



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

# Reducing Restrictive Intervention of Children and Young People

## Case study and survey results

### January 2019

## CONTENTS

Acknowledgements .....	3
Summary .....	3
Family experiences .....	5
Calum	
Laura	
Ella	
Introduction .....	7
Why we wrote this report	
Findings from relevant reports and guidance	
Positive Behaviour Support	
Data	
Types of restrictive intervention: physical restraint, mechanical restraint, seclusion, blanket restrictions, chemical restraint	
Method .....	10
Findings .....	11
Use of restrictive interventions	
Where is restrictive intervention taking place?	
Impact on children and young people	
Impact on families	
Reporting	
Training	
Attitudes and values of staff	
Conclusions and recommendations.....	24
Bibliography.....	27
Appendices .....	30
Appendix A – Questions asked in CBF survey	
Appendix B – Categories of data collected in PABSS case studies	

## ACKNOWLEDGEMENTS

Thank you to all the families who completed the survey or shared their child's experiences. Thank you to family-carers Elly Chapple, Beth Morrison and Kate Sanger for working in partnership with the Challenging Behaviour Foundation to drive this work forward. Thank you to Dr Ahmed Abdullah from Abertay University, Dundee for his help analysing the case study data. Thank you to Viv Cooper, Jacqui Shurlock and Mary Spence for leading on this report and thank you to all the organisations and individuals that have pledged support to work together on a strategy to reduce restrictive intervention and safeguard children and young people across the UK. (Risc)

## SUMMARY OF REPORT

This work was undertaken due to significant concerns about harmful restrictive intervention of the disabled children and young people whose families we support. The report shares data collected by two small family-led charities (A survey by the Challenging Behaviour Foundation (CBF) and case studies collected by Positive and Active Behaviour Support Scotland (PABSS)). Both the CBF survey and the PABSS case study data have revealed concerning results regarding incidents of, and attitudes towards, restrictive intervention. Overall the data showed a high number and regular occurrence of restrictive intervention cases.

- **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.

The negative physical and emotional impacts of restrictive intervention on both children and their families are significant. **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"*

*Summary continued overleaf...*

78% of families said that the use of restrictive intervention had made their child's behaviour worse. The deterioration in behaviour associated with experiencing a restrictive intervention casts doubt on the claim that restrictive intervention can be used as a behaviour management tool.

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

**Accountability** regarding incidents of restrictive intervention and the impact on children and their families is highlighted as a key area for improvement by the data. Families stated that recording and reporting of restrictive intervention and associated injuries is very rare. 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.

The report concludes with changes that families want to see. 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**.

The findings from both the survey and the PABSS case studies raise major concerns about the use of restrictive intervention with disabled children in the UK and cast doubt on the assumption that it is being used only as a last resort.

The evidence families have presented to us suggests that restrictive interventions are being used too readily and are happening at a frequency that reflects a lack of planning or a focus on children's rights. Parents are concerned that restrictive interventions are seen as the main method for addressing challenging behaviour within children's service settings.

There is a clear need for action on this issue. We have called on key organisations with responsibility and expertise to work with us on a strategy to **reduce restrictive intervention** and **safeguard children and young people (Risc)** across the UK.

Our **recommendations** are:

- **Government action:** For the Government to take action to better understand the scale and nature of this problem across the UK and to take action to safeguard disabled children in schools and children's services.
- **Skilled staff:** For Headteachers and service leaders to ensure staff have the skills, values, training and supervision they need to support children with learning disabilities and autism whose behaviours challenge.
- **Family support:** Provision of skilled trauma support for those disabled children who have experienced traumatic restrictive interventions at school or in children's services settings, including effective support for their families.
- **Accountability:** Better accountability is required at all levels including: reporting and recording within settings; effective data collection by local authorities and the Government; inspection and a review of the way restrictive intervention cases are handled by the justice system.

## FAMILY EXPERIENCES

### **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 Intervenor 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.

## INTRODUCTION

### **Why we wrote this report**

This report contains information collected by the Challenging Behaviour Foundation (CBF) and 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.

We have been contacted by many family carers telling us about restrictive interventions used on their disabled children, particularly within school settings but also in the wider community. This has been an area of growing concern, particularly as there is no formal requirement for local authorities or the Government to collect data about the extent or frequency of this practice and the resulting impact on children and families.

There is also no current guidance on the use of restraint on disabled children in schools in England; the Government has been promising imminent guidance since 2014. The guidance '[Included, Engaged, and Involved Part 2](#)'<sup>i</sup> was published in Scotland in June 2017 and is due to be reviewed in April 2019 but, despite this, families tell us that the use of restraint in Scottish schools remains too high.

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

### **Findings from relevant reports and guidance**

In 2014 the Challenging Behaviour Foundation academic expert group published a [briefing paper](#)<sup>iii</sup> 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,<sup>iv v</sup> and can be highly persistent over time.<sup>vi</sup>

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](#)<sup>vii</sup>.

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](#)<sup>viii</sup> and [Good Intentions, Good Enough?](#)<sup>ix</sup> 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.

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

### **Positive Behaviour Support (PBS)**

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*<sup>xi</sup>. (<http://pbsacademy.org.uk/>)

PBS interventions are informed by a functional assessment to determine the reason for, or “function” of an individual’s behaviour.<sup>xii</sup> 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.

By contrast, an aversive or restrictive response to these behaviours (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.

### **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.

The investigation by Five Live highlighted that restrictive interventions in special schools are widespread and that school leaders and staff do not have sufficient knowledge about the reasons for challenging behaviour and most do not have the training in Positive Behaviour Support to enable them to improve their support for children with learning disabilities and autism.



The investigation also highlighted a lack of reporting, and accountability for the use of, physical restraint on children. This has implications for the ability of settings to improve their practices, for local and national Government to monitor the use of these interventions and for regulators, such as Ofsted and Care Quality Commission, to judge provision for children with learning disabilities and autism.

### **Types of restrictive intervention**

When we refer to restrictive intervention with children, we mean responses such as:

- Physical restraint (direct physical contact between the carer and person, including being pinned to the floor);
- Seclusion (supervised containment or isolation away from others in a room the child is prevented from leaving);
- Mechanical restraint (materials or equipment used to restrict or prevent movement);
- Blanket restrictions (including lack of access to certain places or activities);
- Chemical restraint (the use of medication in response to someone's behaviour)

## METHOD

With increasing numbers of families getting in touch with PABSS and the CBF, yet no concrete action from Government or the statutory sector we have worked together to gather data from the families we support. We gathered information regarding children and young people aged 0-25. This report contains data collected from 566 PABSS case studies and results from a CBF survey completed by 204 families.

This research was conducted within a short time frame as we had no funding to take this work forward. We acknowledge that with a longer data collection period we might have had a larger sample size and been able to analyse these results further. However, the high number of responses within the short time period suggests restrictive intervention is an issue of concern to lots of families who engage with our charities.

The Challenging Behaviour Foundation survey was distributed online via our family carer email network and shared on our Facebook and Twitter pages. The online survey was live for four weeks, closing on the 12<sup>th</sup> September 2018. 204 families responded to the survey.

The survey collected information about restrictive interventions including the number of interventions and how regularly children and young people are experiencing these interventions.

It also gathered data on where restrictive interventions were taking place. These settings included:

- Nurseries/childcare
- Residential school
- Special schools
- Respite care/short breaks
- After school clubs
- Holiday clubs
- School transport
- At home (in the company of support workers)
- Community groups

A list of the questions asked can be found in Appendix A.

