



# The future in Cumbria for children and young people with learning disabilities whose behaviours challenge

*The Challenging Behaviour Foundation, August 2019*



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

This paper was commissioned as part of the Challenging Behaviour Foundation contribution to the Cumbria Early Intervention Pilot. The brief was to set out ideas for long term strategic change for this group of children in Cumbria, informed by family carers. In view of the SEND area inspection in March 2019 the paper also now suggests that Cumbria leaders might want to consider the recommendations as part of their August 2019 Written Statement of Action in response to Her Majesty's Chief Inspectorate. Recommendations will also be useful when considering implementation of the NHS Long Term Plan in Cumbria.

- *Jacqui Shurlock, The Challenging Behaviour Foundation, August 2019*

*Cumbria early intervention focus group, June 2018*



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## What the research tells us

The research is clear that children with learning disabilities or autism whose behaviours challenge are currently at risk of poor outcomes, including social exclusion, physical harm, abuse, misdiagnosis, institutionalisation and deprivation. The parents of this group are also at risk of physical and mental ill-health due to the extra challenges they face and the lack of support and services available for their children.

The Challenging Behaviour Foundation (CBF) and the Council for Disabled Children (CDC) led a national project on early intervention for children with learning disabilities whose behaviours challenge, from 2013-2016. As part of this work we convened an academic expert group to review the published research. This section summarises the resulting briefing.

Children with learning disabilities or autism are much more likely to display behaviours that challenge in comparison to their peers. This is because they have not developed the communication and social skills required to get their needs met.

Children displaying challenging behaviours are at greater risk of social exclusion, institutionalisation, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions.<sup>1</sup> Poor outcomes are experienced not just by children themselves but by their families too. Carers face an increased risk of physical and mental-ill health, physical injury, increased financial burdens, and reduced quality of life.<sup>2</sup>

Research demonstrates that residential placements for children with learning disabilities reduce family contact; increase young people's vulnerability and accentuate the difficulties of transition to local adult provision.<sup>3</sup>

Population based samples show an increased risk for behaviour problems in children with learning disabilities, compared to other children, by the time they are 3 years of age.<sup>4</sup>

While challenging behaviour is the product of a complex interaction between biological, developmental and environmental factors, there is strong evidence that some of the key factors causing and/or maintaining challenging behaviour are amenable to change, and that change in these factors can be associated with marked reductions in challenging behaviour.<sup>4</sup>

Approaches that work well with children generally are also likely to be effective for children with learning disabilities. Knowledge drawn from behavioural research clearly indicates the potential benefits of providing evidence-based behavioural interventions and of doing so early.

Support for families is well accepted as a key component of effective support for children. Population data demonstrates that this is the case for the families of children with learning disabilities.<sup>5</sup> Emotional difficulties amongst parents and siblings of children who display behavioural difficulties are high<sup>6</sup> and develop early (often by the time the child is 5 years old).<sup>4</sup> Families often face unusual and distressing challenges. Longitudinal studies show that children's behaviour and wellbeing have an impact on the emotional functioning and behaviour of parents/carers<sup>7</sup> and family functioning in return has a direct impact on the wellbeing and behaviour of the child.<sup>8</sup>

The costs are high in financial as well as human terms. In 2014 our academic expert group found the annual cost of keeping one child as an inpatient in an Assessment and Treatment unit was £250,000. At 2014 figures, that would mean a current annual cost to the public purse of £60 million.<sup>9</sup> The actual cost at 2019 prices is likely to be much higher. However, the children in inpatient settings are just the tip of the iceberg. Many more children are in residential special schools, outside of their Local Authority area, often far from home. Dame Christine Lenehan's 2017 review of residential special schools found 6,146 children or young people boarding in residential schools or colleges, representing a spend in the region of £500m per annum. Research shows that children in residential settings often go on to residential settings as an adult. The annual residential service cost for an adult who displays severely challenging behaviour is £379,000, representing a significant ongoing cost.

## Cumbria strategic context

The CBF reviewed a number of strategic documents relevant to this group of children in Cumbria and the outcome of the 2019 SEND area inspection. The ambitions for Cumbria, across health, mental health, social care and education have the potential to make a huge difference to children with learning disabilities or autism whose behaviours challenge if they are fulfilled.

However, there was no specific focus on targets or outcomes for this particular group of children within any of the strategies named above, despite the particular vulnerabilities of this group and associated high costs, particularly when things go wrong.

The 2019 SEND area inspection report points to a continued reliance on out of area placements and a lack of consistent support for vulnerable children and young people, especially those with ASD or challenges in relation to social, emotional and mental health. It also concludes that co-production with families is weak.

