

# Building the Right Support for Children

Learning lessons from the field work with parents, children  
and young people, commissioners and providers

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**making a difference  
to the lives of people with  
severe learning disabilities**

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# 1. Introduction

Building the Right Support [www.england.nhs.uk/learningdisabilities/natplan/](http://www.england.nhs.uk/learningdisabilities/natplan/) (published October 2015) sets out a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges. It includes a commitment to early intervention for children and young people with learning disabilities.

This follows the publication by the LGA and NHSE of *Ensuring Quality Services* (2013) and three years of work by the joint Challenging Behaviour Foundation (CBF) and Council for Disabled Children (CDC) Early Intervention Project (funded by the Department of Health) which considered what effective support looks like for children with learning disabilities whose behaviours challenge (findings at [www.pavingtheway.works](http://www.pavingtheway.works)).

NHS England asked Carol Robinson (NDTi) and Jacqui Shurlock (CBF) to develop a pathway for children and young people with special educational needs/learning disabilities whose behaviours challenge. The pathway was designed to support Building the Right Support, with practical advice for commissioners.

As part of this work we visited four areas across England to meet with commissioners, families, young people and providers. The intention was that these meetings would inform the content of the national pathway but also help local areas consider how best to deliver the commitments in Transforming Care for the children and young people in each area. The work took place between the middle of April and the end of May 2016. The work was supported by a steering group comprising representation from across education, health and social care sectors. We met with them prior to our fieldwork and again to share our findings and our draft documents.

This report outlines the key activities and some of the learning from the fieldwork. The analysis of the issues and the learning points reflect the co-produced work of the NDTI and the CBF and build on the learning from the Early Intervention Project.



## 2. The Sites

We carried out work in four areas geographically spread across England. We had intended to work in a fifth area but they were unable to participate owing to a lack of capacity to set up meetings for us within our tight timescale. The areas visited included two shire counties and two unitary authorities. One of these being in a large city in the north of the country and the other a small unitary authority.

### Who we met

Across the four sites, we have held face to face meetings or telephone interviews with

- 8 commissioners
- 22 providers
- 24 young people aged 13-20 years
- 27 family carers

It should be noted that some of the young people we met had the label of ‘challenging behaviour’ but only 17 of the 24 appeared to have either autism or learning disabilities. The remaining group either had mental health issues or social and emotional needs and were unable to continue attending mainstream school because of their behaviour. Generally speaking, they were in a Pupil Referral Unit and in a few cases, were being reintroduced to a secondary school. In one area, there seemed to be confusion about who our target group was and when we checked, were reassured that the group met our criteria. Lack of familiarity with the terminology used under the Transforming Care programme within children’s services was also an issue that arose when NDTi and In Control reviewed the commissioning arrangements for this group of children and young people<sup>1</sup>

Overall, our sample was not as representative as we would have liked for two reasons; first because none of the young people selected to be involved had severe learning disabilities and secondly, we were unable to devise a sufficiently accessible way of engaging with young people with the most severe learning disabilities in the timeframe allowed. We are aware that a more individualised approach would have been necessary for many of the target

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<sup>1</sup>NDTi and In Control: Reviewing the Commissioning of Services for Children and Young People who Challenge  
End of project report April 2016

[www.ndti.org.uk/uploads/files/Commissioning\\_Services\\_for\\_Children\\_who\\_Challenge\\_Final\\_Report.pdf](http://www.ndti.org.uk/uploads/files/Commissioning_Services_for_Children_who_Challenge_Final_Report.pdf)

group. This would have necessitated such things as gathering photographs of people and places they know, establishing communication in line with their preferred method and more time to build a rapport with individuals or to train a familiar person to ask questions on our behalf.

## What we learned about engaging families

Many families of children or young people whose behaviours challenge find it **difficult to attend meetings** simply because of the difficulties they experience with their child.

Therefore they are probably less well known to the local parent carer forum and may be difficult to contact so it is important to use a **variety of methods to communicate with families** including through schools, colleges and GP surgeries.

In terms of getting a good spread of families, it helps enormously to **make a payment to attendees**. We found that family carers who are from lower socio-economic groups were willing to participate because we covered their expenses in getting to the meeting and offered a payment for their time and contribution. We paid all attendees £40 for their time for a 2 hour meeting.