In addition to the survey, Positive and Active Behaviour Support Scotland (PABSS) collected case study data for 566 individuals. These case studies were put together from information shared with PABSS over a 12-month period. Following collection, the case study information was put into a spreadsheet and analysed by a statistician at University of Abertay to provide the data for this report. See Appendix B for categories of data collected.

PABSS collected 566 case studies from families whose children have experienced restrictive intervention. As restrictive intervention is often experienced multiple times by one child, these figures highlight the severity of the problem across the UK and the concern of families involved.

**FINDINGS**

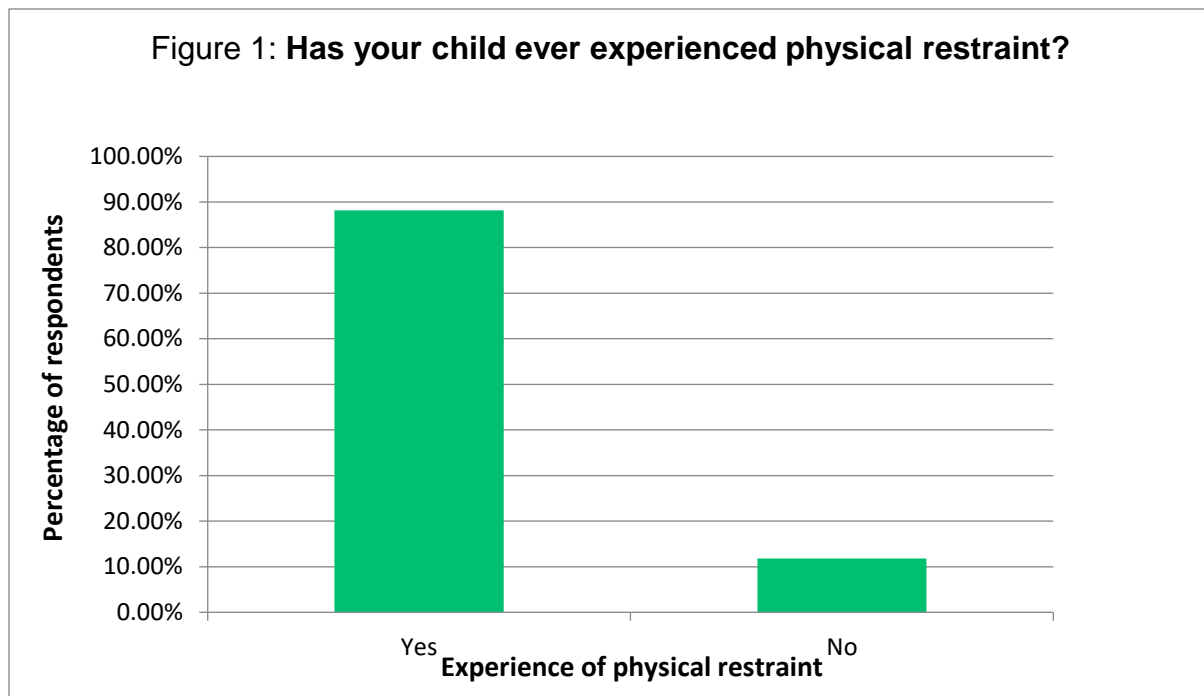
**Use of restrictive interventions**

**Physical Restraint:**

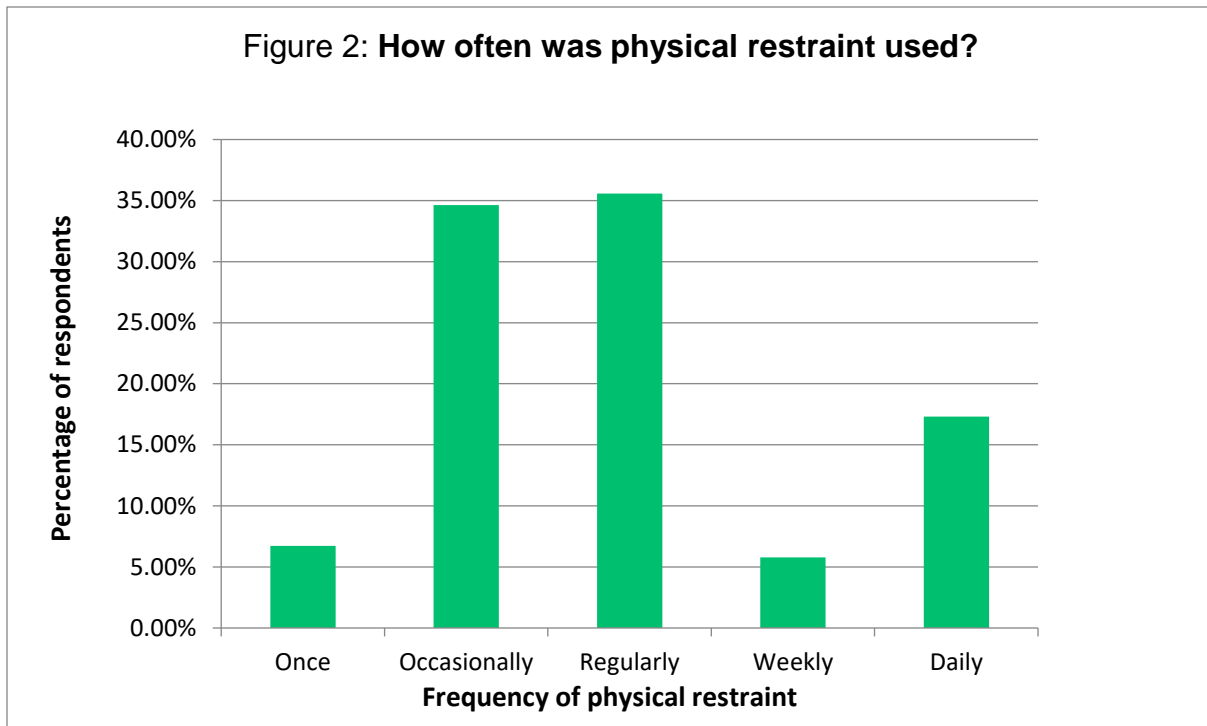
*Direct physical contact between the carer and the person with behaviour that challenges. This includes children being pinned to the floor by multiple people in a prone (face down) position or a supine (face up) position.*

Our survey of families of children with a learning disability and challenging behaviour revealed that physical restraint was experienced by the vast majority of the respondents’ children. Indeed, 88.2% said that their children had experienced physical restraint, with 35% reporting that this happened regularly.

This kind of intervention was particularly prevalent in young children, with 52% of cases reported in the survey responses relating to children aged between 5-10.