## Visions and priorities as set out in strategic plans

There is no shortage of documents and plans which set out how the health care and wellbeing of Cumbria citizens should be improved; some required by national statutory bodies, including NHS England (NHSE), the Department for Health and Social Care and the Department for Education.

In common with (and perhaps reflecting) national initiatives it is rare to find much focus on children with learning disabilities and autism within plans for children's services and rare to find much content about children in documents related to learning disabilities. However, a trawl of local strategic documents demonstrated that, if implemented successfully, Cumbria's ambitions could make a significant difference to children with learning disabilities or autism whose behaviours challenge.

Aims of particular relevance include:

### **Reducing Health Inequalities**

*(Health and Wellbeing Strategy, Sustainability and Transformation Plans)*

The *Cumbria Health and Wellbeing Strategy* identified that "people with disabilities have less access to health care services and therefore experience unmet health care needs and are particularly vulnerable to deficiencies in health care services." However, the focus was very much on adults in terms of addressing this gap.

There are two different *Sustainability and Transformation Plans* (STPs) for Cumbria. *The Healthier Lancashire and South Cumbria Sustainability and Transformation Plan 2016/17-2020/21* identifies one of the weaknesses in the area being the quality of life for people with long-term mental health conditions and long-term conditions. A corresponding priority for 2016-2021 is "introduce population health model at scale across the footprint, with prevention strategies, comprehensive

*health promotion & wellbeing programme, community resilience & mobilisation and support to people to co-produce health gains”*

*The West North & East Cumbria Sustainability and Transformation Plan 2016-2021* prioritises population health & wellbeing, service quality and sustainability. The report sets out a new local health and wellbeing system led by the local authority and a new and more comprehensive clinical service strategy led by the NHS. The focus is on integration and on tackling health inequalities, including the links to mental health support related to health inequalities. The report talks about *“focussing services for people with learning disabilities, physical disabilities and mental health services on recovery and independence, to manage their needs and improve their physical health, and to live a full and integrated life in society.”* However, there is little focus on early intervention for disabled children; obesity is the main focus in early childhood.

### **Reducing Out of Area Hospital Placements**

*(Transforming Care plans; Transformation Plan; Cumbria Children and Young People’s Plan);*

There were two *Transforming Care* plans covering Cumbria (*North Cumbria and the North East and Lancashire and South Cumbria*, reflecting CCG boundaries). This means that the county is split in terms of monitoring progress against Transforming Care ambitions. Although CAMHs tier 4 admissions remain high across the county as a whole, there has been some success in reducing the admission of children with learning disabilities or autism due to pre-admission Care, Education and Treatment reviews (CETRs).

Cumbria and the North East were identified by the Transforming Care Programme as a *“Fast Track Area.”* As part of the fast track process, Cumbria prepared its locality plan to identify how Cumbria will implement national policy in a local context. This was to ensure that there were robust services being developed. These should then be underpinned by the planned trajectories, showing a reduction of 50% in inpatient learning disability beds across the North East and Cumbria. *The North East & Cumbria Fast Track Plan* was submitted to NHS England on 7 September 2015 and the transformation programme aims included:

- Less reliance on in-patient admissions;
- Developing community support and alternatives to inpatient admission;
- Prevention, early identification and early intervention;
- Avoidance of crisis and better management of crisis when it happens;
- Better, more fulfilled lives.

North Cumbria and the North East became a children’s accelerator site in 2018 and was awarded an additional £330,000 to focus specifically on good support for children with autism in mainstream secondary schools.

The *Transforming Care* programme was not just about a reduction in admissions. It emphasised the importance of improved community services and better integrated support for this group of children, alongside improved co-production with families, as key components of a better service

model. Guidance for commissioners<sup>10</sup> explained that early intervention should form part of this picture, reinforced by 2018 NICE guidance.<sup>11</sup>

It is not possible to say exactly how many Cumbria children within the Transforming Care cohort are currently out of area. There is no robust, clear understanding of the needs of the Cumbria population as an area for development and of the mechanisms required for filtering by need. Also, some 'subsets' will number fewer than five and in these circumstances, to prevent individuals being identified, the data is suppressed.

