour” are used when talking about children with learning disabilities or autism, as it is the behaviour which is challenging; not the child. Challenging behaviour is not a condition or something that can be diagnosed, although it may be more likely to be displayed by children with certain diagnosable genetic conditions or mental health conditions.

### **NICE guidelines**

#### Excerpt from NICE guidance on challenging behaviour in people with learning disabilities, published May 2015

Some people with a learning disability display behaviour that challenges. 'Behaviour that challenges' is not a diagnosis and is used in this guideline to indicate that although such behaviour is a challenge to services, family members or carers, it may serve a purpose for the person with a learning disability (for example, by producing sensory stimulation, attracting attention, avoiding demands and communicating with other people). This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal, and disruptive or destructive behaviour. It can also include violence, arson or sexual abuse, and may bring the person into contact with the criminal justice system.

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges.

The behaviour may appear in only certain environments, and the same behaviour may be considered challenging in some settings or cultures but not in others. It may be used by the person for reasons such as creating sensory stimulation, getting help or avoiding demands. Some care environments increase the likelihood of behaviour that challenges. This includes those with limited opportunities for social interaction and meaningful occupation, lack of choice and sensory input or excessive noise. It also includes care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.

Multiple factors are likely to underlie behaviour that challenges. To identify these, thorough assessments of the person, their environment and any biological predisposition are needed, together with a functional assessment. Interventions depend on the specific triggers for each person and may need to be delivered at multiple levels (including the environmental level). The aim should always be to improve the person's overall quality of life.

The NICE guideline on people with learning disabilities and mental health problems which has been recently published emphasised the risk of under-identification of mental health problems in children with learning disabilities, due to diagnostic overshadowing. It emphasised the need for preventative and family-centred services for children with learning disabilities who also have mental health problems.

The NICE guidance on autism in under 19s (2011) states that “Coordination between health agencies and other key services such as education, social care and the voluntary sector is important. Multi-agency staff should also work in partnership with the child or young person with autism and their family or carers”

The descriptions above demonstrate that behaviours described as challenging are the product of a complex interaction between biological, developmental and environmental factors. Each of these factors will be different for each child. There is strong evidence that some of the key factors causing and/or maintaining behaviour are amenable to change, and that change in these factors can be associated with marked reductions in challenging behaviour (*Briefing Paper, 2014*).

## 2. Needs-based commissioning

Historically, the system has led to children being defined by the service/s they are allocated to, rather than by their individual needs. This purchasing of available services as opposed to individualised needs-based commissioning, compounded by a lack of specialist community-based services has meant that children and young people whose behaviours challenge are more likely to be subject to restrictive responses, for example: through admission to assessment and treatment units for those with severe anxiety, depression, or a psychotic illness or significant levels of behaviours that challenge; through admission to 52 week schools for children with severe learning disabilities and autism; through contact with the criminal justice system for those who display risky behaviours (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).

Other children may not be known to services at all and receive little support, e.g. those whose learning disability or autism goes undiagnosed and whose behaviours are ascribed to their home situation (e.g. social disadvantage, substance abuse, troubled family backgrounds)

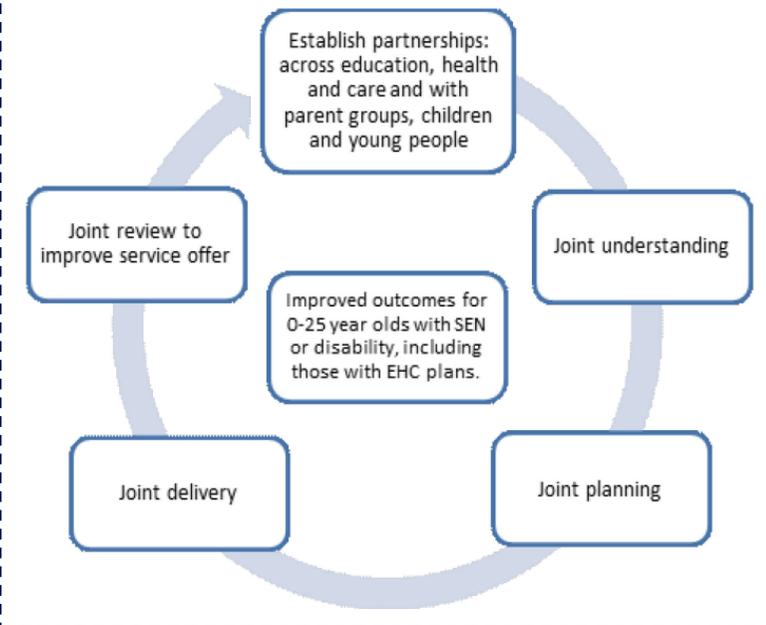
In order to meet the needs of this group of children effectively we need to see clear local pathways which are:

- Child and family centred (based on the needs of children and young people, rather than driven by the provision currently available)
- Lifelong; linked to transition and adult pathways and consistent across childhood (rather than dropping away at key points)
- Preventative (using evidence and data about the local population to put in place effective community support and services at the right times)
- Multi-agency (with co-operation across education, health, social care and other services; avoiding the assumption that any one service provider (e.g. a special school) can provide all the support required.)
- Developed in partnership with families (not as a token gesture but as part of the strategic development work)

These should be reviewed as part of the commissioning cycle set out in chapter 3 of the SEN code of practice. More information on commissioning high quality and safe services for this group is available in *Ensuring Quality Services* (2014), available at: <http://bit.ly/NfkVwS>

### Joint Commissioning Cycle

Taken from Department for Education & Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years* (p.41)



### 3. Person centred and preventative support

All children with learning disabilities and or/autism (including those with mental health problems) should have a person-centred plan, which gives an overview of who they are, their needs and wishes. Support across education, health (including mental health) and social care should be developed in an integrated way, in partnership with children and families, based around identified needs (as set out in chapters 1 and 3 of the SEN code of practice).