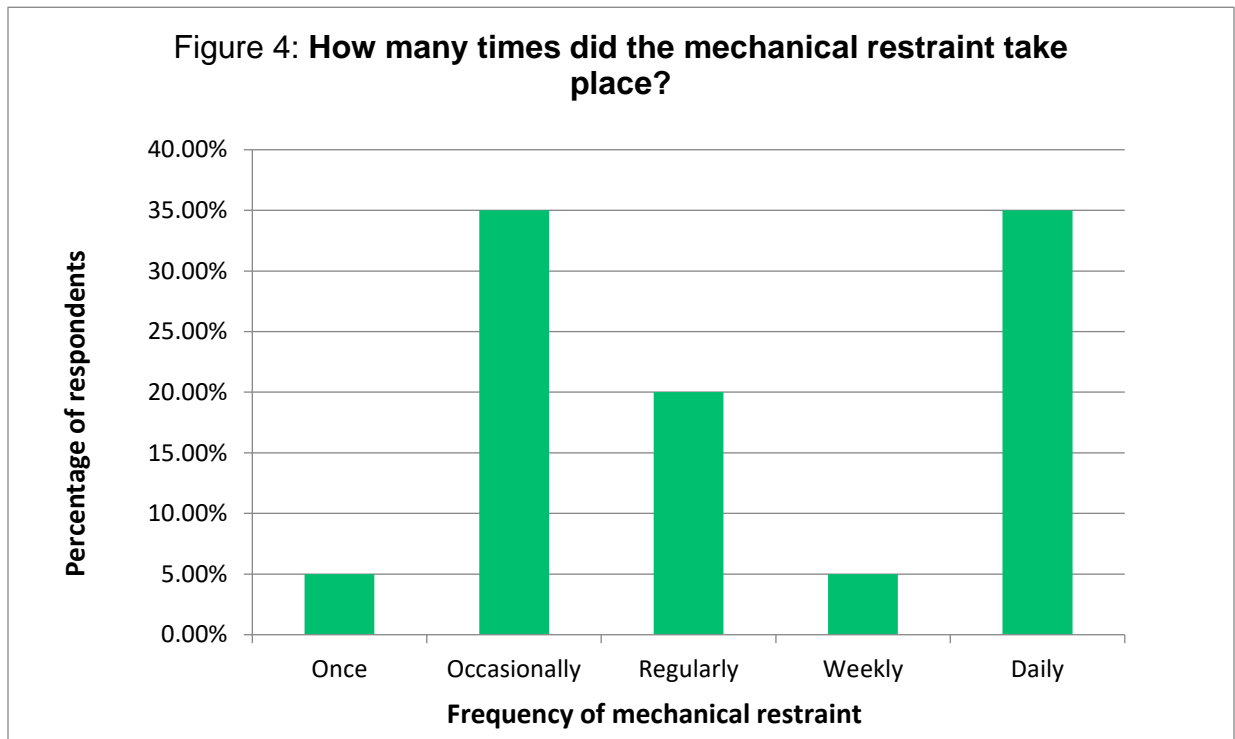
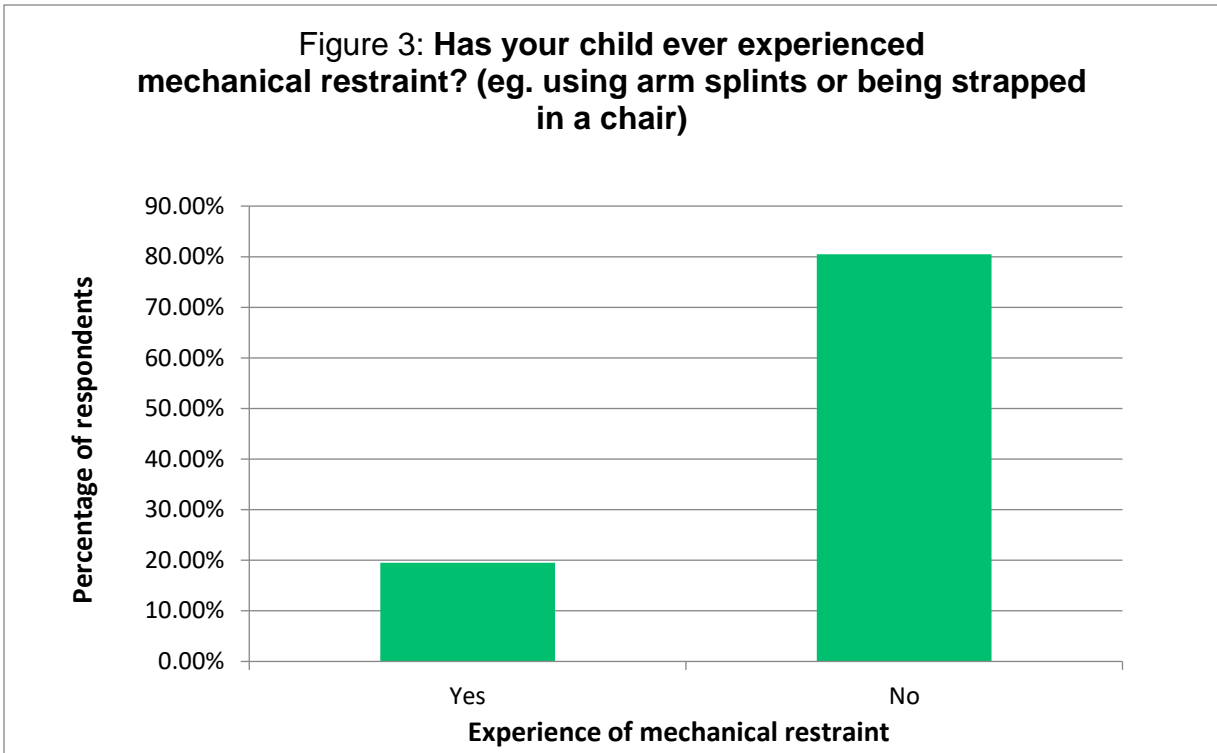
Despite its frequency of use, only 12% of families said that physical restraint was planned in advance, in their child’s best interests and with the input of the parent/s. Furthermore, only a minority of families (17%) said that discussions took place after an incident about how to avoid such restraint in future, something that could help explain the frequency of use depicted above.



**Mechanical restraint:**

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

Reports by families of mechanical restraint being used on their children were slightly lower, with 20% saying it was used. However, as with physical restraint, this intervention was said to have been used daily in 35% of cases.



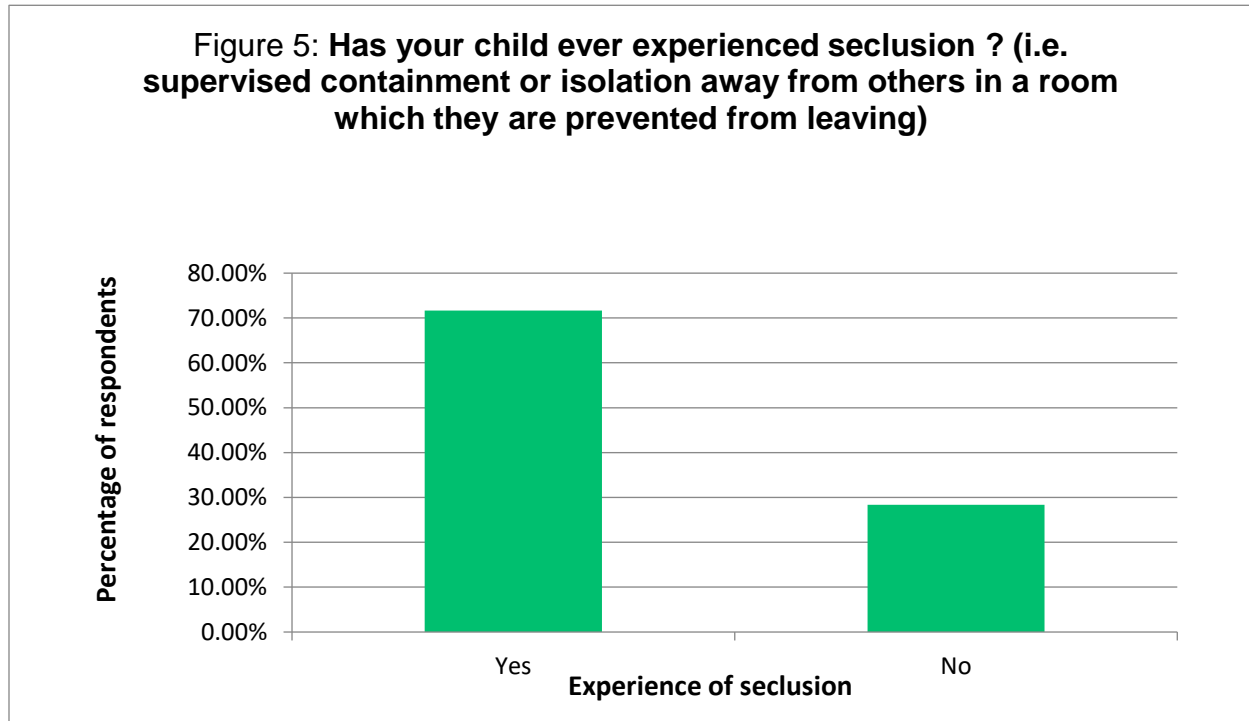
Mechanical restraint was again used mainly with children aged 5-10 (45%), but there was a marked increase (compared to physical restraint) in its use amongst 0-4 year olds, who represented 5% of cases from respondents.