The *Cumbria Children and Young People's Plan for 2016-2019* explains that Cumbria is home to 104,900 children and young people age 0-19. Nearly 17,000 of those children and young people are identified as having special educational needs. The plan was produced by the Children's Trust Board, whose members are decision makers within their respective organisations. The Children's Trust works across all partnerships and organisations whose work has an impact on the lives of children and young people in Cumbria - bringing everyone together around a shared vision and priorities. It has three subgroups focussed on: poverty, emotional health and wellbeing and children with disabilities. The plan states that the three priorities for children 2016-2019 were that they should be:

- Healthy;
- Safe; and
- Achieving

Under the health priority, the plan states that one of the outcome areas should be *"emotional wellbeing: children and young people are experiencing a number of pressures which may be associated with a rise in demand for mental health services. Through the Transformation Plan we are taking a whole-system approach to maximise the opportunities to enable rapid access for all children and young people to high quality support, services and interventions"*. Other planned areas of change included *"more joined-up approaches to supporting children with long term and complex conditions, so the child does not have a disjointed experience of health, care, education and family life."*

In 2016 the evidence showed that *"hospital admissions for mental health issues and self-harm are at a higher rate in Cumbria than nationally. These are measured as admissions per 100,000 of the population, which show as 110.6 vs 87.2 for mental health issues and 467.8 vs 412.1 for self-harm."*

Emotional wellbeing work is led by the Transformation Plan and overseen by the relevant sub-group of the Children's Trust. It plans to create a whole-system approach where *"all our children and young people can access the support they need to achieve emotional wellbeing and mental health"*. Measures of success for this priority included reduced hospital admissions for mental health issues and self-harm and reducing waiting times to access the CAMHs service. The aim for 2019 was to deliver training for Mental Health professionals to avoid admissions/facilitate discharge and to develop better pathways into and out of inpatient care

The rest of the plan involves a strong focus on safeguarding and tackling deprivation and poverty in relation to school achievement. There is no specific mention of children with SEND and the additional challenges this group of children face in all three of the priority areas.

### **Provide Families with Early Help, Providing Preventative Support and Intervention Before Problems Become Complex and Entrenched**

*(Cumbria Early Help Strategy)*

*The Cumbria Early Help Strategy for 2016-2021, published by the Cumbria Local Safeguarding Children's Board has a set of principles which would apply extremely well to this group of children*

*“Early Help means identifying needs within families early and providing preventative support and intervention before problems become complex and entrenched. Early Help means supporting children, families and communities to further develop their networks within communities, recognising that individuals, families and the wider community can often help themselves and can develop their sense of wellbeing and greater quality of life through community engagement. Early Help means both early in life, offering support to very young children, and early after the emergence of a particular need. It includes both universal interventions and targeted interventions to prevent needs from escalating. Early Help allows for proportionate support to be put in place at the right time to meet families' needs prior to issues reaching crisis point. It draws upon families' own skills and promotes self-reliance. Early help services must take a pro-active approach to working with children and families and to preventing adolescent children becoming harder to help through unstructured interventions. All young people must be treated as a child in accordance with the Children Act 1989 until they attain the age of 18 years.”*

Although the language is very similar to that used by *Transforming Care*, the focus is very much on safeguarding and troubled families, rather than on the extra challenges that families of disabled children face. There is no mention of disabled children or those with SEND. It is interesting to reflect on the finding of the academic research group, that interventions which work for typically developing children can also work well for children with learning disabilities, within this context.

### **Provide a More Integrated Approach**

*(Sustainability and Transformation Plans)*

*The Healthier Lancashire and South Cumbria Sustainability and Transformation Plan 2016/17-2020/21 sets out a picture of a challenging environment for children's social care, with financial pressures resulting in a reduction of preventative services. There is recognition of the need for more integration and joint commissioning across health and care.*

*The West North & East Cumbria Sustainability and Transformation Plan 2016-2021 sets out a new local health and wellbeing system led by the local authority and a new and more comprehensive clinical service strategy led by the NHS. The focus is on integration as well as tackling health inequalities.*

The health system in Cumbria is considered to have a funding gap of approximately £80 million. Reports state that the system is spending far more money than it is allocated, with clear evidence of a structural deficit in each of the three main NHS Trusts.

There is an understandable focus on everyone “doing their bit” and promoting healthy lifestyles. However, for families of children with a lifelong condition, they will always need health support. The Cumbria learning disability priorities only kick in when talking about later in life. Children with learning disabilities or autism are almost totally lacking from strategies focussed on giving “*every child [...] the best start in life*”. Such strategies tend to focus on deprivation, safeguarding or social issues. However, as the evidence in part 1 of this report demonstrates, children with learning disabilities are at greater risk of poverty, restrictive intervention, poor outcomes and development of behaviours that challenge without the right support early in life.