The meeting needs to provide an **opportunity for everyone to have their say**. We ensured this by using an approach that had previously developed by the Challenging Behaviour Foundation. It involved constructing two lists of topics to which everyone had a chance to respond. The first focused on the range and nature of local services to support children and young people whose behaviours challenge and the second covered local approaches such as whether they were child and family friendly, person centred, preventative and lifelong. Everyone was expected to 'vote' using a dot to say whether they agreed, partly agreed or disagreed with the statements (please see the local services and local approaches documents).

**Keep the groups small** as some parents are not very confident to speak up if the group goes beyond six people. Ideally, have at least two facilitators so that group activities can run in parallel to reduce group size.

It helps **to keep the activities varied**- we did a range of things to find out about people's experiences of assessments and plans and to find out what made the services that were well liked, good in the eyes of the family carers. Allowing everyone to rate particular elements using stickers ensures that everyone can contribute something.

## What our engagement with young people taught us

It is much easier to engage with people where they are during the day. **Work through school or college** not just young people's advocacy groups as these young people may well be absent from them. Before starting, it is a good idea to do a **simple leaflet explaining who they will be meeting** (use photos) why these people are coming to see them and what they are being asked to do. Below are some additional tips for engaging children with a mild or moderate learning disability or autism, based on our experiences:

- Get consent from individuals and, for under 16's, ensure parents know what is happening. Schools and colleges are usually better placed to do this than visitors.
- Find out about the young person's usual communication mode as much as possible.
- Ensure children and young people know it is voluntary, not a test of their knowledge or skills- just their views
- Let children/young people know how the information you collect will be used – what is it for?
- Make sure you are clear about who you want to involve: age range, gender, children and young people with certain needs/using particular services
- It is hard to get the involvement of children and young people who have the most significant learning disabilities and methods tailored to their needs are important. Good preparation is key to this as it takes time to find out what communication methods are likely to be most effective and to personalise the approach.
- Be very clear about what you are asking children and young people and what you want to find out
- Ideally, make the questions directly relevant to the children and young people's lives. If helpful, personalise your form with photos of people and places they know.
- Focus groups are less useful for this group of young people so do one to one interviews/conversations.
- Keep the questions simple but leave room to capture anything additional that children and young people mention
- Think ahead about what you will do if any safeguarding issues come up. You need to explain before getting consent that you must tell someone if you think they are being hurt, are not looked after properly or are not safe from harm

- Make sure you are aware of how a young person may demonstrate distress or discomfort and be clear that you will stop the discussion if they are unhappy to continue
- For some young people observation may be more helpful particularly in understanding their behaviour.
- We found it helped to reward young people in some way. It was especially helpful if they were becoming distracted because everybody wanted to complete the conversation/interview owing to the reward we offered. We used vouchers that enabled them to choose from a list of popular outlets or generic shopping vouchers to the value of £20. However, if this is too expensive an option you could offer the school/college/club a sum of money to be spent on something of the young people's choice. Alternatively, you may be able to negotiate free access to something they would enjoy.





## 3. Key Themes Emerging

### Differing perspectives

Commissioners and family carers often had a different idea about the effectiveness of the provision to support children and young people whose behaviours challenge with families generally finding that they lacked information about, and access to, support that did exist. This may well be more marked with this group of parents because they are less well connected to parent carer forums and support groups than other parents of disabled children.

### The problem with labels

The kind of label children and young people have often determines what kind of service, if any, they receive. Having no diagnosis/ label that fitted with eligibility criteria for local services could lead to children 'slipping through the net' or their parents being labelled as poor parents despite them sometimes doing fine in raising other children.

'Challenging behaviour' means different things to different people and in some cases, this could be self harmful behaviour that presented more of a threat to the individual than others around them. With hindsight, it would have been helpful to have explained at the outset what we understood by the term<sup>2</sup>. Equally, learning disabilities<sup>3</sup> and learning difficulties are sometimes confused so some children and young people with specific learning difficulties such as dyslexia or dyspraxia were suggested for inclusion if their behaviours were also considered challenging.

The other aspect of carrying a label is that children and young people tend to be placed in education settings where other children who bear the same label are also placed. This in itself can have a negative impact on the very behaviours that led to the placement in the first place.

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<sup>2</sup> 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).

