



Briefing for Backbench Debate

Reducing Restrictive Intervention of children and young people

25th April 2019

Motion for debate:

This House calls on the Department for Education to urgently issue guidance on reducing the use of restrictive intervention of Children and Young People, and further calls on Ofsted to change its guidance to inspectors to recognise the importance of seeking to avoid the use of those interventions with Children and Young People.

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Our full report 'Reducing Restrictive Intervention of Children and Young People' can be read here:
<http://bit.ly/2V1YtuG>

Watch our video of families talking about their experiences here:
<https://vimeo.com/305545904/aa635cd15b>

Appendix: 2016 statement from the CBF and partners on reducing restrictive intervention



Reducing restrictive intervention - safeguarding children and young people (RRISC)

Key messages

These messages have been agreed and endorsed by the following organisations: The Challenging Behaviour Foundation, PABSS, Mencap, the Council for Disabled Children, the National Association of Special Schools,

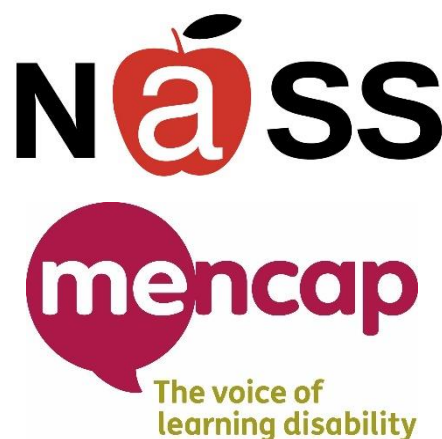
- The Challenging Behaviour Foundation and PABSS report published on 31 January 2019 suggests that vulnerable disabled children are being physically and emotionally harmed by restraint, seclusion and other restrictive interventions. *(see pages 6-9)*
- Families report harmful restrictive interventions in schools as well as health and social care settings (such as hospitals or respite care). Most of the incidents reported by families took place in schools. *(see pages 6-9)*
- With no legal requirement to record or report the restrictive intervention of children in the UK it is impossible to know how widespread the restraint and seclusion of children is. *(see pages 12-14)*
- When children leave their families to go to school, hospital or short breaks, the law is clear that their rights must be upheld. Children have the right to be protected from harm, to be well cared for, to be free from cruel or inhuman treatment and to access education. These rights apply to *all* children.
- There is evidence about how to provide good support for children with learning disabilities or autism who display behaviours that challenge. Schools using Positive Behaviour Support (PBS) report huge reductions in the use of restrictive interventions. We want to build on the good practice that exists and share it across all schools. *(see pages 10-11)*
- Experts agree that evidence-based intervention should begin early. There is strong evidence that some of the key factors causing challenging behaviour can be changed,

and when changed can lead to marked reductions in challenging behaviour. (see pages 10-11)

What we are calling for

- We are calling on the Department for Education to show strong leadership to reduce the use of restrictive intervention on children. This should include:
 - Publication of the promised national guidance; (pages 12-14)
 - Evidence-based early intervention to support families of children with learning disabilities or autism whose behaviours challenge; (pages 10-11)
 - Positive Behaviour Support (PBS) training for school leaders and staff; (pages 10-11)
 - A safeguarding system that is fit for purpose for disabled children; (pages 10-11)
 - A stronger accountability system to include reporting and recording of restrictive interventions and action when children are harmed. (pages 6-9 and 12-14)

#NoHarm #flipthenarrative #HumanToo



About the CBF and PABSS

This briefing was prepared by the Challenging Behaviour Foundation (CBF) working in partnership with Positive and Active Behaviour Support Scotland (PABSS). Both are family led charities focussed on improving the quality of life of children, young people and adults with learning disabilities who display behaviours described as challenging, using evidence-based approaches.

The Challenging Behaviour Foundation (CBF) is a charity which exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy ordinary life opportunities when their behaviour is properly understood and appropriately supported. The CBF supports families across the UK caring for individuals with severe learning disabilities. Information and support around understanding challenging behaviour and supporting behaviour change is provided through a range of written and DVD resources, email networks, family linking scheme, and through individual telephone support.