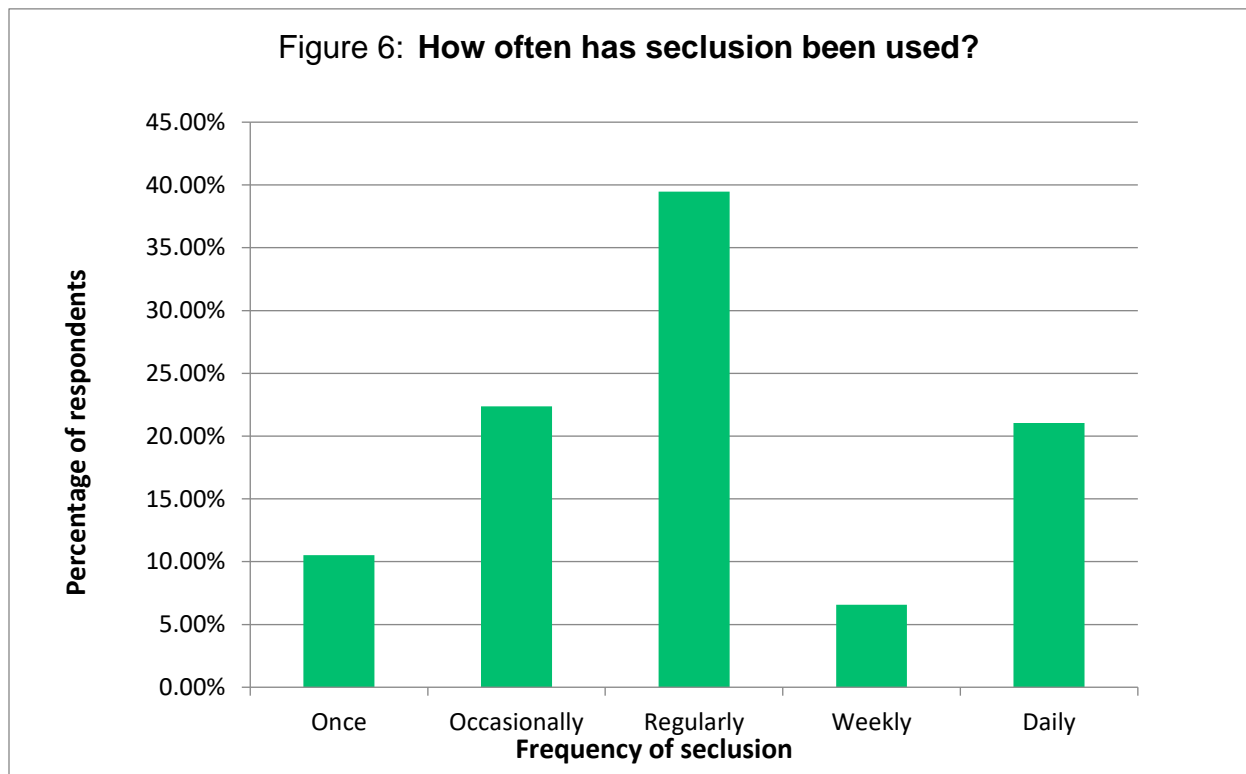
A concerning 74% of mechanical restraints were said to be unplanned and the data indicates a lack of consideration of how to avoid future incidents, with only 6% of respondents claiming that there was a debrief to identify how to avoid it in future. With the high number of daily recurrences of this intervention, this is a figure that needs exploring further.

**Seclusion:**

*Supervised containment or isolation away from others in a room they are prevented from leaving.*

Incidents of seclusion were also high with 71% of survey respondents reporting that this had happened to their child. 39% of the children and young people who were secluded were said to have experienced this on a regular basis and a further 21% daily.





Once more, the survey data suggests that 5-10 year olds were the group most likely to be secluded, with 53% of the incidents occurring to children of that age group. Beyond that, there appears to be evidence that this is a technique that reduces as children get older, with 26% of 11-14 year olds, 14% of 15-18 year olds and 7% of 19-25 year olds experiencing seclusion according to the survey.

Responses indicated that the majority of interventions (65%) weren't planned in advance and there was a lack of reported action from professionals following the incident to avoid the use of seclusion in future. This happened in only 11% of responses.

The survey also asked questions about long term segregation. This should only ever take place when sectioned under the Mental Health Act. Of those families who reported that their children had experienced long-term segregation, 89% reported that their child had not been detained under the Mental Health Act at the time.

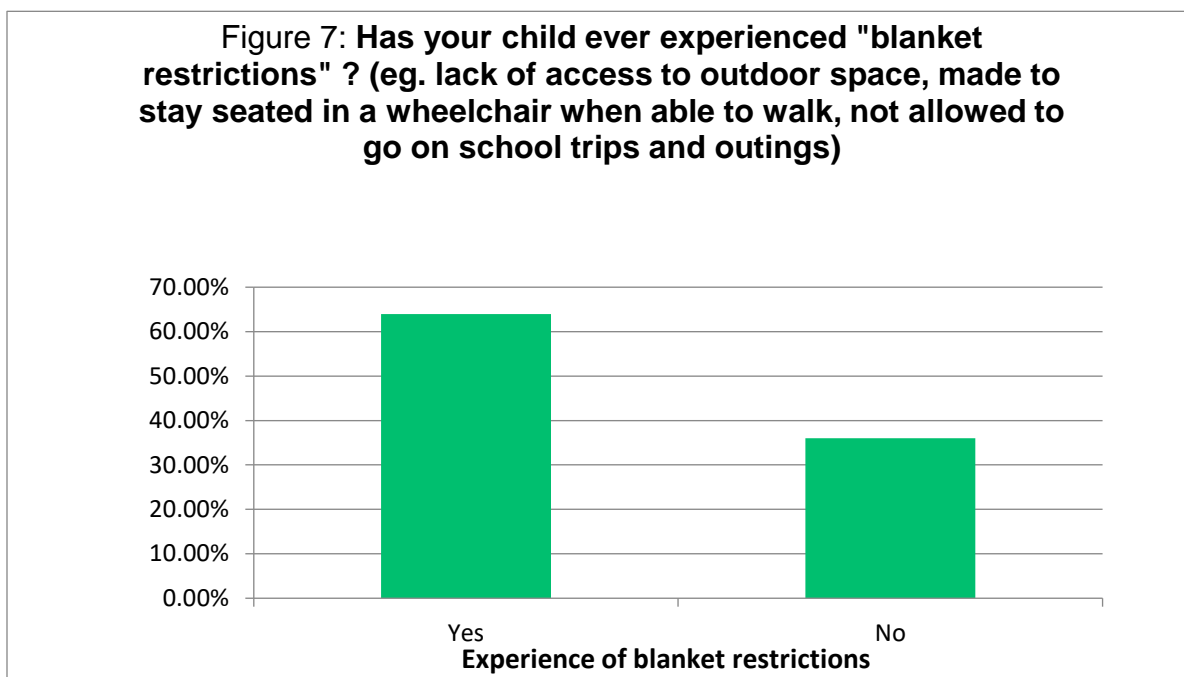
Under the Mental Health Act, long term segregation is defined as "a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis". This definition was not provided in the survey question and therefore interpretation of 'long-term segregation' may have varied between respondents and answers should not be taken at face value. Despite this, families clearly feel that their children are being kept apart from

other children for long periods of time; it is possible that some may have experienced illegal segregation and this should be taken investigated further.