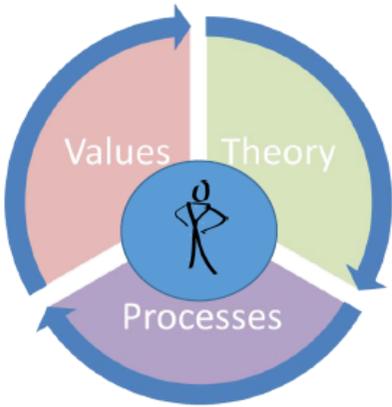
In addition, all services should take a preventative approach; identifying risk factors and signs of challenging behaviours early, gaining an understanding of why behaviours are happening and what function they serve for the individual through a functional assessment and putting in place appropriate strategies to prevent and reduce them occurring. These actions may be both simple and involve no/little cost but a consistent approach across settings is generally necessary if the approach is to be effective. Sometimes workers who are in contact with the child will need some professional support or training to respond appropriately and consideration needs to be given to how any training or support can be provided across settings on a sufficiently frequent basis that all relevant staff and family members feel confident and competent to meet the needs of children and young people whose behaviour challenges. Use of the NICE guidelines outlined above should lead to a proactive approach to early assessment and identification and good data collection and analysis should underpin the commissioning of services to meet need.

For children who display behaviours described as challenging the best evidenced approach is **Positive Behavioural Support** (recommended in the NICE guidelines for challenging behaviour, and the LGA/NHSE guidance *Ensuring Quality Services*). Positive behavioural support (PBS) is an effective and ethical way of supporting children and young people with learning disabilities who are at risk of behaviour that challenges. It is a framework for developing an understanding of behaviour that challenges rather than a single therapeutic approach, treatment or philosophy. It is based on an assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop interventions.

The overall goal of PBS is to improve the person's quality of life and of those around them, thus reducing the likelihood of challenging behaviour occurring in the first place. When a person receives PBS it is unlikely to come from just one individual, one professional group or one service. Families, carers, professionals, service providers and commissioners need to work together and each play their part in supporting that person. (PBS coalition competence framework, 2015). However, PBS is not a well-developed function within children's services at present. Establishment of such functions will require a trained and skilled workforce, able to implement each of the ten elements set out in the box below.

The figure below sets out how the functions of PBS might work in the context of children’s services. This is not an attempt to define the level of staffing required or where these functions might sit, as this is likely to look very different within different areas. It is instead a representation of support which, if available locally, could play a significant role in local evidence-based responses to avert crisis situations and unplanned admissions.

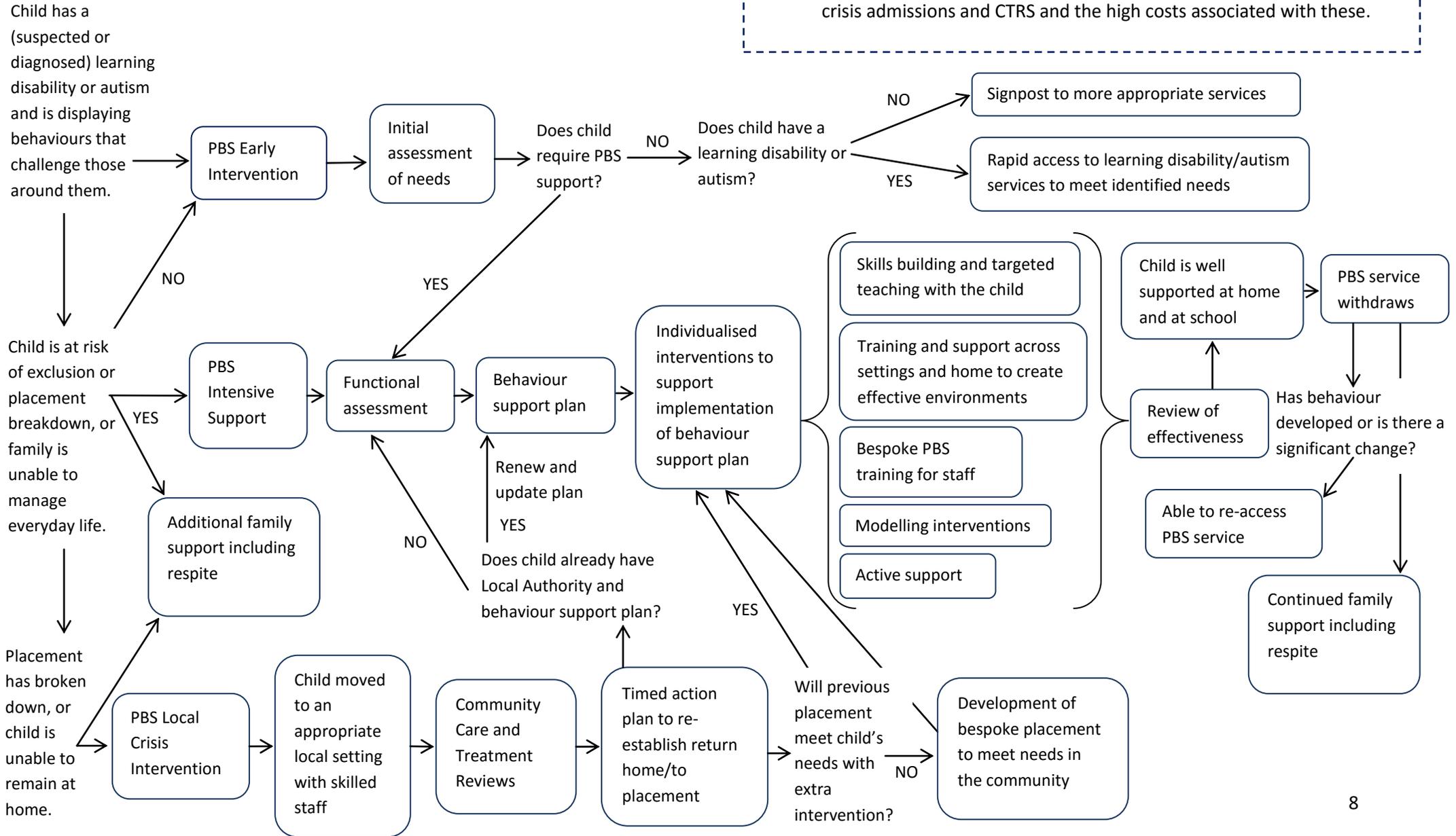
Taken from Challenging Behaviour Foundation & PBS Academy (2016), *Positive Behavioural Support: Resource 1 – What is Positive Behavioural Support*, (p.4)