We reviewed a report of a collaborative action research project; an *Evidence Based Approach to Workforce Development* conducted October 2015-July 2016 commissioned by *Health Education England North* on behalf of *NHS England North East & Cumbria*, it included a focus on family carers as part of the workforce and suggested a blueprint for great services:

- Have access to more information
- Be supported by community services
- Have access to improved specialist services
- Deliver actions set out in local plans

This is an effective summary of how services for the *Transforming Care* cohort of children could be improved through the actions set out in local strategic plans.

## SEND area inspection findings

A *SEND Area Inspection of Cumbria* took place on 18-22 March 2019.<sup>12</sup> The report sets out that some of the recent changes to infrastructure (designed to improve outcomes) have impacted negatively on delivery, but should now start to result in positive change. The inspection found a lack of joint work between health, education and care. It concluded that leaders have not collaborated to plan, commission or deliver services for children and young people with SEND. It also found that many parents and carers have lost faith and trust in the system which has taken a toll on their wellbeing.

*“The local area has not ensured vulnerable children are consistently well supported. In particular, those children and young people with ASD and/or those who face challenges in relation to their social, emotional and mental health often do not receive the support that they need. This sometimes leads to these children and young people falling into crisis”*

The reports states that access to services across the local area is inequitable, e.g. in some areas there is better access to short breaks than in others. It found issues around:

- Identification of needs, especially where they are less obvious
- Unidentified and unmet needs causing deteriorations in behaviour
- Waiting times for paediatric services
- Lack of personal budgets
- Short breaks offer too narrow
- Long CAMHs waiting lists, especially in the West
- Over reliance on out of area placements
- Lack of support leading too many young people to crisis

- Parent Carer forum lacks the capacity it needs to influence and does not reflect the diverse range of families in Cumbria
- Increase in tier 4 admissions
- School staff not trained in specific needs and not making Reasonable Adjustments

As a result of the *Send Area Inspection*, Cumbria must provide a written statement of action to address areas of weakness. Before action can be taken, the letter must show an awareness for, amongst other things:

- Understanding of the needs of the population
- The lack of trust of parents and carers and their limited involvement in co-production
- Weaknesses in the local system for support for emotional, health and wellbeing of children with SEND, particularly those with ASD

The following sections containing family views, suggestions, and recommendations based on the content of this report, could go some way towards meeting some of these requirements.

## Family carer views and suggestions

The CBF, in partnership with a local family-carer (and supported by the *North East and Cumbria Positive Behaviour Support Team* and the *South Cumbria Children's Learning Disability and Behaviour Support Service*) held two focus groups with family carers of children with learning disabilities or autism whose behaviours challenge (June and November 2018) and conducted an online survey from December 2018-February 2019. Despite the huge pressures on their time, geographical and access challenges, plus caring responsibilities, family carers were keen to participate, had lots to offer and were keen for further meaningful participation and coproduction. Key issues raised included:

- Information and support
- Unmet physical and mental health needs
- Co-production with families

### Better local information and support

Of the 38 families who responded to our survey, 50% were dealing with challenging behaviour on a daily basis and 75% said they wanted more information about how best they should support their child and which services locally could help. Families at our focus groups reported a lack of systematic information sharing. When they sought advice from key professionals such as GPs, paediatricians, and schools, those professionals were unaware of other behavioural support on offer in Cumbria. Some families were not aware of the *Learning Disability Nursing Team* or their entitlement to a *Social Care Assessment* under the *Children Act (1989)* or a *Carers Assessment*. Where families knew that specific forms of support were available, they did not know how to get referred to those services. This included whether they could self-refer or who could help them to access the service. Families were clear that by "information" they did not just mean the Local Offer, a website or a leaflet (although those things are useful), but a network of informed professionals and other family carers able to help them navigate a complex system.

### Address unmet physical and mental health needs

Children with learning disabilities or autism whose behaviours challenge experience **significant unmet health needs** (both physical and mental health) in Cumbria. Concerningly, half our survey respondents were unable to access paediatric support when they needed it for their child and 35% were unable to access mental health support. Most families had not had the Health Visitor check when their child was two years old. Families explained that this reflects a perception among generic health professionals that they can step back and hand over to specialists, when in fact no such specialist steps in to support families. Instead they are left to try and find the right sorts of support

by themselves, which often happens by accident. Families explained that their disabled children often did not receive the healthcare they needed, with many health problems going undiagnosed and untreated for long periods of time. Families were clear on their view that “Episodes of Care” was an inappropriate model for vulnerable children with lifelong conditions, known to be at risk of poor health and social outcomes when they have don’t have the right support in place (e.g. paediatrics, SLT, physiotherapy, OT) to review their health and development. This is at odds with national research, guidance and best practice about support for children with learning disabilities which suggests regular monitoring and health checks. Unmet health needs are a common cause of behaviours that challenge (potentially leading to behaviour crises dealt with under the mental health system) and people with learning disabilities are known to experience significant health inequalities across the country.