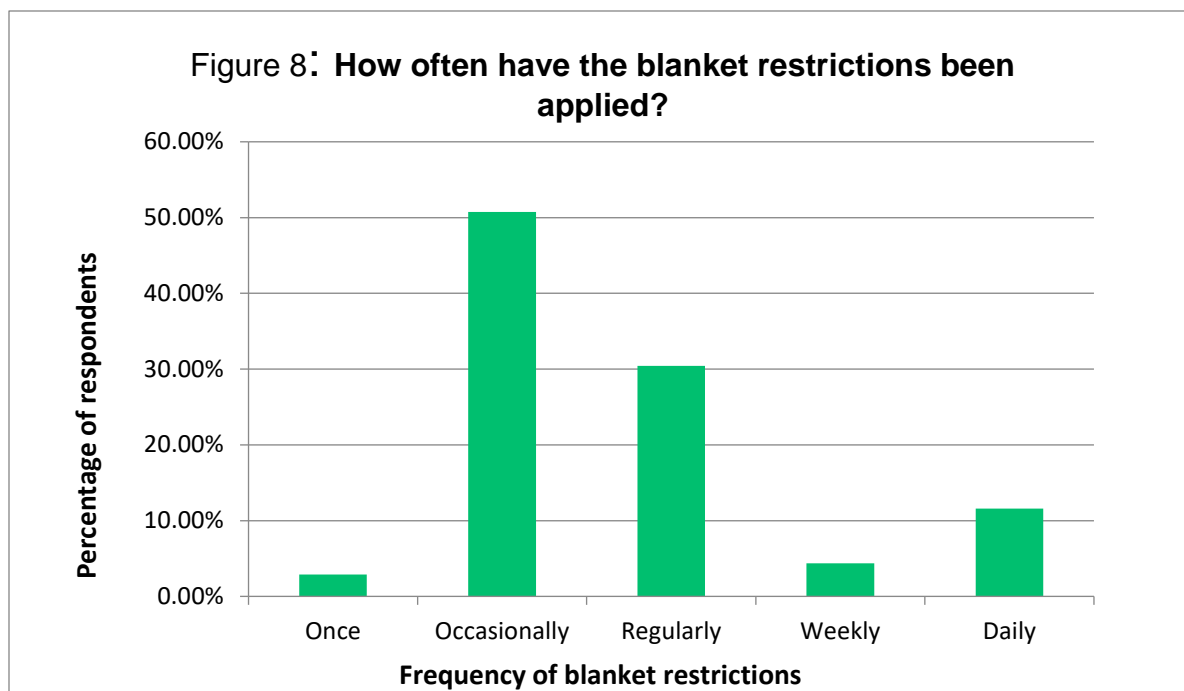
**Blanket restrictions:**

*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.*

Families who responded to the survey said that blanket restrictions are used in nearly two thirds (64%) of cases, with 50% reporting incidents occurring occasionally and 30% regularly.







Reasons given for blanket restrictions included...

*“Unable to watch him to prevent the behaviour so remove him from the situation to prevent it”*

*“Told to stay home during Ofsted visit. Not even considered eligible for year 6 residential. Cannot guarantee safety of others”*

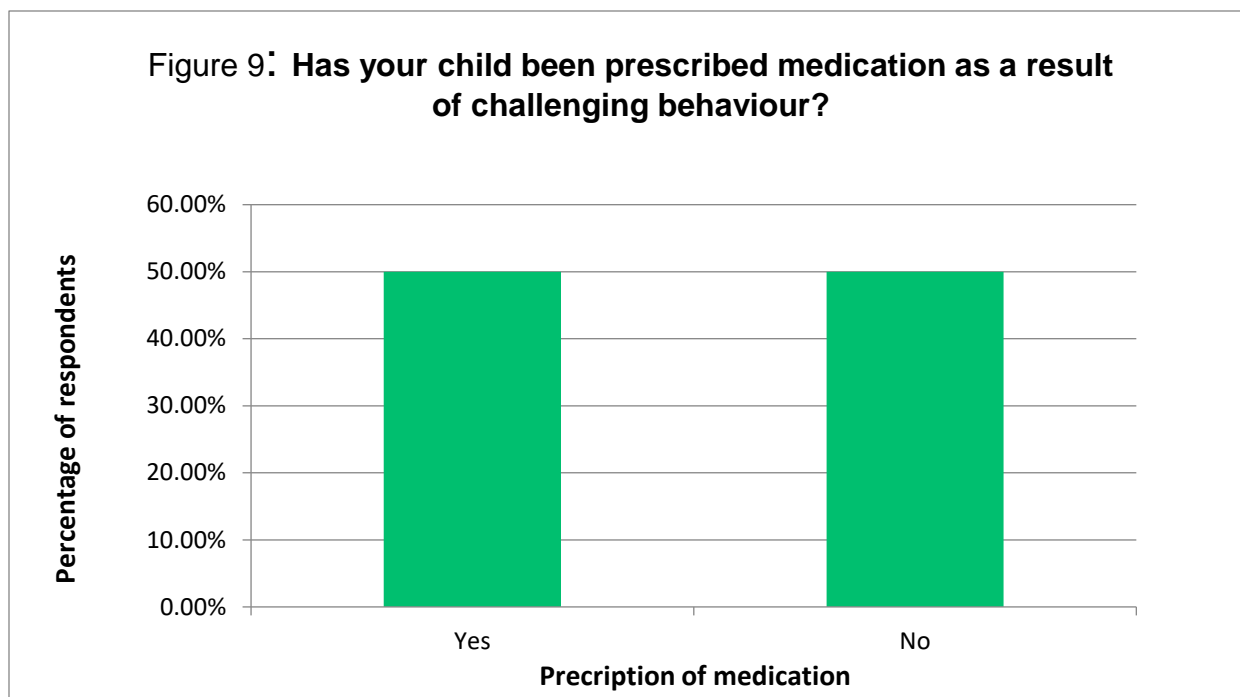
*“Behaviour was unmanageable in the community- dangerous to themselves and others”*

*“Child was easier to move without being able to walk. Encouraged use of SEN (Special Educational Needs) buggy to facilitate movement that were easy walking distances. Said child felt 'safer' in the buggy. Child is non-verbal so couldn't express distress.”*

These findings raise questions about how person-centred children’s support arrangements are and whether the necessary reasonable adjustments are being made under the Equality Act.

### **Chemical restraint**

The survey asked about the medication of children in response to behaviour described as challenging. The results show that 50% of respondents answered that their children had been prescribed medication because of challenging behaviour.



We did not ask about what medication is being prescribed but the overuse of psychotropic medication among people with learning disabilities is well documented and there is work underway which aims to reduce this<sup>xiii</sup> and ensure that medication is only given at the right time and for the right reasons. We welcome this and hope it will investigate and address the high levels of medication identified here.

### **Where is restrictive intervention taking place?**

Schools are the setting for all the case study data collected by PABSS and the CBF survey shows most restrictive intervention taking place in schools. For example, of the reports of physical restraint, 68% were in schools.