|  |   |
|--|---|
| <p><b>Box 1: The Core Elements of PBS (Gore et al., 2013)</b></p> <div style="text-align: center;">  </div> <p>Each of the 10 elements described opposite must be included and visible in any service delivering PBS; and each must have as their central focus, the person being supported and their family.</p> | <p><b>Values</b></p> <ol style="list-style-type: none"> <li>1. The core aim of PBS is to improve the quality of life of the person and those around them by preventing and reducing challenging behaviour.</li> <li>2. It works by developing and building skills of the person and of those who support them rather than using aversive (i.e. unpleasant) or restrictive (i.e. limits the person’s movement or activities) interventions</li> <li>3. Practitioners work in partnership with the person and all of those who are important to them including their family and friends, carers, and other professionals and actively include them in assessments, defining targets, implementing interventions, and reviews</li> </ol> <p><b>Theory</b></p> <ol style="list-style-type: none"> <li>4. All behaviour, including challenging behaviour, happens for a reason - understanding what this is (practitioners call it the <i>function</i> of the behaviour) can suggest how to make sure the person has access to the things they need in other ways (e.g. by changing the environment, teaching them new skills etc.)</li> <li>5. PBS uses the principles and procedures from behaviour analysis to assess and support skills teaching and behaviour change</li> <li>6. Other, complementary evidence-based approaches may be included in PBS plans (e.g. Cognitive Behaviour Therapy, Parent training for children who display challenging behaviour, early intervention for children 3-5 with emerging challenging behaviour)</li> </ol> <p><b>Processes</b></p> <ol style="list-style-type: none"> <li>7. PBS bases decisions on information gathered about a person’s skills, behaviour, and needs</li> <li>8. A functional assessment helps to identify the reasons (<i>function</i>) for a person’s behaviour and is used to create a clear and structured plan of action</li> <li>9. A PBS plan will include proactive strategies to prevent challenging behaviour from happening, strategies to teach new skills to make the challenging behaviour less likely and reactive strategies that minimise restriction if it does occur</li> <li>10. PBS is not a quick fix: the aim is to actively support people over the long-term and to monitor and maintain their quality of life</li> </ol> |
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## 4. Referral routes for Functional Assessment and Positive Behavioural Support interventions

**Aims:**

- To improve quality of life for children, young people and families
- To reduce frequency and intensity of behaviours that challenge
- To avoid placement breakdown, out of area placements, unplanned crisis admissions and CTRS and the high costs associated with these.



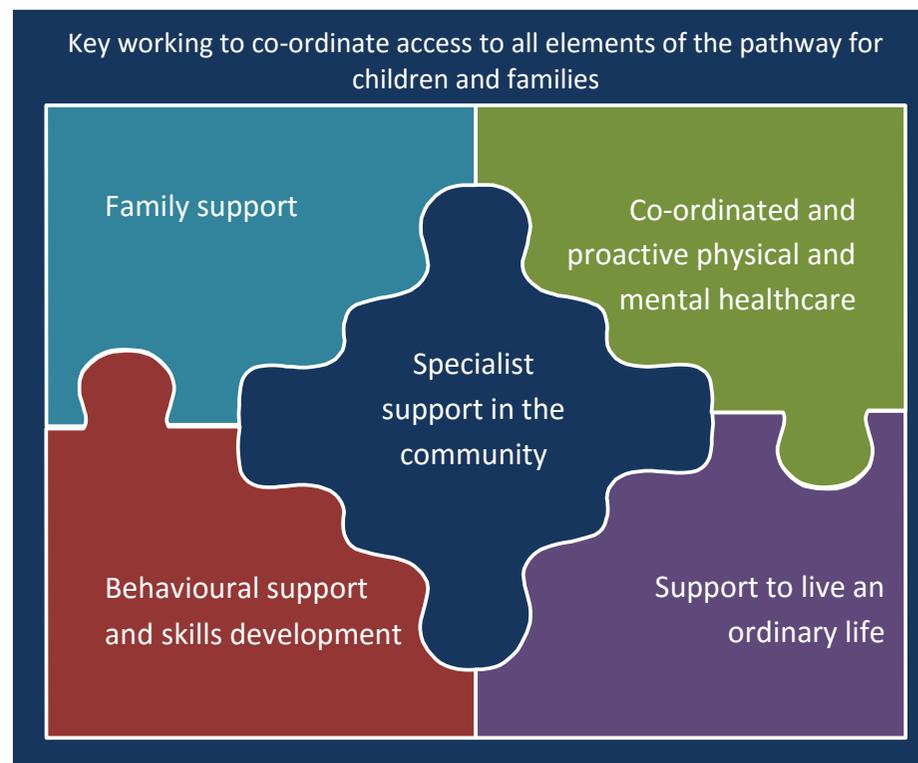
## 5. Challenging behaviour is everyone's business

Families regularly report the difficulties they face finding support for children with behaviours that challenge. Many of those we spoke to in scoping these resources reported fragmented services which don't work together. Children were often ineligible for or excluded from particular services due to their behaviours or the level of their support needs. It was not unusual to find professionals or staff concerned or confused about how to respond to behaviours that challenge because they are not equipped with the right skills. Where this is the case challenging behaviours are likely to increase and outcomes are likely to become worse.

Not everyone is able to be an expert in behaviours that challenge; but with a clear, person-centred behaviour support plan, everyone supporting a child should be able to understand their own role, so that all the elements of effective support can fit together coherently.