<sup>3</sup> 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

Sometimes, simple things like children feeling hungry (mentioned by two young people) can make heighten the likelihood of behavioural challenges and it may be important to take steps to address this possibility before assigning a label or looking for a more complex understanding of their behaviour.

See [www.pavingtheway.org](http://www.pavingtheway.org) for more information about effective support for children with learning disabilities and behaviours that challenge and [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) for more information about behaviours that challenge associated with severe learning disabilities.

Below are the key issues we encountered:

- A lack of “Open Door” early intervention support for children with all children with learning disabilities or autism displaying behaviours that challenge.
- The way parents sought diagnosis was driven by the perceived services available for that group. Generally an autism diagnosis was seen to lead to extra support, although this was not always the case in practice.
- Sometimes services were only available to a particular age group or condition, e.g. pre-school children or children with autistic spectrum conditions and therefore families needing support often fell outside the criteria.
- Some of the young people who were in special settings for children and young people whose behaviour is regarded as challenging, cited other children as the main source of their frustration or anger.

### **Lack of timely information and support**

Many families found it difficult to track down information about local services despite the Local Offer being a statutory requirement. Families often said that it was easier to locate information from national sources than local ones. In addition, there was sometimes confusion about the route to get a referral to a service and the existence of narrow eligibility criteria could lead to parents feeling they did not qualify even before an assessment had taken place.

Access to CAMHS was often mentioned as being poor either with long waiting lists or a perception that the service would only respond if the child or young person had a mental health condition. This finding was mirrored in the review of children and young people services mentioned previously. However, where a learning disability service existed within the CAMHS provision, it was generally appreciated by both parents and other providers.

In general, we had the impression from providers and parents that access to therapies such as speech and language therapy and occupational therapy was patchy with speech and

language therapy sometimes not available or so infrequently available that it made little difference.

Some specific gaps that were mentioned in at least two of our four areas were:

- Transition to Adulthood
- Practical support for specific things like feeding, sleep, behaviour support, Pathological Demand Avoidance or ADHD.

## Transition to adulthood

This was often a time when parents felt there was a lack of information both for themselves and for young people. This was endorsed by our conversations with young people with almost half of them (N=11) saying they were not getting help to plan for their futures. Few of them were thinking about employment and few appeared to be receiving careers advice to support a pathway into work.

The four Preparing for Adulthood outcome domains listed in the SEND Code of Practice (Employment and higher education, independent living, community inclusion and good health) did not seem to be part of planning for these young people possibly having been largely overshadowed by concerns about how to manage their behaviour. Where young people did not have a statement or education, health and care plan, there was less likelihood of any person centred planning taking place because it is not enshrined in law for children and young people who do not have a statutory plan.

Although we were not alerted to any major problems with children and young people being able to access health care if needed, the majority of parents did not know about the possibility of their son or daughter having a health check from age 14. Similarly, few knew about health transition plans being written with young people prior to them moving into adult health care services. <sup>4</sup>

## Practical support

Parents often spoke about being tired and needing help to **manage their child's sleep** (or lack of it). Sometimes, they were not clear where their first port of call should be nor what approaches they should try. Sleep clinics or specialists were mentioned by a few parents but knowledge about where to get help was patchy.

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<sup>4</sup> For resources about Preparing for Adulthood see:  
[www.preparingforadulthood.org.uk/resources/resources-stories-and-videos](http://www.preparingforadulthood.org.uk/resources/resources-stories-and-videos)

Another area where additional support was needed but mentioned by fewer parents was around **feeding**, particularly with children who have a low tolerance of certain foods or who eat erratically. Again, knowing where to get local advice and support was sometimes a struggle.

In addition, **information about dealing with certain conditions** such as Pathological Demand Avoidance (PDA) or Attention-Deficit/Hyperactivity Disorder (ADHD) tended to be more readily available through national websites than through the Local Offer.

Parents were not aware of how to access behaviour support and regularly encountered the message that challenging behaviours were either their fault or their problem to deal with. There was no clear sense of how to access support to deal with challenging behaviours and this information was not available via the Local Offers in the areas we visited.