### Co-production with families

Families want to be part of **co-producing a more effective way forward** for this group of children. All the families who attended our focus groups were keen to be involved in future co-production and to try and help reach more families of children with learning disabilities or autism whose behaviours challenge. Many families had not heard of the Parent Carer Forum before attending our meeting. A recent Transforming Care survey of families across Cumbria and the North East received over 200 responses, but only 4 from families in Cumbria. We received 36 responses to our survey, which was less than we had hoped. However, once families were involved via focus groups, they had a huge amount to offer, including constructive ideas for change. Following our second focus group families agreed to set up and run a Facebook group “*Cumbria Challenging Behaviour*” which was joined by over 200 families in the first 48 hours. This demonstrates the appetite for information and networking with others if the format is right for families. Families at our second focus group listed ways that other families might be reached. Clearly, much more needs to be done to ensure that families of this vulnerable group are involved and able to inform decision making.

## National policy priorities for this group

Government policy is clear that children with learning disabilities or autism whose behaviours challenge should have the community support they need to live at home. However, recent reports agree that the five-year *Transforming Care* programme (2014-2019) has failed to deliver the community support required. Families are still falling into crisis and children are being admitted to Assessment and Treatment Units due to challenging behaviour or leaving their home area for residential schools. The programme has been followed by commitments in the NHS *Long Term Plan* for children with learning disabilities and autism, recognising the need for more specialist community support and better co-ordination of services for this group.

The Department of Health review, *Transforming Care*, published following the discovery of abuse of people with learning disabilities at Winterbourne View states that “*the norm should always be that children, young people and adults live in their own homes with the support they need for independent living within a safe environment. People with challenging behaviour benefit from personalised care, not large congregate settings.*”<sup>13</sup>

The latest data published by NHS digital shows 2,270 children and adults in inpatient settings, 1,340 of whom are under 35 (including 245 children), indicating clear issues with the transition to adulthood. Two reports published this year by CQC<sup>14</sup> and the Children’s Commissioner<sup>15</sup> show that vulnerable children and adults with learning disabilities or autism are being routinely restrained, secluded and deprived of their rights to a family life in inpatient hospital settings. These include both NHS and private hospitals. In addition, an episode of Panorama broadcast in June 2019 demonstrated a culture of psychological and physical abuse of residents at Whorlton Hall in County Durham;<sup>16</sup> a live-in facility for people with learning disabilities and complex needs.

Despite five years of the *Transforming Care* programme, it is generally agreed that progress has been too slow in bringing about systemic change to improve the lives of children with learning disabilities or autism whose behaviours challenge.

*The Challenging Behaviour Foundation* and the *Council for Disabled Children* led a three-year national project on early intervention for this group of children (2013-2016), funded by the *Department of Health*. The project found that evidence-based early intervention and early family support can significantly improve the quality of life for children and families and reduce behaviours that challenge. This approach has the potential to increase the wellbeing and resilience of families, to support children’s development and to prevent future crises as well as reducing overall public costs. The findings helped to inform the commitments in the NHS *Long term Plan*.

The NHS *Long term Plan*<sup>17</sup> (published January 2019) includes a commitment for the whole NHS to improve its understanding of the needs of people with learning disabilities and autism and to work together to improve their health and wellbeing. It sets out infrastructure changes, including the role of *Sustainability and Transformation Partnerships* (STPs) and *Integrated Care Systems* (ICSs) in making reasonable adjustments to support people with a learning disability or autism and in implementing new standards over five years; these should include working more effectively with

people and their families. The NHS makes a commitment to “*work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.*”

Specific reforms focus on the healthcare of children with learning disabilities and autism, which are very relevant to concerns raised by Cumbria families. Examples of such reforms are: a digital flag for learning disability on NHS records, testing and implementing the most effective ways to reduce waiting times for specialist services and diagnostic assessments (e.g. for autism), jointly developed packages to support children with autism or other neurodevelopmental disorders, and greater use of personal health budgets. There are clear commitments to provide better support in the community, including specialist community teams, seven-day multidisciplinary services, and keyworkers. However, there is an emphasis on crisis support and risk of admission and it is not clear whether local areas will be expected to provide early intervention; likely to be much more successful in the longer term to prevent out of area or restrictive services for children. The CBF is also conscious that many of the previous aims for children in Cumbria were slow to be implemented due to infrastructure change. The structural changes in the *NHS Long term Plan* therefore have the potential to slow down reform rather than to accelerate it – this is a very clear risk which will need to be managed.