Those involved in supporting a child should work together across disciplines using a positive behavioural support approach. The aim should be to provide a co-ordinated package of support, not just to reduce challenging behaviour in the short term, but to improve long term quality of life and reduce the future risk and impact of challenging behaviour.

The graphic above shows the key areas of support required and how these link to the principles of Building the Right Support (and therefore to the legal duties and benchmarking questionnaire which form part of this resource and are also set out under the 9 principles). Graphics included on pages 16-18 summarise the elements local areas should consider including in their pathway at different stages to deliver this support effectively over time.



## Family Support: Principles 4 and 5



*“The best thing was that they helped me find my own solutions”  
Parent.*

The stress, emotional strain and practical difficulties experienced by those caring for children with learning disabilities whose behaviours challenge have been well documented. Providing appropriate information and support (and co-ordinating that support) to the family is a critical element in providing effective support for the child. Effective family support is non-judgemental; not “blaming” families but working in partnership to equip them with the information, skills and resilience they need to support their child. NICE guidelines highlight the importance of evidence-based parenting training. This should be training appropriate to families of children with learning disabilities and autism (rather than programmes aimed at those with typically developing children) and should be offered as part of a much wider package of support which is responsive to families’ needs. Families report that support in their own homes (rather than attending clinics or other settings) is particularly useful.

The early support programme and portage can provide support in the early years as can links with other families going through similar experiences. Peer support is highly valued by families.

Other key elements of family support include Social Care, and practical support including communication aids, benefits, adaptations and equipment. Siblings may need support from young carers groups. Short breaks must be available, flexible and able to cater for the needs of this group of children, with appropriately trained staff. The Local Offer should set out what support is available for families of children with learning disabilities and/or autism whose behaviours are described as challenging.

### Principles in the New Service Model for Commissioners

Principle 1: My care is planned, proactive and coordinated.

Principle 2: I have choice and control over how my health and care needs are met.

Principle 3: I live in the community with support from and for my family and paid carers.

Principle 4: I have a choice about where I live and who I live with.

Principle 5: I have a fulfilling and purposeful everyday life.

Principle 6: I get good care from mainstream NHS services.

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

Principle 8: I am supported to stay out of trouble.

Principle 9: If I need 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.

LGA, ADASS and NHS England (2015) *Supporting people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges.*

## Behavioural support and skills development: Principles 1 and 2



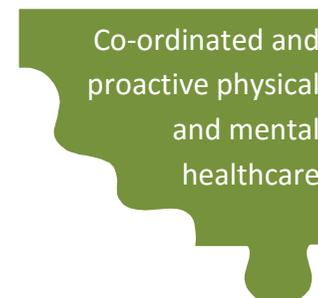
*“Children without learning disabilities display challenging behaviour during the “terrible twos” but then develop communication and social skills which enable them to get what they want and need. Many children with learning disabilities do not develop these skills and are left with the same needs as other children but are much less able to get them met” Professor Peter McGill, Tizard Centre, University of Kent*

Developmental learning and the development of new skills equip children for life and can help to reduce the frequency and intensity of behaviours that challenge. Children and young people are best supported to develop these skills when all settings including education, health and social care professionals, support staff and families work together on an agreed area or skill. This means finding way to communicate clearly across disciplines how best to move forward with learning, recording and celebrating progress as this helps to provide consistency for the child or young person. Skill areas to focus on are likely to include general skills (social skills, academic/employment skills, self-care skills and fun skills), functional skills (communication skills, choice making, responding to instructions/requests from others), and coping skills (coping with waiting, coping with not being able to get what you want, coping with triggers and coping with demands). Schools and colleges should have an educational adjustment plan to ensure they are clear about how to meet the child’s needs effectively but it is important that this is linked with other areas of their life to create a consistent and effective approach to developmental learning.

## Co-ordinated and pro-active physical and mental healthcare: Principles 3 and 6

*Children have the right to the highest attainable standard of health and appropriate support to enable this (Challenging Behaviour National Strategy Group Charter, 2013).*

When Health Visitors, Paediatricians or other health professionals have a concern about behaviour related to learning disability or autism, they need to have clear information about where to go for extra support. Children with learning disabilities and/or autism whose behaviours are described as challenging should all have a Hospital passport and a plan for medical visits. This should include reasonable adjustments (e.g. appointment at a quiet time of the day, multiple surgeries under one anaesthetic). Regular health assessments are key for children with learning disabilities whose behaviours challenge (both general & for undiagnosed pain or discomfort which can result in challenging behaviours). These can be accessed in primary care from the age of 14 years although not all GPs are signed up to the voluntary scheme<sup>1</sup>. All children and young people with learning disabilities and autism can access paediatric services as required via GP referral or from other



<sup>1</sup> For more information on health checks and health action plans including good practice:  
[http://www.improvinghealthandlives.org.uk/publications/1243/Health\\_checks\\_for\\_people\\_with\\_learning\\_disabilities:\\_including\\_young\\_people\\_aged\\_14\\_and\\_over,\\_and\\_producing\\_health\\_action\\_plans](http://www.improvinghealthandlives.org.uk/publications/1243/Health_checks_for_people_with_learning_disabilities:_including_young_people_aged_14_and_over,_and_producing_health_action_plans)

agencies according to local referral pathways (These should be clear in the area's 'Local Offer'). Children should have a comprehensive paediatric assessment to identify and treat any health conditions that are contributing to their behaviours, such as pain, constipation, reflux, spasticity, dystonia etc.

Children with learning disabilities and/or autism are at risk of developing mental health problems than their peers but problems often go undetected as the symptoms can be mixed up with the child or adult's learning disabilities or challenging behaviour. Many factors increase the chance of a child developing a mental health problem. These include: poor social support, low self-esteem, having little control over ones' life, not having anything to do and poor coping skills. Children with learning disabilities and/or autism are more likely to experience all of these factors. Challenging behaviour does not automatically imply a mental health problem, but anxiety disorders, depression and mania are all more prevalent in people with learning disabilities who display severe challenging behaviour than in the general population.

