



CC: Christine Lenehan, Anne Longfield, and David Nuttall

18th March 2020

Dear Claire Murdoch, Ray James, and Roger Banks,

I am writing to you as leaders for learning disability in NHSE – and have also written to the Permanent Secretaries for Health and Social Care and Education.

The CBF is a small, national charity supporting families of children and adults with severe learning disabilities whose behaviour challenges. We provide a range of information and resources for families and prioritise providing individual casework support to families in complex situations. We are uniquely placed therefore to understand the lived experience of those families and their challenges in accessing the right support in the right place at the right time.

The current Coronavirus outbreak has exacerbated an already difficult situation for many of the families we support, and is posing new challenges. With limited capacity we are adjusting how we work whilst trying to ensure that we are available to provide tailored information and guidance to families in need.

I am contacting you to ask for your assurance that this group of individuals and families are on your agenda as a high risk vulnerable group and that you are proactively planning their support and services. Please confirm the following:

1. **That the rights of this group will be protected in the face of the emergency coronavirus Bill.** There is a huge body of evidence demonstrating that removal of health and support systems for this group of children, adults and their families and the reduction of meaningful activities is likely to result in increased challenging behaviour, seriously risking the welfare of vulnerable, children, adults and their families. It is well known that sectioning increases the welfare risks and should be avoided; yet the emergency Bill makes that a more likely outcome for this group. Instead, we propose this should be considered as one of the “indirect impacts” referred to by the Chief Medical Officer, so that maintaining care and support for this group should be prioritised on a par with being able to maintain A&E capacity for those with health needs other than Coronavirus. We cannot overstate how likely it is that children, adults and families risk injury, and extreme measures will result in much greater cost to this vulnerable group and to the state if this is not considered.
2. **That a senior individual with knowledge and skills regarding the support needs of this client group is part of the national strategic response team** to ensure that their needs are

considered, and that key expert groups and families are consulted. If possible, please confirm the name of this individual.

In addition, families have been asking us specific questions about the impact on them. In order for us to answer these queries, please provide the following more specific information:

1. If a child or adult has been assessed as needing 1:1 or 2:1 support in a service, and the service closes and the individual has to return to the family home, how will the 2:1 or 1: 1 support be deployed to support that individual where they are? (For example, if a child has a EHCP that identifies 1:1 support at school, and the school closes and the child is sent home; or a day service where an individual receives 2:1 support closes)
2. It is well established that supporting a child or adult with complex needs whose behaviour is very challenging can be extremely emotionally draining and difficult. What provision will be put in place urgently for providing both practical and emotional support for families?
3. The new emergency measures being brought in allow individuals to be sectioned by one doctor – what safeguards have been put in place to protect the individuals with learning disabilities and/or autism from inappropriate sectioning and detainment in secure hospitals, given the known significant detrimental harm this causes, and the difficulties with discharge meaning the average length of stay remains at over 4 years?
4. There is clear evidence that the health needs of children and adults with learning disabilities are not adequately met. In addition, individuals who display challenging behaviour are at greater risk of having unmet physical health needs and being denied health screening. In view of this, please provide a DHSC / NHSE statement about accessing healthcare for this group of individuals during the Coronavirus pandemic.
5. The individuals who are within the Transforming Care programme currently within inpatient services are at heightened risk. Please provide details of how their health needs will be monitored and met, and what additional scrutiny will be applied to ensure that staffing levels are appropriate, and there is not an increase in the use of restrictive practices and inappropriate medication.

It is important that there is oversight of the “pathway” which the new emergency measures risk increasing: lack of appropriate support under the Care Act, leading to increased likelihood and ease of sectioning under the MHA, and admission to an inappropriate and harmful inpatient services.

These are all key issues for people with learning disabilities and their families. In the current situation **please can you advise who family carers need to contact regarding their support needs in both hospital and community settings**, and what the escalation process is if they do not get an appropriate response?

We look forward to receiving this information so that we can appropriately support and provide information to families at this very difficult time.

You will note that this letter has been sent to NHSE, the Department for Health and Social Care, and the Department for Education, with others copied in- this is because there are multiple responsibilities and accountabilities. We need assurance that all parts of the system are aware of the issues and taking appropriate action, and we are therefore expecting comprehensive responses.

Yours sincerely,

A handwritten signature in black ink that reads "Vivien Cooper". The signature is written in a cursive style with a large initial 'V'.

Vivien Cooper OBE, Chief Executive, Challenging Behaviour Foundation