Positive & Active Behaviour Support Scotland (PABSS) is a small parent-led charitable organisation who support families caring for children and young people with disabilities and who may display challenging behaviour. PABSS promotes understanding behaviour as a form of communication and advocates the use of a communication passport incorporating a bespoke positive behaviour support plan. The PBS plan tells the child's carer how best to prevent any episodes of challenging behaviour, but also how to respond when the child is becoming or has become distressed without resorting to harmful physical intervention (restraint) or punishment. PABSS currently support over 700 families whose children have been physically and emotionally harmed through the use of restrictive intervention and campaign for change at a National Level.

Types of restrictive intervention

Physical restraint: *Direct physical contact between the carer and the person with behaviour that challenges. This includes children being pinned to the floor by multiple people in a prone (face down) position or a supine (face up) position.*

Seclusion: *supervised containment or isolation away from others in a room the child is prevented from leaving*

Mechanical restraint: *Materials or equipment are used to restrict or prevent movement e.g. arm splints or being strapped into a chair.*

Blanket restrictions: *These are rules which restrict what an individual is able to participate in, for example: lack of access to outdoor space, being forced to sit in a wheelchair when able to walk and not being allowed to participate in school trips.*

Chemical restraint: *the use of medication in response to someone's behaviour*

Prone restraint: *Positive and Proactive Care (2014) – the guidance for reducing restrictive intervention of adults with learning disabilities, states that prone restraint – holding a person face down to the floor – is extremely distressing and poses a risk to the person's breathing and therefore*

their life. The guidance makes it clear that prone restraint should no longer be used as a planned intervention.

Families have contacted us following prone restraint being used on their children but there is no equivalent guidance to Positive and Proactive Care to say this method should not be used with children. For example, Calum, featured in this report was restrained prone on the floor because he kicked out at a teacher when she removed him from a bike he was riding the school gym. Calum had multiple bruises on his arms and legs and abrasions to his spine. Calum also had widespread petechial haemorrhaging on his upper chest and his lips were blue.

There is no evidence base for the effectiveness of prone restraint in reducing the frequency or intensity of behaviours that challenge. It is a hugely traumatic and damaging experience for children and their families. The deaths of several people have been associated with prone restraint¹. (O'Halloran RL, Lewman LV. Asphyxial death during prone restraint revisited: A report of 21 cases. Am J Forensic Med Pathol (March) 2000, 21(1); 39-52)

The regular use of prone restraint is not consistent with the United Nations Convention on the Rights of the Child.

Due to the lack of guidance we published a statement on the use of restrictive physical interventions (including prone restraint) with support from the Tizard Centre, University of Kent, the Children's Commissioner for England, the Council for Disabled Children and Mencap. This is attached as an appendix.

Facts and figures

CBF/PABSS data

Our [report](#), published 31 January contained findings from a CBF survey of families (with 204 respondents) and 566 family case studies collected by PABSS. We found that:

- **88%** of the 204 respondents to the CBF survey said their disabled child had experienced physical restraint, with **35%** reporting it happening regularly.
- **71%** of families completing the CBF survey said their child had experienced seclusion - **21%** reported that this was taking place **on a daily basis**.
- Of the respondents to the CBF survey **50%** of children had been prescribed medication to manage challenging behaviour.
- Most of the restrictive interventions reported in the CBF survey were taking place in schools; for example **68%** of the physical interventions.
- The PABSS collection of case studies included **1058** reports of restraint and **544** reports of seclusion.

Over half of the cases of **physical intervention or seclusion** reported were of children between the ages of **five and ten**. The youngest case involved a 2 year old child.

Families reported negative physical and emotional impacts of restrictive intervention on both children and their families. **58% of families whose child experienced restraint said that it led to injury.**

“Unexplained bruises, what looked like carpet burns to knees and ankles, unexplained broken wrist”

91% of CBF survey respondents reported an emotional impact on their child.