When a child or young person has mental health problems and displays challenging behaviour, the clinical picture becomes very complex so early access to assessment is important in order to determine the right treatment and support within the community. Children and Adolescent Mental Health Services should ensure all tiers of the service are accessible to children with learning disabilities and/or autism experiencing mental health problems or displaying behaviours that challenge, making reasonable adjustments as appropriate.

### **Support to live "an ordinary life": Principles 1 and 5**



*"I want the same thing for my son as for my other children – to live a happy and fulfilled life – he just needs more support to do so" Family Carer*

A good and meaningful life for children and young people involves family, friends, home, the leisure activities they enjoy, education and access to healthcare. The evidence shows there are significant barriers to a good and meaningful life for children and young people whose behaviour challenges and families face the risk of isolation. When a genetic condition, learning disability or autism is diagnosed, parents should be offered timely access to information about potential behaviours and how to access further support, if necessary. This should help them overcome barriers to participating in everyday activities such as play groups, playgrounds, shopping and leisure activities. It should also support them to make an ordinary life at home possible, including addressing problems with sleeping, feeding or toileting. As young people grow older they should be supported to access leisure activities of their choice within their local community. This is not a "luxury" or a "nice to have" but an essential component of a good quality of life and a protective factor against admission to a restrictive setting.

Reasonable adjustments must be made to enable children to access childcare settings, including after school and holiday clubs and activities, to enable parents to access work, education and leisure. An appropriate environment reduces the risk of developing behaviours that challenge and the risk of children 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, so they don't disturb siblings, or space outside to run around safely<sup>2</sup>.

If children live away from home, efforts should be made to support contact between children and their families; their accommodation must meet their needs and the placement reviewed regularly.

### **Specialist support in the community: Principles 7, 8 and 9**

"I was told my son was not eligible for specialist support, that at 13 it was too late and his behaviours were set. The GP diagnosed liquid diazepam and said there was nothing more he could do. Social Services advised us to call the police when family members are at risk...This can't be right can it?" Family Carer.



Many children in this group are likely to need specialist input in order to access education and to live an ordinary life (for example Speech and Language Therapy, Occupational therapy, Physiotherapy, Improving Access to Psychological Therapies (IAPT), Children and Adult's Mental Health Service (CAMHS), Cognitive Behavioural Therapy (CBT), Liaison and Diversion Teams). This should include 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<sup>3</sup>. These services should recognise the high risk needs of this group and provide a responsive service within the local community. Where challenging behaviours are significant or children are at risk of exclusion or an unplanned out of area residential placement specialist behaviour support should be provided, including:

- a functional assessment by a behaviour analyst or Clinical Psychologist ,
- a comprehensive health assessment to identify any unmet health needs and
- development of a Positive Behavioural Support Plan.

Children in in- patient settings should all have a Care and Treatment review, involving commissioners from education, health and social care and an expert by experience. The recommendations of the Care and Treatment review<sup>4</sup> should be acted upon in a timely way, and local bespoke packages of care must

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<sup>2</sup>Challenging Behaviour Foundation and Mencap (2016) Keeping in Touch with Home <http://pavingtheway.works/project/wp-content/uploads/2016/07/Keeping-in-touch-with-home-web-version.pdf>

<sup>3</sup>NHSE (2015) Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414024/Childrens\\_Mental\\_Health.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf)

<sup>4</sup>NHSE (2015) Care and Treatment Review (Policy and Guidance) <https://www.england.nhs.uk/wp-content/uploads/2015/10/ctr-policy-guid.pdf>

be developed to meet the requirements of the Children and Families Act 2014). There should be a significant focus on children at risk of admission. Community Care and Treatment Reviews should be carried out, with the aim of developing more effective local support in a way which can meet the needs of the child and family and offset the need for admission (See CTR pathway: <http://bit.ly/29yickl>). To make that a reality, there will be a need for effective local crisis response arrangements; for example, using short break settings where staff have expertise in learning disability, autism and challenging behaviour.

### **Key working: Principle 2**

*“We need a key worker to guide us through the system” Families focus group.*

“Building the right support” highlights the importance of a Care and Support Navigator, often called a key worker in children’s services. Such a role should be established to help co-ordinate support for a child and their family. This role should support regular multi-agency planning and reviews of provision, ideally managed as a “team around the child” package of support. Families should be offered a personal budget, with sufficient individual support arrangements in place to enable them to manage the budget effectively. The development of Integrated Personalised Commissioning<sup>4</sup> has the potential to support this approach.

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<sup>5</sup>NHSE (2016) Integrated Personal Commissioning: Emerging Framework. <https://www.england.nhs.uk/healthbudgets/wp-content/uploads/sites/26/2016/05/ipc-emerging-framework.pdf>

