



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

## **Education Committee Inquiry**

The inquiry will look at how the outbreak of COVID-19 is affecting all aspects of the education sector and children's social care system and will scrutinise how the Department for Education is dealing with the situation.

It will examine both short term impacts, such as the effects of school closures and exam cancellations, as well as longer-term implications particularly for the most vulnerable children.

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The Challenging Behaviour Foundation (CBF) aims to make a difference to the lives of children, young people and adults with severe learning disabilities whose behaviour is described as challenging across the UK. We support, equip and empower families through our family support and casework. This informs our strategic influencing work to drive change nationally based on sharing information and best practice evidence. We aim to represent and encourage the voice of our beneficiaries via their families at an individual, local, system-wide and national level through a strategic influencing approach to key stakeholders, to ensure policy and best practice reflect lived experience and provide robust and practical guidance.

Our vision is for all people with learning disabilities whose behaviour challenges to have the same life opportunities as everyone else and, with support, to live full and active lives in their communities. Those individuals with severe learning disabilities who display behaviour that challenges do so as a communication of unmet need which, without proper support, results in increased use of restraint, inappropriate medication, segregation, and health and care needs not being met.

We know that many families we are in touch with are very concerned about the impact of COVID-19. There are people who care for their family member at home who want to know what will happen if they become ill and cannot look after them. There are families who are concerned about the staff support their family member receives in the family home/their own home or with a provider organisation. As you would imagine, the families we support are significantly impacted by the current situation and we have been working extremely hard to support them via our helpline and through new resources produced to support them during the pandemic. The current guidance does not enable us to answer some of the key questions that families have raised. The impacts of the pandemic, including recommendations to address the impact of the pandemic on children with severe learning disabilities and their families will be analysed below.

## **The Government need to find innovative and properly funded ways to secure the aims of the Transforming Care programme during and beyond this pandemic.**

The Transforming Care programme (set up in response to the scandal exposed at Winterbourne View in 2011) failed to deliver against targets set in Building the Right Support (2015-2019). At the end of

March 2019 bed closures were approximately 19% against a target of 35%-50%. In response, the NHS Long Term Plan incorporated the bed closure target and moved it to 2024.

The NHS Long Term Plan commits to '*working with the Department for Education and local authorities to improve their support for children and young people with learning disabilities, autism or both*'. In addition, the plan includes a commitment to '*increased investment in intensive, crisis and forensic community support to enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services.*' (NHS Long Term Plan, 2019)

There is a significant risk that the gains which have been made since Transforming Care will all be lost and that children and their families will see a huge dip in quality of life and huge increases in behaviours that challenge, without the usual safeguards and scrutiny in place. We know that children with learning disabilities or autism were already at significant risk of poor outcomes before the pandemic, particularly those with complex needs and/or communication challenges. They were historically expected to fit into a system that did not work for them. That system is now being re-shaped and evolving daily. We know that better community support and investment in families is key, along with more effective multi-agency working. Rather than watch the old system erode and crises increase, we suggest that the Government takes steps to work with families, local authorities, health commissioners, schools, the VCS and providers to identify how we use this time to re-shape services and support around the needs of children and families.

## **EHC provision**

Families tell us that special schools have closed where they don't have sufficient staff despite the commitment to educate children with EHCPs within school. Some schools, especially academies, have pooled resources into 'hubs'. This means that some of our families felt it would be too much of a change for their child to cope with and so had no option but to keep them home. Families of children with severe learning disabilities were not actively encouraged to send their child to school, meaning that families of children with EHCPs have felt judged or ostracised for making use of the school provision.

Children with severe learning disabilities are **extremely disadvantaged by home schooling**. One family were told that a 'pack' with their son's communication aids, learning resources etc would be sent home, when they went to collect it no one knew what they were talking about.

As schools now begin to open from 1 June it is not clear how quickly they will be able to safely re-introduce children who have been at home. We are hearing concerns around hygiene/ fears that schools will not accept children back when lockdown is over. Schools are discussing taking temperatures on entry – some children with learning disabilities won't be able to tolerate this. Despite the guidance suggesting that children with the greatest need should return there are fears that the children with more complex needs may be seen as "too difficult" to accommodate.

**Access to therapies** such as CAMHs, SLT and OT has been suspended for many, especially where this was provided via school and school has closed. In practice many families are currently doing the work of expensive placements 24/7 with no practical or financial support. Although some have managed to use direct payments flexibly other requests have been refused and those who do not usually receive direct payments are left with little support.