“Incontinence, meltdowns, shutdowns, unable to communicate as overloaded with emotions and information”

78% of families said that the use of restrictive intervention had made their child’s behaviour worse.

Restrictive intervention also had a significant impact on families with respondents reporting mental health impacts, family breakdown and financial strain. Only 32% of parents were offered emotional support.

From the 566 case studies collected, **only 19% of families reported that injuries were recorded** and only 17% reported that the restrictive intervention was recorded.

The PABSS case study data found that more restrictive interventions were recorded where staff had received training. More work is needed to understand this correlation and the nature of the training staff received.

61% of survey respondents felt that Headteachers were using restrictive intervention as their main method of addressing behaviours that challenge among disabled children. 42% felt that staff were trying to punish their child.

91% of families who completed the survey called for **better training for teachers and school staff** in learning disability, autism, challenging behaviour and Positive Behaviour Support (PBS). 84% also called for **more accountability** for harm caused and **stronger safeguarding arrangements**.

Other data

There is no formal requirement for data collection of restrictive physical interventions that take place within schools. On 2 April 2017, *Five Live Investigates* broadcast an investigation into restraint in special schools. Their Freedom of Information request to local authorities in England, Scotland and Wales revealed **13,000 physical restraints over the previous three years**, resulting in **731 injuries**. However, these figures only reflect data collected by around a fifth of authorities as most authorities said they didn't keep the information. That suggests the true number of injuries caused by restraint in special schools is likely to be far higher.

NHS Digital data collected on people with learning disabilities or autism in inpatient units shows that young people aged under 18 are the age group most likely to be subject to restrictive interventions (12% of children and young people compared to 7% of adults in inpatient units/wards) and, if they do, to experience more than twice as many instances of restrictive intervention (18.2 instances of restrictive interventions per person in November 2018) as other age groups. Children and young people are both more likely to be subject to restraint, and if they are subject to restraint they are subject to that restraint more frequently than adultsⁱⁱ.

Analysis by Chris Hatton (<https://chrishatton.blogspot.com/>)

Family experiences (these are from the published CBF/PABSS report)

Calum

by Beth, Calum's mum

Calum is a loving, happy boy who has epilepsy and learning disabilities. We were delighted when he got a place in a “special school.”

On the first day in the new class Calum came home with multiple bruises on his arms and legs and abrasions to his spine. Calum also had widespread petechial haemorrhaging on his upper chest and his lips were blue. The school said he had been restrained on the floor (prone) by staff because he had kicked out at a teacher when she removed him from a bicycle he was riding in the school gym. Calum urinated during the restraint but staff put him in a “time out chair” still in his urine soaked clothes whilst showing him an egg timer to indicate he was being “punished.” They did this twice in 3 days. Calum was 11 years old, but small in size, wearing clothes for a 7 year old.



Our GP recorded Calum’s injuries and made a referral to child protection. The Police said there was “no intent” so no charges were brought. The school were surprised that we were angry and made no apology. We were left feeling extremely frustrated.

The school had a control and management approach to “discipline”. They had a “safe space” and the staff wore whistles around their necks. They claimed they’d been trained in safe restraint techniques, yet Calum had horrific injuries. They hadn’t even heard of “Positive Behaviour Support.”

Reluctantly, we sent Calum back but to a new class and teacher, but Calum was very unhappy. He wasn’t sleeping well. He started having nightmares and woke each night crying out about “bad teachers.” He began to write “stories” about how “scary” school was. He flinched when anyone went near him and he was extremely withdrawn. Every morning, he would beg “no school, it’s bad for me.” His epileptic seizures increased, he lost weight and was diagnosed with PTSD. We removed him from the school.

We are determined to make sure that what happened to Calum never happens to another child.