## 6. Co-ordinated assessments and plans

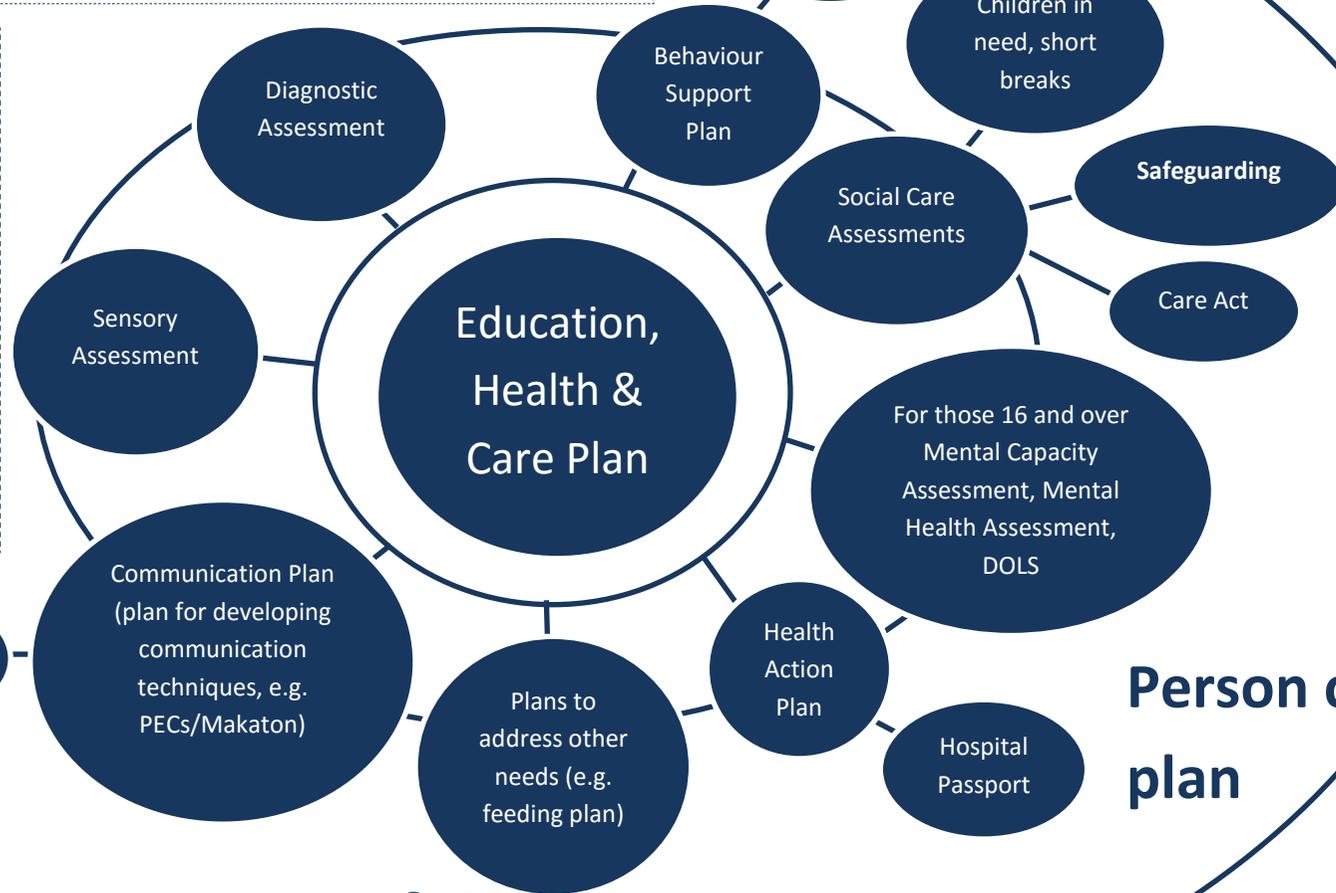
Children with learning disabilities and/or autism whose behaviours challenge should have access to a range of assessments. Assessments should inform plans which enable effective support to be provided, based on assessed needs. Assessments and plans should not be developed in isolation; each should be:

- developed in partnership with the child and family
- developed with regard to the child's person centred plan and behaviour support plan
- co-ordinated and relevant links drawn by a key worker/team around the child/care and support navigator

Plans should be applied consistently across all settings accessed by the child, including at home, at school and in short break settings.

All children with learning disabilities and/or autism whose behaviours challenge should have a person-centred plan (PCP). Education Health and Care Plans, for those eligible (or individual education plans for those who are not), should be developed using a person-centred approach. It is good practice to have a circle of support to help develop and implement person-centred plans

**Co-ordinated & Supported by  
keyworkers/Team Around the  
Child/care support  
navigator**



**Developed in partnership  
with children and families**

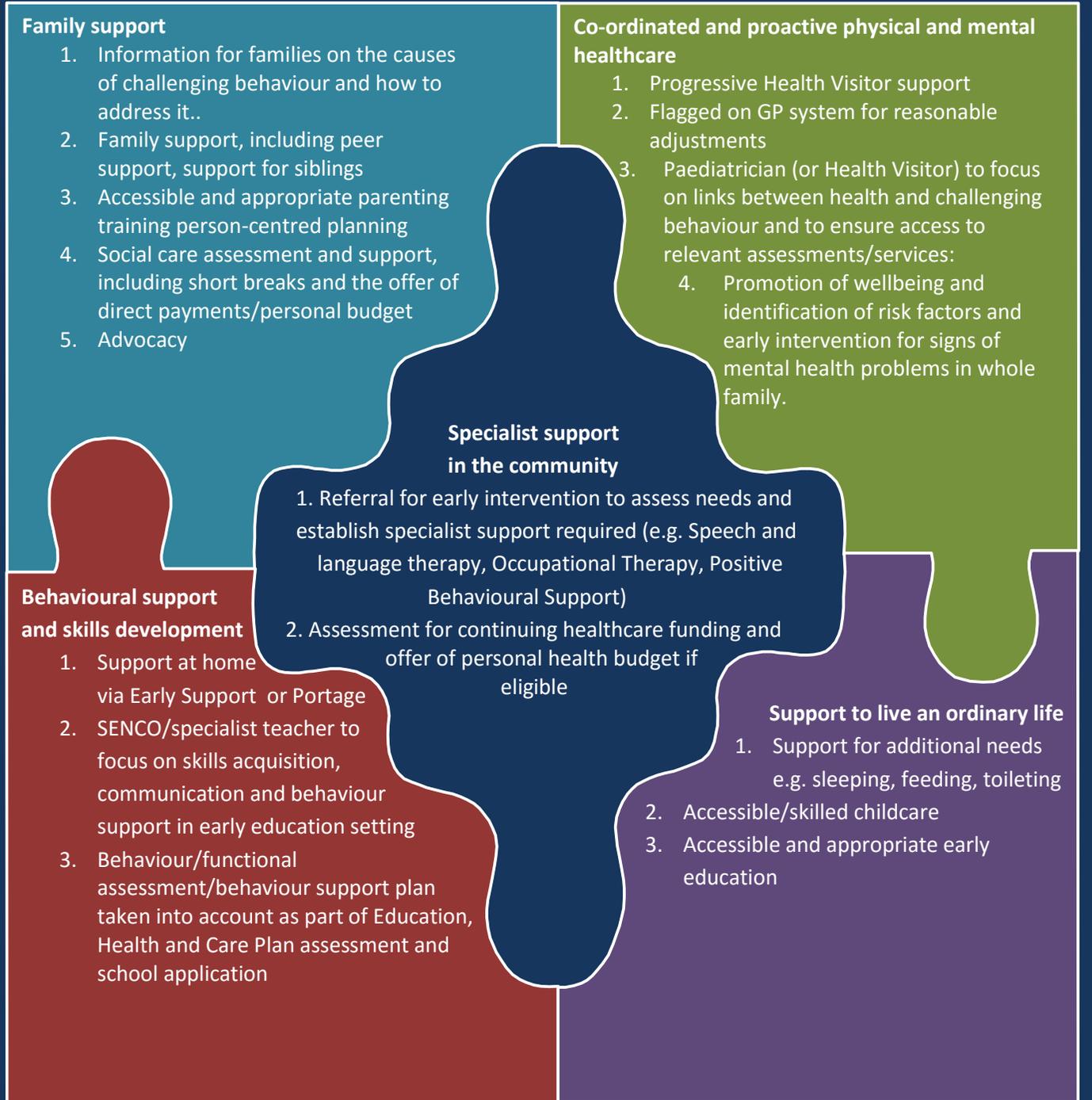
## Suggested Checks and Opportunities by life stages