There is a lack of clarity about how the new models of care will operate. This is a mental health approach which is being rolled out to learning disability where it has not yet been tested. Providers will have greater control over budgets and commissioning decisions. The CBF is concerned that this will create a conflict of interest. We would like to see family-carers fully involved in the process of developing the new models of care.

Another section of the *Long Term Plan* makes a commitment to a *Children and Young People’s Transformation Programme* which will oversee the delivery of the children and young people’s commitments in the *NHS Long term Plan* - including holistic care across local authority and NHS services, including primary care, community services, speech and language therapy, school nursing, oral health, acute and specialised services. Although laudable in principle, it is not yet clear how this will operate in conjunction with some of the lifelong commitments around learning disability and autism.

The NHS says that local *Implementation Plans* should set out:

- How proposals for people with learning disabilities and/or autism align with their plans for mental health, special educational needs and disability (SEND), children and young people’s services and health and justice;
- The local offer for autistic young people, people with a learning disability and their families;
- How NHS-led provider collaboratives will be developed locally and should ensure that digital plans use the reasonable adjustment ‘digital flag’ in the patient record or, where this is not available, use the Summary Care Record as an alternative.
- System investment should identify what community provision is in place for intensive, crisis and forensic community support. This includes seven-day specialist multidisciplinary services and crisis care and community teams for children and young people that can be built upon or strengthened with clear alignment with mental health and social care.

The NHS states that funding to deliver the improvements set out in the *Long Term Plan* will be provided through CCG allocations and additional service development funding, distributed to all systems, which includes agreed transfers to cover specialised services, community service investment and for *Transforming Care Partnerships*.

There are also clear statements about how local support should look within the 2019 *NICE Quality Standards*<sup>18</sup> on people with learning disabilities whose behaviours challenge (NB NICE use the term “people” to include children, young people and adults). These include:

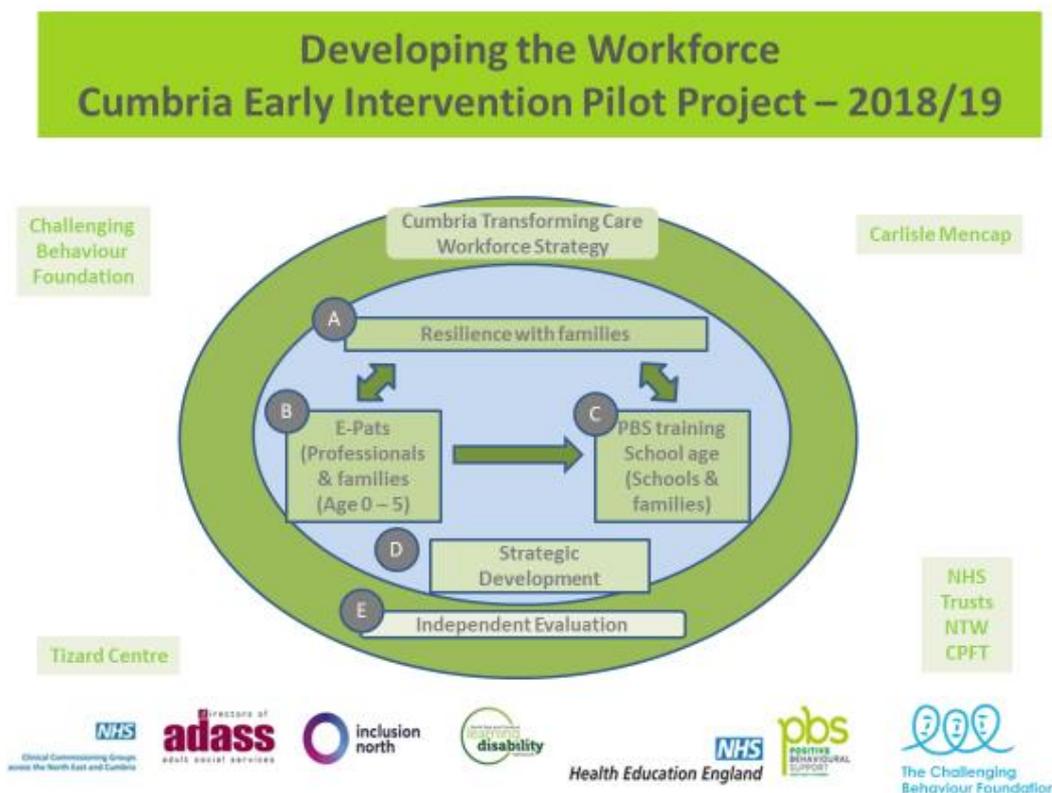
- A lead person to oversee strategic commissioning of services for all people with a learning disability;
- assessments to determine the function of behaviour;
- a lead practitioner for each individual;
- families involved by services in developing the person's care and support plan and parents of children under 12 to be offered a parent-training programme