*Betsy is 11, she has SLD and a genetic condition. She does not communicate verbally and sometimes uses a wheelchair. Her father is her full-time carer, her mother is a keyworker. They have decided to keep Betsy away from school.*

*Betsy's family have received a list of iPad apps to use at home. However, Betsy finds using an iPad difficult and the educational games are not matched to her cognitive ability.*

*Recently Betsy's behaviour has become more and more challenging. Her family feel she is trying to get control over her life. It has been identified that she needs support to communicate her wishes and to make choices as she enters her teenage years. However, Betsy's family have been told that support from a SALT is very unlikely to be available during the current pandemic.*

*CAMHS involvement is limited and the strategies suggested have been generic and not evidence based e.g. play some calming music.*

*Betsy's family are now struggling with her behaviour, her siblings are spending more and more time in their bedrooms and Betsy has no way of communicating with those around her.*

## **Lack of monitoring**

We are not optimistic that the monitoring regarding children and young people with severe learning disabilities whose behaviours challenge in different settings has been organised as it should be. We are waiting for the DfE to reply to our questions regarding the monitoring process.

- Does the Government know how many special schools have closed and what alternative provision is in place? Is this being monitored?
- How well have LAs complied with the requirement to consult parents over changes to EHC provision?
- Will the amendments to the SEND regulations cease on 31 May so that EHC provision must be provided again from 1 June?
- Schools still get full SEND funding – where is this going if children are not in school? Who is checking if it goes to those with greatest need?
- How is non-covid healthcare being provided to children with learning disabilities during this period?
- What is being done to monitor the impact of the pandemic on the Transforming Care cohort of children and young people?
- We welcome the Family Fund announcement but what else is being done to support families of disabled children with the practical and financial implications of the current situation?

## **Safeguarding**

The amendments to children's social care legislation remove the safeguards designed to protect children living away from home. The evidence shows that children with severe learning disabilities living away from home were already more likely to experience restraint, seclusion, over-medication or abuse. These amendments increase that likelihood and reduces the safeguards in place to detect and act on such practices. The 6 May amendments to the children's social care guidance include the addition that "staff in children's homes are allowed to restrain children as a last resort" and signpost the Ofsted guidance which says that restraint does not have to be recorded or reported to parents.

As these issues are ongoing, we have put together a few questions you could ask DfE.

- What is being done to protect vulnerable children from restraint, seclusion, and other restrictive interventions?
- What is being done to safeguard the Transforming Care cohort of children? What happens (in terms of practical input and support) as a result of being added to the dynamic risk register?
- Will these amendments remain beyond the Coronavirus pandemic?
- If a child with a learning disability is detained in a children's home with suspected coronavirus how is effective treatment, care and support arranged? Who is responsible for this and how is it monitored?
- What arrangements are being put in place for families to keep in touch with their child or young person if they are away from home e.g. in an inpatient unit?
- Who is visiting children with severe learning disabilities who are subject to care orders?
- What is being put in place to make sure discharge to the community from inpatient settings is not delayed due to Covid 19? The risks associated with staying in inpatient settings are increased by Covid 19.

We have asked DfE to prioritise guidance and practice in support of children with learning disabilities or autism during this period, in line with their 30 April pledge. There is a huge amount of expertise among families, researchers and organisations which could be harnessed in order to minimise the impacts of the pandemic on this group and to re-shape services for the better as we emerge from it.

### **We are calling for cross Government guidance for children with learning disabilities and autism**

The global pandemic, lockdown situation and closure of many schools was bound to have a serious and negative impact on children with learning disabilities and their families. However, this has been compounded by the weakening of legal frameworks designed to secure education, health and social care provision in a timely way and to ensure that vulnerable children are safeguarded. We know from our family support work that levels of behaviours that challenge are increasing, and that the already fragile support system families depended on has almost entirely disappeared. Many families are having to provide the education, health and care previously provided by expensive services with no additional financial or practical support. Others are unable to see their children at all where they live away from home. Children with severe learning disabilities often do not understand why and online communication is not always possible for them. Where families do come up with creative suggestions, they are often dismissed by providers. A strategic review of HOW we support families of children with disabilities is necessary. The focus is always on how to fit this group of children into existing support and services (which they often won't fit into!). In this period of significant change, how can we use this opportunity to reconfigure the approach to support.

The Government must produce **clear guidance** to Local Authorities, health commissioners and all those supporting children with learning disabilities or autism during this period, bringing together the key messages. The learning disability and autism guidance is currently mainly adult focussed and was produced before the amendments to the children's legal framework were made. There is also a need to ensure that accessible and **practical information for families** is provided.

We hope this is helpful. The pandemic has posed many problems and challenges for families of children with SEND, and the learning must be utilised going forward to improve co-ordinated and timely support.