In particular, seclusions and blanket restrictions were reported to happen overwhelmingly in school settings compared to non-school settings such as nursery, respite care and holiday clubs.

This raises questions about the extent to which such interventions are embedded in the culture of some schools. 64% of responding families said the setting in which the seclusion had taken place had a specific room that was allocated for the purpose of seclusion and this room was used regularly in 80% of responses. The rooms where children and young people were being secluded were described as:

*“Seclusion suite, until I complained about its use, then it became an ‘area of low stimulus’. The Trust still has a seclusion policy, which is used.”*

*“Chill out room / reflection room”*

*“Time out room”*

*“IEU (internal exclusion unit) by teachers and the cell by students”*

*“Behaviour room”*

*“The rainbow Room.”*

*“Quiet room”*

*“There was a room which was padded where they said children were placed to 'calm down' it had a gate at the doorway to prevent children from leaving.”*

The wide range of names used for seclusion rooms could be misleading. There is a significant difference between a calm space where a child voluntarily agrees to spend some time and a room in which they are held, alone, against their will, unable to get out.

Mechanical restraint is the only intervention not to have a majority of incidences in schools, although 42% of cases were still reported there.

### **Impact on children and young people**

The survey suggests that restrictive intervention has a significant physical and emotional impact on children.

The responses of families to our survey shows how restrictive intervention often leads to physical injury: 58% of children and young people were physically injured by restrictive intervention.

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

*“Caused her to have bruises all over her body”*

*“He has had nose bleeds and put on weight”*

*“During the period she was secluded she self-harmed by headbutting kicking and hitting the walls, she had broken toe nails, sore hands and bruising soreness to her head. As we were not advised of the severity at the time she did not get checked out by a medical professional for head injury. She gained 24kg during the 15 months she was on anti-psychotics and this weight hasn't all been lost yet.”*

The figures for emotional impact were even higher, with 91% of respondents reporting emotional impact from restrictive intervention.

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

*“No trust in adults, anxiety, lack of sleep, low self-esteem, signs of depression and hopelessness”*

*“Increased frustration & reduced trust in adults to protect him”*

*“Destroyed him and family”*

*“I believe he is suffering from PTSD which manifests itself in anger towards all staff and particularly us as parents”*

Supporting the results of the online survey, PABSS data on diagnosis found that there is a marked increase in the diagnosis of anxiety in children around the age of 8. This finding suggests further research is needed to identify whether restrictive interventions at an early age are having negative impacts on children's mental health later and should be treated as an adverse childhood experience (ACE).

### **Impact on families**

Our survey highlighted that restrictive interventions not only impact on the lives of children and young people subject to them, but also their families. Survey respondents have described mental health impacts on parents and siblings, family breakdowns, and financial strains.

*"Family currently needing therapy around trauma - unable to cope with knowing how disabled children are treated"*

*"Stress between mum and dad"*

*"Anxiety at how to resolve situation"*

*"Cost of childcare to look after other pre-school children to meet with school to discuss"*

*"Loss of money from not being able to go to work that day"*

*"Exhaustion, despair, trauma & distress"*

*"Horrific, have fought for 8 years for some kind of accountability - none"*

This finding is supported by the family support work we do. In addition, families tell us there is no support for them or their child to help recover from the trauma.

### **Reporting**

PABSS collected data on the recording and reporting of restrictive intervention. The PABSS research found that the number of injuries inflicted on children far exceeded injuries reported by the school. As can be seen in figures 10 and 11, in the PABSS case studies 81% of all injuries were not recorded. In addition, only 17% of all incidents of restrictive intervention were reported to parents and carers. These figures raise questions about transparency around restrictive intervention.

Figure 10: Recording Injuries

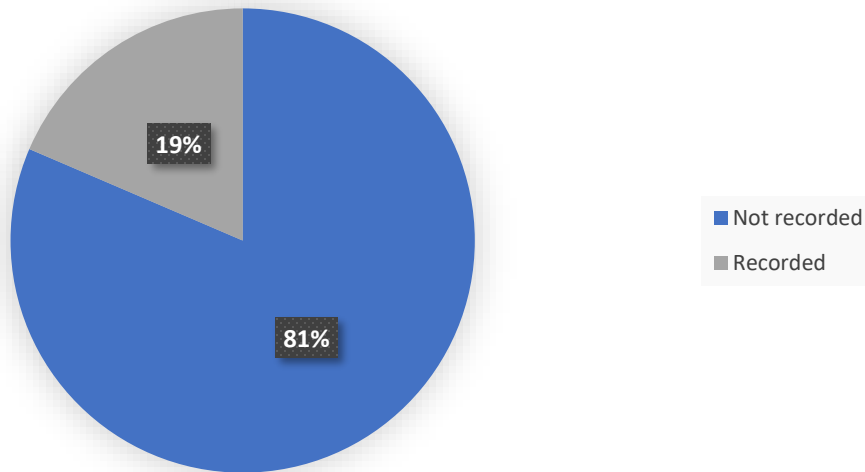
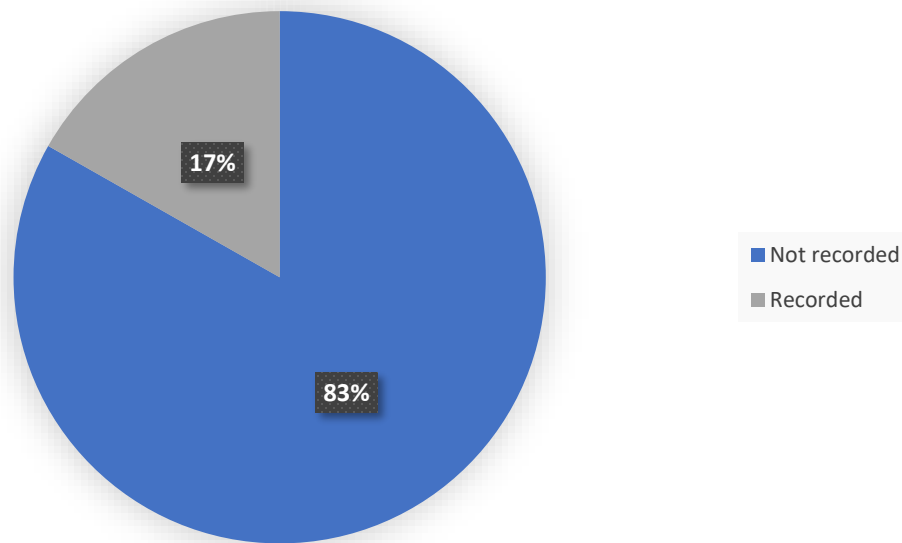