The NICE commitments go beyond what is included in the NHS plan and are based on evidence and expert input. The CBF believes they are a good starting point for the development of local frameworks.

## Cumbria early intervention pilot

Cumbria has identified the workforce as key to delivery of *Transforming Care* and has recognised that the workforce includes unpaid family carers as well as professionals. In addition to significant workforce reform and training led by the *Positive Behaviour Support* team, the region is pioneering an early intervention pilot for children with learning disabilities or autism whose behaviours challenge and their families, which brings together a range of agencies and families in a collaborative approach. This is being funded by HEE, with additional funds from *Cumbria Local Authority* and CCG and is being delivered in partnership with the *Tizard Centre* and the *Challenging Behaviour Foundation*.

The pilot project began with a stakeholder event in 2017 and includes the following elements:



### 1. E-PATs

*(Early Positive Approaches to Support)*

Is a programme for family carers of children aged 0-5 with learning disabilities, autism or developmental delay, led by the *Tizard Centre* (the Learning Disability Centre at the University of Kent).

It is comprised of eight sessions for a group of families of young children (0-5) who have a learning or developmental disability. It supports resilience and wellbeing for family caregivers, positive development for children, and proactive access to services. E-PATs is facilitated by a trained professional and trained family carer who work in partnership. Cumbria family carers and professionals have been trained to deliver the intervention.

Materials and sessions have been co-produced by family carers and professional experts (prior to this project) and provide strategies for using now and in the future. Group sessions are designed to be emotionally supportive and meet the needs of a diverse range of families, supporting children with a variety of needs.

Sessions cover:

- Accessing services and supports
- Emotional wellbeing and resilience for caregivers
- Supporting sleep for children
- Supporting communication
- Supporting skills development
- Positive approaches to behaviours that challenge

The E-PATs intervention was initially delivered, as part of the pilot, in Carlisle, Ulverston, Penrith and Workington between June and December 2018. Since then Carlisle Mencap secured further funding for two subsequent programmes in Kendal and Barrow. Six staff from the *Community Learning Disability and Behaviour Support Team* were trained as professional trainers and are currently able to deliver as part of their core work within their NHS service. Four Cumbrian parent experts by experience were trained as family carer co-trainers. *Carlisle Mencap* hosted many of the sessions, recruited the initial families and were key local facilitators. Overall so far 32 families have benefitted from attending. The last session was completed in June 2019.

## **2. Positive Behaviour Support**

(PBS)

Training for families of school age children, alongside the staff supporting their children, is underway, led by the *Challenging Behaviour Foundation*. PBS workshops will train up to 40 families of school-age children and 40 professionals working in schools or respite services directly with children. This will promote and enable a consistent PBS approach to supporting children.

Workshops:

- Cover how to use PBS to reduce challenging behaviour displayed by children or adults with severe learning disabilities
- Are run flexibly, for staff and families together
- Are delivered by a PBS trainer and family-carer co-trainer.
- Are led by the *Challenging Behaviour Foundation* in collaboration with *the Cumbria and North East PBS Community of Practice*

Workshops are underway at Sandgate school in Kendal and in Carlisle in partnership with respite services.

The **mindfulness** intervention for families of children in this group (of any age) will help build resilience and capacity in family carers of children with learning disabilities and challenging behaviour.

The programme looks at:

- Learning new ways to manage stress.
- Understanding behaviours that challenge.
- Exploring difficult feelings and ways to cope with them.
- Learning about and practising mindfulness
- The programme emphasises working in collaboration, building on family expertise, gentle conversational meetings and “no teaching”.

This will take place in Autumn/Winter 2019

All three interventions are run by a qualified trainer, alongside a family-carer trainer with lived experience.

The final element of the pilot was:

**Seeking the views and experiences of families** with children with learning disabilities or autism whose behaviours challenge, to help inform proposals for longer-term strategic change for this group in Cumbria. This is covered in more detail in part 3 of this report.

The **evaluation** of the pilot (due winter 2019, once all interventions are complete) will outline the learning from the project as a whole.