We also noted that few parents seemed to know about the option of **personal budgets** although a handful, had a direct payment. For some children and young people who were unable to access the range of short breaks on offer, having a personal budget would have made a positive difference. For example, we were told by one mother that her son could not attend any of the holiday play schemes because he could not cope with the noise level created by the other children and this meant the family was not having any breaks at all. She had not been offered a personal budget and did not know this was possible. Moreover, families were sometimes told about direct payments but in the same breath told that they are 'a lot of hassle' and were not given the option of a personal managed fund or Individual service fund

## Courses for Parents

The issue of parenting courses came up in all our conversations with parents. There was a range of courses available to families in the four areas although the same courses were not always available across all the authorities. Some of the parents were not offered any kind of course to help them understand and manage their child's behaviour but several courses for parents of typically developing children that were mentioned as being available were:

- Webster Stratton (Incredible Years)
- 'Triple P'
- Baby Steps
- Solihull Approach

Some parents were offered and attended one of these courses but they did not always find them helpful or appropriate to their circumstances. In reality, some family carers perceived such training courses as a punishment because they thought they were seen by

professionals as poor parents or they were told they had to attend the course in order to become eligible for further support. Some reported feeling excluded in a room of parents with typically developing children who did not face the same degree of behavioural challenge. However, a minority of parents had been offered courses such as Cygnet (designed for parents and carers of children and young people with an autistic spectrum condition) or CBF training for families in Positive Behaviour Support (PBS) and these more specialist courses were well liked.

- Even where there is an early intervention or PBS service, there is an issue about the extent to which PBS training has been undertaken by staff in early years, short breaks and school settings. This impacts on whether staff in various settings such as short breaks services are capable of effectively managing children's behaviours.
- Schools within an area often varied enormously in terms of their response to children and young people and the extent to which the staff felt competent to meet the needs of this group. Special schools were also not always able to respond effectively to need according to several parents.

### Training for staff in support services

- Some parents told us that the support that was available to their child was variable; schools, whether mainstream or special, were by no means guaranteed to be tolerant or constructive in their approaches to dealing with children's behaviour. Parents perceived a need for dedicated SENCOs with appropriate training to support teachers to take a consistent approach to managing children's behaviours.
- Similarly, staff in short breaks services need to be able to access good training that will allow them to effectively manage the child's behaviour. This training should be in line with what school and parents have accessed to maximise consistency and facilitate the development of a behavioural support plan that everyone understands and can use<sup>5</sup>.
- We became aware that where there had been a lack of training input into staff in one setting, the staff were inclined to 'write off' children and young people as having undesirable behaviours that were 'fixed' or immutable.

### The importance of data

When we asked commissioners about the information they keep on children and young people whose behaviours challenge who also have special educational needs or disabilities,

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<sup>5</sup> This reflects findings from the NDTi and In Control review (see footnote1)

we found that in general, children were known about but the various databases where they appear are not brought together to develop an overview of the need.

Paediatricians, health visitors, pre-school nurseries, schools, colleges and social care all tend to have some information but this is not feeding into either a register of disabled children<sup>6</sup> or a dynamic register as recommended under Transforming Care<sup>7</sup>. Consequently, the data are not being used for strategic planning and may lead to the preventative services being either too scarce or wrongly located. We were also told that there is generally a shortage of personnel who would have the time and skills necessary to do the data collection, collation and analysis. This was commented upon particularly in small unitary areas.

### Things that parents told us make services effective for them

Below is a list of the key things that parents across the four areas told us made for a good support service for them and their child. However, it was pointed out that first of all, families need to know that services exist or that they might be able to help. As mentioned above, getting information to parents when they need it can be a hit and miss business so a strategy is needed for informing staff and parents about local provision in places where children might go.

- **Easily accessible** services: this was not just about physical location but also about the services themselves being welcoming, not bureaucratic, not involving a waiting list and being responsive when families turn up or staff are made aware of a need.
- **Non-judgemental**: parents wanted the staff in services to be good at listening and not blame or judge parents' parenting skills. They particularly valued support from people who had lived experience of coping with someone whose behaviours challenge.
- **Practical help and positive solutions** being offered to families rather than children and young people being directed to segregated, stigmatising services that moved them further towards to specialist residential services.
- Services need to **deliver what is promised**
- Services that are **available when needed** not just between 9am and 5pm
- **Positive Behaviour Support Service** – parents said that one of the benefits of PBS is that everyone talks the same language and takes a consistent approach. This reduces anxiety and improves the child's and family's confidence.