|   |  |  |  |   |
|---|--|--|--|---|
| <p>Birth checks/early diagnosis</p>   | <p>2.5 year health check</p> <p>Educational assessment in preschool setting informs transition to school</p> | <p>Annual education review</p> <p>If there is an risk of exclusion – do a functional assessment of behaviour</p> <p>Refer to therapies/ other services if needed</p> <p>Primary school info passes to secondary school at transition</p> | <p>Annual education review</p> <p>From year 9 focus on life outcomes such as housing, employment , friendships &amp; community inclusion</p> <p>From 14 annual health check for those with learning disabilities</p> <p>Transition assessment under the Care Act for social care when beneficial</p> | <p>Young person’s plan transfers to college. (EHCP or other)</p> <p>Behaviour support factored into study programmes and training modules. Assessment for supported internships</p> |
| <p>Education, health and care assessment leading to a plan possible from age 2 years</p>  |  |  |  | <p>Education, health and care plan could last to 25 years but ceases if young person starts a paid job or is not in education.</p>  |
| <p>For those who do not have an education, health and care plan, develop an education support plan with behaviour support built in.</p> |  |  |  | <p>Education support plan lasts as long as required</p>   |

**7. Multi-disciplinary working using a positive behaviour support approach – pre-school**

Does the child have a (suspected or diagnosed) learning disability or autism and are they demonstrating behaviours that challenge those around them?



Family feel equipped to support their child and address current levels of behaviours that challenge

Family knowhow to seek further help if things change

Assessments to date have been developed in partnership with the family and are well-co-ordinated across different services.

Child is receiving appropriate support based on the assessments of their needs.

School is aware of behaviour support plan and able to access additional training/support/expertise to implement the plan where required.

Local Authority and Transforming Care Partnerships have flagged the child on the dynamic risk register

## 8. Multi-disciplinary working using a positive behaviour support approach – School age pathway

Does the child have a learning disability or autism and are they demonstrating behaviours that challenge those around them?



Family feel equipped to support their child and address current levels of behaviours that challenge

Family knowhow to seek further help if things change

Child has a behaviour support plan based on the functions of their behaviour.

Behaviour support plan is understood and implemented by all those supporting the child.

School feels equipped to enable child to learn and develop and to implement behaviour support plan.

School is able to draw on PBS team for expertise or training where needed

Assessments to date have been developed in partnership with the family and are well-co-ordinated across different services.

ECHP incorporates other assessments including Behaviour Support Plan.

Child is receiving appropriate support (e.g. from CAMHS, SLT, OT Physiotherapy) based on the assessments of their needs.

Local Authority and TCP have flagged the child on the dynamic risk register

Quality of life measures have improved since pathway was accessed

Crisis situations are managed locally

## 9. Multi-disciplinary working using a positive behaviour support approach – Transition to Adulthood Pathway

Does the child have a learning disability or autism and are they demonstrating behaviours that challenge those around them?



Young person is accessing person-centred care in their local community

Young person/Family knowhow to seek further help if things change

Young person has a behaviour support plan based on the functions of their behaviour.

Behaviour support plan is understood and implemented by all those supporting the young person

Assessments to date have been developed in partnership with the young person and family and are well-co-ordinated across different services.

Young person is receiving appropriate support based on the assessments of their needs.

Local Authority and TCP have flagged the young person on the dynamic risk register

Quality of life measures have improved since pathway was accessed

Crisis situations are managed locally

Person-centred plan for the future with key life outcomes

## 10. Strategic approach to developing local pathways

This resource sets out, in headline terms, what needs to be in place to provide effective local support for children and young people with learning disabilities and/or autism whose behaviours challenge and signposts further sources of information. We recommend that it is used by SEND joint commissioning boards and Transforming Care partnerships to inform a strategic approach to developing a local pathway.

This might include:

### Review and Assessment

- Assessing current service provision in partnership with families and young people, including gaps and strengths (see annex on duties/guidance and benchmarking questionnaire)
- Reviewing CTRs of children of children from the area covered by the TCP to identify any key themes/common barriers to effective local support/common points in the system where things went wrong
- Reviewing data currently collected and changes required to inform better planning
- Reviewing spend on this group across Education, Health and Social Care in order to identify better co-ordinated and more efficient methods.