Laura

by Kate, Laura’s mum

My daughter, Laura, often becomes anxious in environments that she cannot cope with. Because she has a sensory processing disorder, as is often the case for people with severe or complex needs, she can find her surroundings and contexts (lights, noise, people, unfamiliarity, bad night’s sleep...) more stressful than your typical person. Furthermore, Laura cannot easily communicate her frustration and discomfort to those around her. This leaves her with only one option – acting with her behaviour to try to escape the situation.



Sadly, in many cases, the training for those supporting individuals like Laura is grossly inadequate leaving staff without the necessary skills and knowledge to recognise the triggers and function of behaviour. Even worse, the misunderstandings that are perpetuated, due to a lack of correct guidance, frequently result in the use of forceful restraint as a form of control and even punishment.

As a family we have spent many years working with the professionals to create an evolving Positive Behaviour Support plan for Laura, helping her support staff understand what she is communicating with her behaviour and why; keeping her safe and happy. We want to see all those in similar need receive such care as it is everyone's right to live free from pain and fear.

Ella

by Elly, Ella's mum

Our daughter Ella was born with a rare syndrome. She was diagnosed as Deafblind when she was aged seven, in 2013, despite being congenitally Deafblind (from birth). Being Deafblind does not necessarily mean that you are totally deaf or totally blind – most individuals who are Deafblind have some residual sight and/or hearing and Ella had enough vision to navigate independently, watch TV and read books close up. You may have heard of Helen Keller and her story: *'Helen Keller's life was defined by what she could do'* despite being Deafblind; her work helped shape a path for many disabled people. As a parent, that is something that I believe in, especially when you have the right approach to education, teach with high expectations and treat children equally regardless of difference.



Ella's disability was recognised so late in her life, and therefore her right to the appropriate education and to learn how to communicate her needs and wants (like any child must) was severely delayed. Ella became extremely stressed in 2013, the significant delays to support her meant that she deteriorated very quickly. Our daughter, like so many children, was not supported appropriately and the use of restrictive intervention both increased her stress and anxiety, and left her traumatised, which resulted in tragedy.

Unfortunately, and tragically our daughter became so stressed she head banged until she detached both of her retinas. She had to have five operations to try to save her sight, but they failed and she went blind.

"Viewing behaviour as a choice to be swayed through fear or coercion is deeply flawed."

Jarlath O'Brien

For the past five years we have worked tirelessly to piece our daughter back together and heal her trauma. It takes a huge amount of work to enable a child to move past such a life-changing experience of failure (by those who were trusted to identify her needs and support her) and begin to be able to be part of life and indeed education again. We focus now on how to ***#flipthenarrative***. We look at what **we** are missing and following **Ella** to understand how we can best support her positively, free from restrictive interventions and harm. She is a human being with the right to education and life like any other. We have worked with professionals, a phenomenal team of Intervenors and fellow changemakers to develop an approach that proves there is a better way. We believe that together we can change the way our children are perceived and supported. We must **all** reflect on what we bring to that much needed change – that we view our children equally and with respect and dignity like any other human being.

Research and evidence

Reasons for challenging behaviour

In 2014 the Challenging Behaviour Foundation academic expert group published a [briefing paper](#)ⁱⁱⁱ based on available research which stated that children with learning disabilities are much more likely to show behaviours that challenge than their peers, as they don't develop the social and communication skills other children develop in order to get their needs met. These stark differences in risk for the development of behaviours that challenge emerge in early childhood,^{iv v} and can be highly persistent over time.^{vi}

There is always a reason for challenging behaviour. Skilled support enables children to have their needs met without the use of restrictive interventions, which should only ever be used as a last resort. The academic group recommended **evidence-based early intervention** (including Positive Behaviour Support) and better support for families. The CBF shared best practice examples in the 2015 report [Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge](#)^{vii}.