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<sup>6</sup> This remains a statutory requirement under the Children Act 1989

<sup>7</sup> Intended to help identify individuals who are at risk of admission to secure accommodation

- **A holistic approach** that factors in the other aspects of the child and family's life so that management of behaviour does not become a stressful juggling act nor take too much time away from other children in the family.
- **Services are co-ordinated** either through a paediatrician or a key worker as recommended in the service model.<sup>8</sup> Many families had input from a range of education, health and social care providers for their disabled child. In the few instances where it existed, families really appreciated having someone to coordinate these various inputs so that they were not always the ones who had to communicate any changes to the support, medication or approach being taken. In one area, a paediatrician was the coordinating person but in another, a designated key worker was available to a few families<sup>9</sup>. It was not clear to us from our visits, what criteria were being used to decide who needed a key worker.
- **Home based support** is available if there is a crisis so that the child does not have to leave the family home.

### Some suggestions made by parents to improve services

At the end of each of our sessions with parents, we asked them to identify things that would improve services in their area. Below is a list of the commonly mentioned suggestions.

- **Provide good information** about where to get help with behavioural issues in the local offer and ensure staff know it is in there! It is helpful to have someone sit down with parents and go through what is available locally
- Put more **emphasis on early intervention**; start working with families when they identify a problem, listen to their concerns and respond with help. Do not wait for a diagnosis and do not assume they are poor parents - do not wait until there is a crisis
- At the **2 year old check**, ensure good signposting by health visitors if the child is likely to need behavioural support
- Introduce **behaviour support plans** and ensure that schools understand the importance of working to them- they need expert input to help them achieve a

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<sup>8</sup> See point 2.3 of Building the Right Support (the service model): <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

<sup>9</sup> for more information about key working in children's services see: [councilfordisabledchildren.org.uk/sites/default/files/uploads/documents/import/developingkeyworkingfinal.pdf](http://councilfordisabledchildren.org.uk/sites/default/files/uploads/documents/import/developingkeyworkingfinal.pdf)

consistent approach. This should be supported by dedicated SENCOs with appropriate training

- **Ensure provision is available near to where people live.** It can be difficult to travel to regional centres
- Plug some of the **gaps caused by eligibility criteria** whether they are age or condition specific ones- there is a need for a wider range of commissioned services to meet a greater range of needs
- **A drop in facility** where parents can discuss issues such as sleep, feeding ADHD, etc. without feeling judged.
- **Better and more training for staff** in a range of settings so that they feel confident and competent to meet the needs of all children. This includes short breaks services (universal and targeted).
- Ensure there is some **help available 24 hours a day**
- **Offer courses** such as PBS training and Cygnet without a long wait
- **Provide better co-ordination of appointments** and make it possible for us to 'passport' within and between different services so that we do not have to keep repeating the same information in different settings. Effective key workers who are well trained and proactive would help many families who are struggling.
- A **short breaks service** skilled for children who present challenging behaviours
- More information about **personal budgets/personal health budgets** and how they could help. Direct payments that allow higher pay rates for personal assistants for children and young people whose behaviour challenges
- **Change the current 'blame culture'** to more partnership working with parents
- More **dedicated resources and services** for this group – families are struggling
- More **advocacy** for families and young people





## 4. Some general points about working with sites

- Transforming Care is currently a long way removed from the everyday business of children's commissioners
- Capacity is an increasing problem with areas unable to field some key commissioners or professionals for a one or two hour meeting to which they are genuinely committed. Many areas have limited scope for taking on anything new that is not a legal requirement or a target/indicator such as a CQUIN<sup>10</sup>, a priority from the Joint Strategic Needs Assessment (JSNA),<sup>11</sup> etc.
- Local leadership is critical, the areas most committed to change had senior commissioners able to see the long term gains to early behaviour support and willing to make systemic changes. Sometimes they had developed a business case for the investment in services such as positive behaviour support or local crisis intervention teams and this had helped them secure sustainable funding, sometimes in partnership with neighbouring areas.
- Input to local areas needs to be practical – people welcomed the chance to talk through the issues specific to their areas and consider how to build on the good bits and change the things working less well. Our approach was to recognise their starting point and help them understand how to move on, rather than asking them to adopt something developed centrally.

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<sup>10</sup> CQUIN stands for commissioning for quality and innovation. The system was introduced in 2009 to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care.

<sup>11</sup> The Joint Strategic Needs Assessment identifies 'the big picture', in terms of the health and wellbeing needs and inequalities of a local population".