Figure 11: Recording of Restrictive Interventions

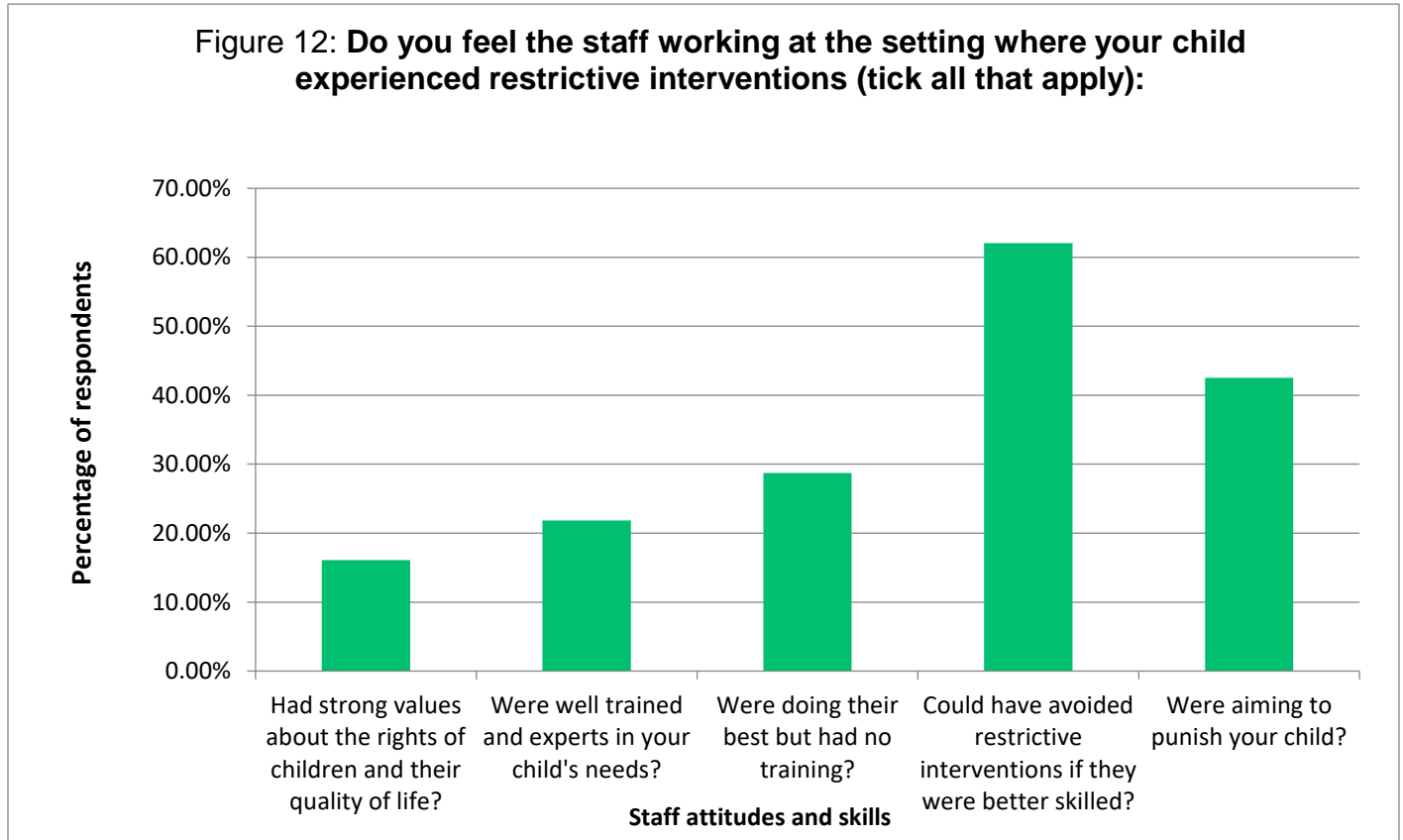


### **Training**

The case studies collected by PABSS included information on the restrictive intervention training received by staff. A correlation was found between training and incidence of restrictive intervention – families reported that the number of restrictive interventions was higher when staff had received training.

More research is needed to investigate whether there is any causative link between restrictive intervention training and incidents; this correlation raises questions about whether staff training focuses on how to implement restrictive intervention rather than on how to provide Positive Behaviour Support.

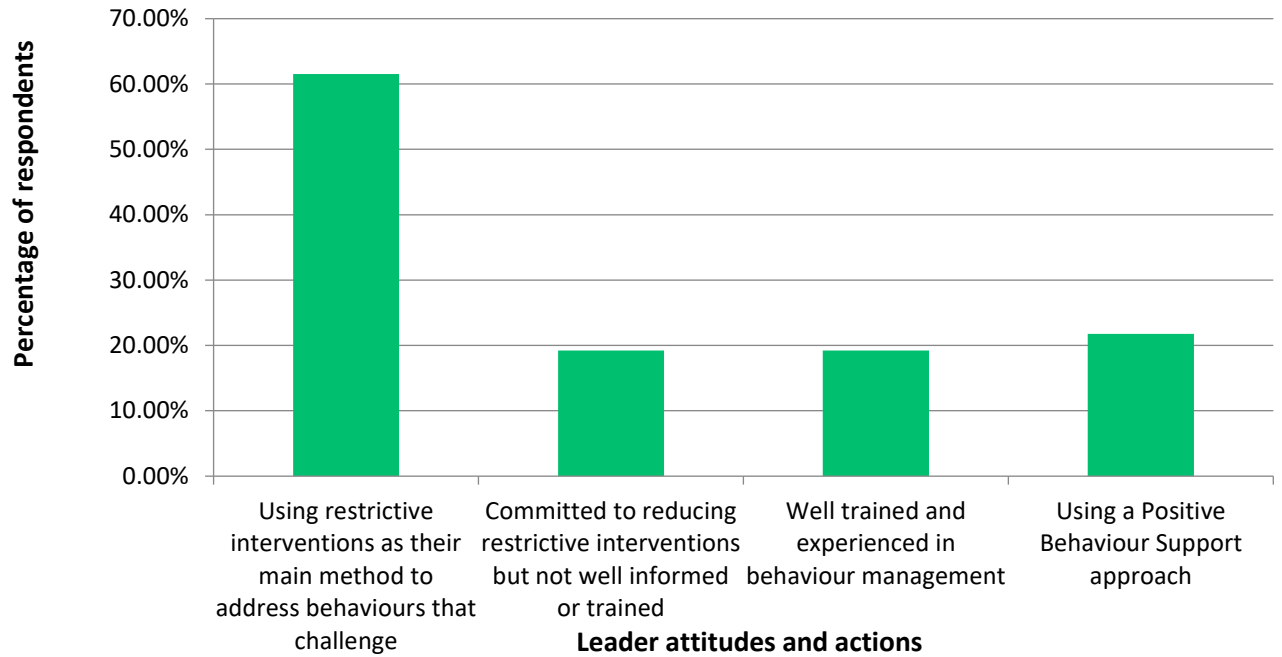
The CBF survey found that families thought better training could have prevented restrictive intervention being used on their children. Respondents were asked to answer statements about the staff responsible for the care of their child. In answer to this question, 62% of respondents thought that if staff had better training, restrictive interventions could have been avoided for their child. Figure 17 shows opinions about staff attitudes and skills from the CBF survey.



**Attitudes and values of the staff**

Figure 13 shows that 61% of respondents agreed that the leaders of the setting where restrictive intervention took place were using restrictive intervention as their main method to address behaviours that challenge. Furthermore, figure 12 shows 42% of respondents felt that staff, by using restrictive interventions were trying to punish their child. This attitude suggests a misuse of restrictive practices as a punitive measure, which is in opposition to its intended use as a last resort intervention to control behaviour.

Figure 13: In your view, are the leaders of that setting (e.g. the Headteacher) doing any of the following? (tick all that apply)



## **CONCLUSIONS AND RECOMMENDATIONS**

### **Conclusions**

The findings from both the CBF survey and the PABSS case studies raise major concerns about the use of restrictive interventions on disabled children in the UK and cast doubt on the assumption that it is being used only as a last resort.

The evidence families have presented to us suggests that restrictive interventions are being used too readily and are happening at a frequency that reflects a lack of planning and a lack of focus on children's rights. In some cases, they are seen by parents as the main method for addressing challenging behaviour within a setting.

The collected case studies show the highest number of these interventions are being experienced by very young children. The research conducted by PABSS revealed that, across their case studies, 26% of the reports of restrictive intervention were children age 6, and this was closely followed by children aged 5 and 7. One child was as young as 2 years old. Across all the PABSS case studies 98% of children subject to restrictive intervention were aged 11 or under.