Risks created by inappropriate responses

A lack of evidence-based responses to challenging behaviour can increase the individual's risk of experiencing physical interventions and being placed in services out of area when local areas do not meet children's needs. These increased risks are set out in two reports by Dame Christine Lenehan: [These Are Our Children](#)^{viii} and [Good Intentions, Good Enough?](#)^{ix} which chart common pathways out of area for children with a learning disability and/or autism. This often stems from a lack of local expertise, exclusion from services (including schools) and poor transition from out of area residential specialist schools and colleges.

An aversive or restrictive response to challenging behaviour (for example shouting at a child with heightened sensory awareness, placing a child in a seclusion room for throwing a plate, restraining a child to stop them biting, or locking a child in to stop them running away) will fail to address the underlying cause of behaviour. In addition, a restrictive intervention will likely increase that behaviour as well as increasing the anxiety and risks to wellbeing of both the children and staff involved in the incident.

Research by the Richmond Fellowship and the Tizard Centre in 2011^x found that people who had experienced restrictive physical interventions found them painful, emotionally distressing and indistinguishable from abuse and violence.

The alternative - evidenced-based support

The National Institute for Health and Social Care (NICE), the Department of Health and the NHS England Transforming Care guidance^{xi} all recommend **Positive Behaviour Support (PBS)** as the best evidenced approach for people with learning disabilities or autism whose behaviours challenge.

The Positive Behaviour Support Academy defines PBS as: *a multicomponent framework for developing an understanding of behaviour that challenges. It is based on the assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop a range of evidence-based support. The overall goal is to enhance the person's quality of life, thus reducing the likelihood of challenging behaviour occurring in the first place*^{xii}. (<http://pbsacademy.org.uk/>)

PBS interventions are informed by a functional assessment to determine the reason for, or “function” of an individual’s behaviour.^{xiii} Once the reasons behind an individual’s behaviour are established, factors can be altered to reduce the challenging behaviour. For example, elements of a child’s environment can be changed (for example, noise levels reduced for someone with heightened sensory awareness) or the child taught new skills (for example, learning to sign “finished” so they don’t throw their plate at the end of a meal), resulting in more effective and more acceptable behaviour. If the functional assessment finds that health or mental health needs are the reason for behaviours that challenge (for example, biting a table due to toothache or running away due to anxiety), these can then be addressed appropriately with input from the right professionals.

NHS England and the challenging behaviour academic expert group recommend **early intervention** for this group of children; including family support and training. Knowledge drawn from behavioural research clearly indicates the potential benefits of providing evidence-based behavioural interventions and of doing so early. There is robust evidence that early behavioural interventions can have positive effects on both parent and child outcomes and NICE recommends parental training.^{xiv}

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.^{xv} Emotional difficulties amongst parents and siblings of children who display behavioural difficulties are high^{xvi} and develop early (often by the time the child is 5 years old).⁴ Families often face unusual and distressing challenges. Longitudinal studies show that children’s behaviour and wellbeing has an impact on the emotional functioning and behaviour of parents/carers^{xvii} and family functioning in return has a direct impact on the wellbeing and behaviour of the child.^{xviii}

Government policy

Government guidance on behaviour management of disabled children and the use of restrictive intervention (where the Department for Education leads) is unclear and inconsistent with Government guidance on supporting people with learning disabilities and autism (where the Department for Health and Social Care and NHSE lead)

The National Institute for Health and Social Care (NICE), the Department of Health and the NHS England Transforming Care guidance^{xix} all recommend Positive Behaviour Support (PBS) as the best evidenced approach for people with learning disabilities or autism whose behaviours challenge.

Primary legislation Section 93 of the Education and Inspections Act 2006 allows the use of reasonable force

- To prevent the committing of an offence
- To prevent personal injury to or damage to the property of any person
- To maintain good order and discipline

Department for education guidance

The Government has been promising **non-statutory guidance** on reducing restrictive interventions with children since 2014. **Nothing has yet been published.** There are national minimum standards for children's homes which cover this issue, but not for schools. Current *non-statutory* guidance for schools is inconsistent and cross-refers to other guidance making it difficult for schools to work out how it all relates in practice.

