

**Vicky Ford MP, Parliamentary Under-Secretary of State  
for Children and Families  
Helen Whately MP, Minister of State for Care**



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

By Email

22<sup>nd</sup> May 2020

Dear Ministers

Your 30 April letter to children and young people with special educational needs and disabilities (SEND), their parents/carers and families, and others who support them explained that you are committed to doing everything possible to support them during this difficult time and that supporting the most vulnerable children, young people and adults is a priority.

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.

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, so the purpose of this letter is to highlight to you some of the issues families are facing, some key concerns we have, to suggest some actions which would help and to ask for answers to our questions.

### **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.

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. We are asking that you

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 and answering the outstanding questions below.

**We are asking the Government to find innovative and properly funded ways to secure the aims of the Transforming Care programme during and beyond this pandemic.**

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.

- Do you know how many special schools have closed and what alternative provision is in place? Is this being monitored?
- Do you know how well LAs have 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? Are you 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.

- 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 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

We would urge you to prioritise guidance and practice in support of children with learning disabilities or autism during this period, in line with your 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.

I look forward to your responses to our asks and to our questions.

Yours sincerely



Vivien Cooper, OBE  
CEO

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