## Recommendations and Next Steps

Based on the findings of the Cumbria Early Intervention pilot to date, our recommendations for local leaders are to:

1. **Collect meaningful data in order to better understand the population of children with learning disability or autism whose behaviours challenge and use this to make informed commissioning decisions about community support in Cumbria.**
2. **Develop a Cumbria-wide pathway for children with learning disabilities or autism, in co-production with families**, so families are aware of and able to access the right services in the right place at the right time. This could be driven by the Lead Commissioner (as recommended in NICE guidelines) The pathway could include:
  - A key-worker role, in line with the NHS *Long term Plan*
  - The roles of different agencies and how they should work together
  - A long-term commitment to rolling out the *Early Intervention* approach pioneered in Cumbria (incorporating the learning from the pilot and from the Cumbria early intervention team)
  - A long-term commitment to the awareness work with mainstream schools, initiated under the *Transforming Care* accelerator site
  - Families' proposal for network hubs to provide information and support on challenging behaviour in each of the 3 areas of Cumbria
  - Local crisis support for children with learning disabilities whose behaviours challenge, in line with the model recommended in the NHS *Long Term Plan*. This could build on the expertise of services valued highly by families, such as the *Community Learning Disability Team* and the respite support provided by *Mencap Carlisle* and *Westhouse*.

In our experience, if a successful pathway is developed and actioned for the children with the most complex needs, it proves effective for a much wider group of children. Alternatively, if this group are excluded from reforms, they will continue to experience disproportionately poor outcomes, at a high cost, both in human and financial terms.

3. **Take urgent action to better understand and address the unmet health needs of children with learning disabilities or autism in Cumbria.** The findings of our survey and focus group were extremely concerning. Families suggested initiating a system to log unmet needs. For example when families are told "you can't see a SLT/Paediatrician/OT/Physio etc as there is no one in post/a long waiting list" there should be a way to capture and record that so commissioners have clear data about the impact on families in order to consider how to address those unmet needs. We suggest this issue demands significant scrutiny and that action will be required to meet the priorities in the NHS *Long term Plan*.

Recommendations 1 and 2 would help to meet Cumbria's ambitions to reduce out of area CAMHS tier 4 placements, better integrate services and provide a preventative approach, and could form part of the plan to address the requirement in the 2019 SEND area inspection to "address the

*weaknesses in the local areas systems for supporting the emotional health and wellbeing of children and young people with SEND, particularly those with ASD”*

4. **Fund a specific co-production group for Cumbria families of children with learning disabilities or autism whose behaviours challenge.** Two family carers will translate the findings from this report and the other CBF reports from this project into a presentation that they would like to share with the *Parent Carer Forum*, the *Transforming Care Boards* and other local decision-making groups with an interest. We are funding that work to the end of December 2019 through the early intervention pilot, but there is a long term need for co-production with this group (potentially operating within the *Parent Carer Forum*), particularly in view of:
- The NHS *Long Term Plan* priorities around learning disabilities and autism
  - The 3 co-production hubs focussing on short breaks and personal budgets. This group should be represented in those discussions as both are key to effective community support for this group.
  - The findings of the *SEND Area Inspection*
  - The need to reach and involve more families – which, in our experience, is most successful when done by families themselves

This recommendation could help to address the requirement in the *SEND Area Inspection* to improve on the “*limited involvement of children, young people and families in the co-production of services, resources and support.*”

*This version is to be treated as a draft until signed off by the Early Intervention Project Steering Group*

## References

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Cumbria Children and Young People's Plan (2016-19)

Cumbria Early Help Strategy (2016-21)

Cumbria Transformation Plan (2015-20) and 2018 refresh

Cumbria Health and Wellbeing Strategy (2016-19)

Scoping the workforce development needs of health and social care providers delivering Positive Behavioural Support for those with Learning Disabilities across the North East and Cumbria: A report of a collaborative action research project conducted October 2015-July 2016 Commissioned by Health Education England North on behalf of NHS England North East & Cumbria For the Workforce Development Task & Finish group of Transforming Care Programme (2016)

Healthier Lancashire and South Cumbria Sustainability and Transformation Plan 2016/17-2020/21

West North & East Cumbria Sustainability and Transformation Plan 2016-2021

North East and Cumbria Transforming Care Community Model for people with Learning Disabilities and / or Autism

NHS Cumbria CCG Transforming Care Programme Learning Disabilities (2016)

### Other useful documents

DH Winterbourne View Review: Concordat: Programme of Action

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)

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Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education*, 31(4), 199-206.

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