Timeline of promised guidance

April 2014- Positive and Proactive Care (adult guidance) published by Department for Health and children's guidance promised

Oct 2014- Expert group convened to advise on equivalent children's guidance and a number of meetings held over the following year. DH agreed to publish joint guidance with DfE on advice of expert group but excluded mainstream schools.

Jan 2016 – After queries about when the guidance would be published and in response to concerns about prone restraint, we published a statement with some other organisations (see attached Appendix)

Dec 2016 – we wrote to Edward Timpson, Minister for SEN at the time

Jan 2017 – Edward Timpson replied promising guidance early 2017

Jan 2017 – stakeholders received a draft for comments

29 Nov 2017- 24 Jan 2018 – public consultation on draft guidance

<https://www.gov.uk/government/consultations/restraint-and-restrictive-intervention-draft-guidance>

2018-2019 – many queries from us about publication date, we were told before Christmas 2018, then January 2019, then March and now April 2019

Ofsted guidance

The latest document to be published on this topic is Ofsted guidance ***Positive environments where children can flourish; a guide for inspectors about physical interventions and restrictions of liberty (2018)***.

Paragraph 14 of the Ofsted guidance says “there is nothing in statutory guidance which state that any of the following are not permissible”. (In our view that means the following are permissible)

- the use of prone holds and/or taking children to the floor and/or ‘ground’ holds
- restraining children in their bedrooms and/or on their beds
- periods of physical intervention that are lengthy
- high numbers of staff involved in an incident
- situations that are escalating, with restraint being used more frequently
- restraint practices becoming the norm/being applied universally or indiscriminately
- children sustaining injuries
- repeated incidents or patterns that are easily identifiable
- incidents that involve care staff being used on school premises to ‘manage’ children’s behaviours (as opposed to staff who hold multiple roles)
- incidents that involve children being administered prescribed medication on an ‘as required’ basis to calm, relax or sedate them
- incidents that involve the intentional use of equipment to physically restrict children with or without staff being physically present (e.g. safe space beds, a wheelchair, reins or a safety harness or a seatbelt).

If Ofsted find evidence of the above, inspectors are advised to ask questions about “why these were the best or the only solutions, how the action was proportionate to the circumstances and how the child’s rights were respected”

Paragraph 32 states that “schools are not required to record and report incidents of the use of restraint. Similarly, informing parents is good practice, but not required”. Inspectors are advised to focus not on what is recorded, but on how that information is used.

Previous DfE guidance

Guidance on Behaviour and discipline in schools (Department for Education, 2016) states that schools must have a behaviour policy and that this should be available via their website (unless they are an Academy, when they do not have to publish their policy). It states that discipline should comply with other legal frameworks (human rights, disability etc) but gives no details on how this should be achieved. The guidance states that staff should consider whether the behaviour gives cause to suspect that a child is suffering or has unmet needs and in this case should follow the safeguarding policy, and potentially secure a multi-agency assessment. Again, no details of how. It states that isolation, where a child can’t leave of

their own free will, can only be used in “exceptional circumstances”. There is no content about recording or reporting.

Earlier guidance was more relevant to children with learning disabilities and autism, but it is not clear whether schools still see this as current or how it fits with the latest guidance from Ofsted.

Guidance on the use of restrictive physical interventions for staff working with children and adults who display extreme behaviour associated with learning disability and/or autistic spectrum disorder (Department for Education, 2002) starts from the position that use of force should be a last resort and gives a reasonable amount of detail about what restrictive interventions are and how they should and shouldn't be used. It has content explaining prevention and de-escalation; it states that seclusion should only be used for those under the Mental Health Act (and draws the distinction between section and time-out) and states that equipment such as lap belts should never be used to manage behaviour. It refers to a 2001 circular to Chief Education Officers which gave minimum standards of recording and reporting which should be adhered to. However, the guidance states that, to be consistent with care homes, schools should go beyond the minimum standards.