### Agreeing vision/outcomes

Based on the review of local services there will be clear local priorities. We would suggest that additional considerations for local services could include:

- Invest to save methodology; reducing spend on out of area placements and crisis interventions on increasing spend on effective, evidence-based local support.
- Child and family centred (based on the needs of children and young people, rather than driven by the provision currently available)
- Using the least restrictive methods possible and planning for a reduction in restrictive interventions within all services.
- Lifelong; linked to adult pathways and consistent across childhood (rather than dropping away at key points)
- Preventative (using evidence and data about the local population to put in place effective support and services at the right times)
- Multi-agency (with co-operation across services; avoiding the assumption that any one service provider (e.g. a special school) can provide all the support required.)
- Market development (one of the barriers to direct/payments/personal budgets has been the lack of services to purchase with them. Market development may be required to enable effective integrated personalised commissioning)
- Developed in partnership with families (not as a token gesture but as part of the strategic development work)

## **Pathway development**

- Getting the right people round the table
- Identifying how to fill gaps/better co-ordinate services for this group
- Recognising areas where more expertise/information/training/workforce development may be required
- Developing a pathway
- Agreeing a plan for implementation of the pathway
- Establishing quality measures/data collection
- Workforce development plan
- Clarifying responsibility (overall and for each component part)
- Agreeing a timed plan for implementation
- Agreeing data collection and reporting mechanisms.

## **Implementation**

Take forward the implementation plan

- Include the pathway within the local offer
- Raise awareness of the pathway

## **Review the pathway**

## 11. Working in partnership with children and families

Local challenging behaviour pathways should be developed in partnership with local children, young people and families. Families offer a wealth of experience and can offer practical examples about 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 whose behaviours challenge 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 (Challenging Behaviour National Strategy Group Charter, 2013<sup>5</sup>). 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.

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<sup>5</sup><http://www.challengingbehaviour.org.uk/learning-disability-files/CBF-Charter-2013.pdf>

The following list of considerations may help.

|   | What works   | Try to avoid   |
|---|--|--|
| Identifying the right children, young people and families | <p>Advertising the opportunity as widely as possible, through Parent Carer Network, services people are likely to access and social media of organisations they are likely to follow. Be specific about the client group in the invite.</p> <p>The use of incentives such as vouchers, lunch or the opportunity to get some extra advice or do some planning around their own child's needs.</p> | <p>Inviting only existing forums to participate where young people/families of this cohort may not be represented</p> <p>Only engaging the same few families each time and missing the harder to reach families.</p> |
| 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.   |
| Arranging meetings with families                          | <p>Plenty of notice.</p> <p>Timed during the school day or during the evening for working parents.</p> <p>Well planned meetings with a clear purpose.</p> <p>Funding travel costs/replacement care.</p>  | Short notice or meetings in school holidays.   |
| 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.  |

## 12. Workforce development

There are a number of identified gaps, where increased workforce capacity will significantly improve the local support available to children with learning disabilities whose behaviours challenge. These include:

- Clinical and educational psychology teams able to diagnose learning disabilities/autism
- Parenting training programmes appropriate for families of children with learning disabilities/autism (not those designed for typically developing children)
- Additional capacity in learning disability nursing and psychology teams
- CAMHS teams that are accessible for all children and young people regardless of intellectual ability
- Local PBS teams
- Care and support navigators (key working or team around the child) to co-ordinate support across all services

Everyone working with children and young people with learning disabilities and/or autism at risk of behaviours that challenge requires a certain level of knowledge and skills in order to provide effective support.

- Professionals and staff likely to be key in early identification of challenging behaviour (e.g. through parental reporting, 2.5 year old check or school/EHC plan assessments) should have information about challenging behaviour (see [www.pavingtheway.works](http://www.pavingtheway.works) and [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)), a basic level of awareness about common causes and risk factors and information about how to access further support.
- Professionals working in a PBS service should have specific training and qualifications in PBS and be registered with an independent regulatory body. See the PBS competency framework at [www.pbsacademy.org.uk](http://www.pbsacademy.org.uk) for more information, and see [www.pbs4.org.uk/resources](http://www.pbs4.org.uk/resources) for more information about qualifications and registration.
- Those providing direct day to day support to a child or young person whose behaviour challenges, as well as basic information and awareness, should have the opportunity to attend PBS training and to have personalised support/training or modelling to enable them to implement the behaviour support plan effectively.



### 13. Data and quality

At the outset Transforming Care Partnerships and SEND joint commissioning Boards will want to establish the data and quality measures they will use. As well as assessing the success of the pathway, data should be used to inform the Joint Strategic Needs Assessments, future planning (for individuals and at a strategic level) and to assess the quality of service delivered at each component part of the pathway. These are drawn from the LGA/NHSE guidance Ensuring Quality Services, where further detail can be found.

At a strategic level, measures might include:

- The experiences of children and young people with learning disabilities and / or autism and their families
- Timely and regular review and audit of specific services to ensure they are safe, meeting needs and delivering outcomes
- Local quality requirements, including initiatives to make marked improvements e.g. Commissioning for Quality and Innovation (CQUIN)
- National quality requirements, for example Ofsted and Care Quality Commission inspections of services and joint local area inspections
- Early warning and learning from complaints and serious incidents

Mechanisms are also required to monitor the quality of commissioning procedures and should form part of the Joint Strategy as per Action 57 of the 'Concordat: Programme of Action' (DH, 2012). This should be assessed by measuring outcomes for children with learning disabilities and / or autism and other stakeholders and should include:

- The satisfaction of individuals and families regarding service provision
- Positive increases in quality of life for individuals and families
- Population level changes in prevalence of behaviour that challenges
- Reduced numbers of children with learning disabilities and / or autism in residential school/out of area placements/in-patient settings

At an individual level, data should include:

- Extent and variety of participation in meaningful activities
- Development of skills
- Attainment of specific objectives identified in PBS plan
- Frequency and severity of challenging behaviour
- Use of restrictive practices (physical intervention, seclusion, PRN medication)
- Injuries sustained as a result of challenging behaviour
- Safeguarding alerts