The impact of these interventions is shown to be great on both children and parents. Restrictive interventions not only cause physical injuries to children, but also have negative long-term impacts and can be detrimental to the child's quality of life for years to come.

Research shows that adverse life experiences during someone's formative years drastically increase their chances of developing mental health problems and other negative outcomes.

We are concerned that these interventions are being misused, sometimes for punitive effect. This may be as a result of a lack of understanding of how to meet needs, or because of a lack of proper training to enable staff to meet more complex needs. Our research suggests there is a need for better training to help staff understand learning disabilities, autism and challenging behaviour and the use of Positive Behaviour Support (PBS) to guard against restrictive practices.

Furthermore, there is emerging evidence through our research of a distinct lack of accountability for the inappropriate use of restrictive practice and difficulties in achieving redress when things do go wrong. The CBF survey found that, following the use of a particular restrictive intervention, the majority of families were not aware of there being a written record of the incident, nor of plans to avoid a recurrence of this in the future.

Many families also reported to PABSS that, when incidents involved disciplinary action either within the setting or in the justice system, children were not able to give evidence as they weren't seen as credible witnesses. This severely hampers families' trust in the system and the ability for malpractice to be prevented from occurring in future.

### **Recommendations**

These findings highlight a sector struggling to meet the needs of children with behaviour that challenges. To change this, we need a system-wide approach that helps to stop challenging behaviour from developing; promotes a PBS approach to understand behaviour; trains staff to understand children with a learning disability better and to meet their behavioral needs appropriately and proactively, and



clear leadership on how to work with families to plan support and care. Senior leaders must do more to reduce restrictive practices and reinforce the message to staff that there are better and more effective approaches available.

There must be more accountability to provide justice for families and to learn from when things go wrong to help inform a better understanding of the use of restrictive practices across the country. This should include support to children and their families after restrictive practices are used to help reduce the emotional impact on them. In the CBF survey, 91% of respondents reported emotional impact on the child from restrictive intervention. The need for support after restrictive intervention has taken place was further highlighted by 77% of survey respondents wanting local support to be available for children who have experienced restrictive intervention, and 84% wanted local family support to be available.

The CBF survey ended by asking respondents what changes they would like to see regarding restrictive intervention. The suggestion of better training for teachers and school staff in learning disabilities, autism, challenging behaviour and Positive Behaviour Support was most popular amongst respondents, with 92% agreeing this is a necessary change. Other suggestions for change that received particularly high response rates included settings and staff being held accountable for the harm caused using restrictive intervention (84%). Stronger safeguarding arrangements for those with disabilities and local family support were also both areas where 84% of respondents thought change was needed.

There is a clear need for action on this issue. We have called on key organisations with responsibility and expertise to work with us on a strategy to reduce restrictive intervention and safeguard children and young people, so we have a strategy for the whole of the UK.

For England our **recommendations** are:

**Recommendation 1: Government action.**

For the Department for Education to take the lead on reducing restrictive intervention with children; to work with partners (including Department of Health and Social Care, NHS England, Local Authorities, Headteachers, VCS partners, Parent Carer Forums, Ofsted and Care Quality Commission) to better understand the scale and nature of this issue by collecting data, commissioning research and to take immediate practical action to safeguard disabled children in schools and children's services.

**Recommendation 2: Skilled staff**

For a national, cross-sector workforce strategy for those working with children with learning disabilities or autism whose behaviours challenge. For Headteachers and leaders of other settings to ensure staff have the skills, values, training and supervision they need to support children with learning disabilities and autism whose behaviours challenge.

**Recommendation 3: Family support**

For the Department for Education to fund skilled trauma support for those disabled children who have experienced traumatic restrictive interventions at school or in children's services settings, including effective support for their families. For early intervention services to be provided within local communities, to prevent the escalation of behaviours that challenge and the use of restrictive responses.

**Recommendation 4: Accountability**

For Ofsted and CQC to review safeguarding and accountability arrangements within the current system in order to strengthen procedures. For the justice system to review the way restrictive intervention cases are handled by the justice system and the current barriers in place which deny families access to justice.

**This is a hidden issue that must be exposed and addressed. Children should not be experiencing practices like these in settings that should be supporting, encouraging and enabling them to fulfil their potential.**

**We hope this report can be part of that exposure and drive action to address the issues.**

## BIBLIOGRAPHY

### In-text references

<sup>i</sup> *Included, Engaged and Involved: preventing and managing school exclusions*. Scottish Government, June 2017.

<sup>ii</sup> 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*.

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

<sup>iv</sup> 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.

<sup>v</sup> 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.

<sup>vi</sup> 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.

<sup>vii</sup> *Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge*. The CBF, 2015

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

<sup>ix</sup> *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*

<sup>x</sup> *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.

<sup>xi</sup> Positive Behavioural Support Academy. <http://pbsacademy.org.uk/> . Accessed 18/01/2019

<sup>xii</sup> 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.

<sup>xiii</sup> *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.

### **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

### **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/>

This 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/>

## Appendix A

### The Challenging Behaviour Foundation restrictive interventions survey questions

The online survey asked questions around the following themes

#### *Background information*

Which country of the UK do you live in?

Please tick any of the following statements that apply to your child:

My child has

- been diagnosed with a learning disability
- been diagnosed with a severe learning disability
- been diagnosed with a profound and multiple learning disability
- been diagnosed with autism
- a suspected learning disability (but no diagnosis)
- suspected autism (but no diagnosis)
- additional needs
- special educational needs
- developmental delay
- needs which are undiagnosed

How old is your child?

- 0-4
- 5-10
- 11-14
- 14-18
- 18-25

Is your child

- male
- female

Does your child behave in ways that challenge you or others around them?

- Never
- Sometimes,
- Often
- All the time

How serious do you feel the behaviour is in terms of the likely risk to your child or others around them?

0+ not at all serious and 5+ extremely serious.

0-5 scale

How does your child communicate?

- verbally
- Using sign language/Makaton
- Using PECs
- Using other alternative forms of communication support (please specify)

*Support, Plans and Services*

Does your child:

- Live at home
- Live away from home (please specify where)

Does your child have any of the following (please tick all that apply)

- a positive behaviour support plan
- a communication passport
- a hospital passport

Which of the following services do you use for your child (tick as many as apply):

- Nursery/childcare
- Residential School
- Local School
- Respite care
- After school clubs
- Holiday clubs
- School transport
- Short breaks
- Support workers at home
- Other (please specify)

*Experience of restrictive intervention*

Questions about the use of restrictive interventions

For each type of restrictive intervention (Physical, mechanical, seclusion):

- How many times
- Where
- When
- Description of intervention
- Age of child
- Planned intervention
- Debrief following incident
- Involvement in debrief
- Outcome of debrief
- Written record of incident

*Blanket restrictions*

- How often
- Location
- Explanation

*Long term segregation*

- Length of time
- Description
- Detained under Mental Health Act?
- Hospital setting
- Ongoing issue?

*Medication*

Has your child been prescribed medication as a result of restrictive intervention?

- Yes
- No

*Impact of restrictive intervention*

- On child/ young person
- On family

*Skills and attitudes of staff*

- Staff
- Leaders

*Support offered to families*

- Support offered
- Changes families would like to see



## Appendix B

### Categories of data collected in case studies by Positive and Active Behaviour Support Scotland

This data set included information for the following categories for each family:

- Area
- Sex
- Age
- Restraint?
- Seclusion?
- Educational needs neglected?
- Recorded?
- Diagnosis
- Injuries
- Injuries recorded?
- Family complaint?
- Accountability
- Training provider (of those supporting the child/ young person)