A protocol for local children's services authorities on restrictive physical intervention in schools (ADCS, 2009) states that incidents should be recorded as quickly as possible and within 24 hours, it also gives details of what should be recorded. The protocol states that the Headteacher should be notified and should submit a report to Governors at least annually. The Governing body should have “due regard” to safeguarding procedures. However, this guidance also states that the use of pain compliance is justified in “exceptional circumstances”

Related areas of work

Various work being led across Government at present could have a significant impact on improving support for children with learning disabilities or autism whose behaviours are described as challenging. However, despite their extreme vulnerability and high risk of harm through restrictive intervention, there is very little work going on at present to look at the specific needs of this group. These areas of work include:

Transforming Care/The NHS Long Term Plan

The commitments to children with learning disabilities and autism within the NHS Long term plan are welcome, however the number of children in Assessment and Treatment units are currently rising. At the end of February 2019 there were 2,294 children, young people and adults with learning disabilities and/ or autism in inpatient units. This includes 250 individuals under the age of 18. There is little clarity on how the Long Term plan commitments will be delivered in partnership with DfE. Much of the early intervention and prevention work will need to take place in the early years and within schools.

ACES

Research into adverse childhood experiences (ACES) shows the significant impact on adult life. Children with learning disabilities or autism who have experienced the emotional and physical effects of restrictive intervention have not been a focus of the research to date but this work is starting to show how they should be a core group in terms of applying what we know from the ACES work. There is no trauma support currently available for children who have experienced restrictive intervention.

Further reading

Policy documents

Included, Engaged and Involved: preventing and managing school exclusions. Scottish Government, June 2017.

Early intervention for children with learning disabilities whose behaviours challenge. Challenging Behaviour Foundation Academic Expert Group, November 2014

Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge. The CBF, 2015

These are our children: A review by Dame Christine Lenehan Director, Council for Disabled Children Commissioned by the Department of Health, January 2017

Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges by Dame Christine Lenehan, commissioned by the Department for Education, November 2017

Positive and Proactive Care: reducing the need for restrictive interventions, Department of Health, April 2014

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, NICE guideline [NG11], May 2015

Learning disabilities and behaviour that challenges: service design and delivery, NICE guideline [NG93], March 2018

Human rights framework for restraint: principles for the lawful use of physical, chemical, mechanical and coercive restrictive interventions. Equality and Human Rights Commission, March 2019

Useful websites

The following websites provide more information about PBS and the charities who have been involved in producing this report:

This is the website for the **Positive Behaviour Support Academy**, a collective of organisations and individuals in the UK who are working together to promote Positive Behavioural Support as a framework for working with children and adults with learning disabilities who are at risk of behaviour that challenges. <http://pbsacademy.org.uk/>

This is the website for the **Challenging Behaviour Foundation (CBF)**, a charity for people with severe learning disabilities and behaviour described as challenging. The website resources include information sheets about Positive Behaviour Support. <https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/positive-behaviour-support.html>

This is the website for **Paving The Way**, a project about early intervention for children with learning disabilities whose behaviours challenge. <http://pavingtheway.works/learning-from-families/calum-restrictive-interventions-restraint/>

The is the website for **Positive and Active Behaviour Support Scotland (PABSS)**, a charity aiming to provide awareness, training, support, campaigning and advocacy in Positive Behaviour Support to those families and professionals involved in the care and education of children and adults with learning disabilities and/ or additional support needs. <https://pabsscot.wixsite.com/pabss>

This is the **Mycompass** website about communication passports which aim to provide a practical and person-centred way of helping children, young people and adults who cannot easily speak for themselves. <http://www.mycompass.com/>

References

ⁱ O'Halloran RL, Lewman LV. *Asphyxial death during prone restraint revisited: A report of 21 cases*. *Am J Forensic Med Pathol* (March) 2000, 21(1); 39-52

ⁱⁱ Chris Hatton, March 2019. 'Children and young people with learning disabilities and autistic children and young people in inpatient units- what do the statistics tell us?' <https://chrishatton.blogspot.com/>

ⁱⁱⁱ *Early intervention for children with learning disabilities whose behaviours challenge*. CBF Academic Expert Group, November 2014

^{iv} Totsika, V., Hastings, R.P., Emerson, E., Berridge, D. M., & Lancaster, G.A. (2011). Behavior problems at five years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology*, 39, 1137-1147.

Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology & Psychiatry and Allied Disciplines*, 52, 91-99.

^v Einfeld, S. L., Ellis, L., Doran, C. M., Emerson, E., Horstead, S., Madden, R., & Tonge, B. J. (2010). Behaviour problems increase costs of care of children with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, 3, 202-209.

Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: A bi-national perspective. *Journal of Child Psychology & Psychiatry and Allied Disciplines*, 51, 583-593.

^{vi} Emerson, E., Blacher, J., Einfeld, S., Hatton, C., Robertson, J., & Stancliffe, R.J. (2014). Environmental risk factors associated with the persistence of conduct difficulties in children with intellectual disabilities and autistic spectrum disorders. *Research in Developmental Disabilities*, 35, 3508–3517.

^{vii} *Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge*. The CBF, 2015

^{viii} *These are our children: A review by Dame Christine Lenehan Director, Council for Disabled Children Commissioned by the Department of Health, January 2017*

^{ix} *Good intentions, good enough?* A review of the experiences and outcomes of children and young people in residential special schools and colleges by Dame Christine Lenehan, commissioned by the Department for Education, November 2017

^x Macdonald et al (2011) "You squeal and squeal but they just hold you down" Restrictive Physical Interventions and people with intellectual disabilities: service user views. *BILD, International Journal of Positive Behavioural Support*.

^{xi} *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, NICE guideline [NG11], May 2015

Learning disabilities and behaviour that challenges: service design and delivery, NICE guideline [NG93], March 2018

Positive and Proactive Care: reducing the need for restrictive interventions, Department of Health, April 2014

Supporting people with a learning disability and/ or autism who display behaviour that challenges, including those with a mental health condition. Service model for commissioners of health and social care services NHS England, 2015.

^{xii} Positive Behavioural Support Academy. <http://pbsacademy.org.uk/> . Accessed 18/01/2019

^{xiii} O'Neill, R. E., Horner, R. H., Albin, R. W., Storey, K., & Sprague, J. R. (1990). *Functional analysis of problem behavior: A practical assessment guide*. Sycamore Publishing Company, Sycamore: IL.

^{xiii} *STOMP Stopping the overmedication of people with a learning disability, autism or both*. NHS and MixIt, 2018.

Medication Pathway- for families of people with learning disabilities, autism or both who are prescribed or may be prescribed psychotropic medication.

<https://medication.challengingbehaviour.org.uk/> (Accessed 24/01/2019) The Challenging Behaviour Foundation and STOMP.

¹⁹ NICE (2013). *Antisocial behaviour and Conduct Disorder in Children and Young people: The NICE guidance on recognition, intervention and management* [Online]. Available at: <http://www.nice.org.uk/guidance/cg158>.

^{xv}Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45(8), 1338-1349.

^{xvi} Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4-5), 217-230.

Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *Journal Information*, 107(6).

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability*, 27(3), 149-160.

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.

^{xvii} Neece, C. L., Blacher, J., & Baker, B. L. (2010). Impact on siblings of children with intellectual disability: The role of child behavior problems. *Journal Information*, 115(4).

^{xviii} Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: a transactional relationship across time. *American journal on intellectual and developmental disabilities*, 117(1), 48-66.

^{xix} *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, NICE guideline [NG11], May 2015

Learning disabilities and behaviour that challenges: service design and delivery, NICE guideline [NG93], March 2018

Positive and Proactive Care: reducing the need for restrictive interventions, Department of Health, April 2014

Supporting people with a learning disability and/ or autism who display behaviour that challenges, including those with a mental health condition. Service model for commissioners of health and social care services NHS England, 2015.