

Written evidence submitted by Mr Paul Bennett (MRS0256)

My Brother David is 47 years old and has profound and multiple learning disabilities including cerebral palsy and refractory epilepsy. He is nonverbal and is also unable to walk or live independently and resides in a specially adapted bungalow with 3 other adults with similar but unique needs. He requires one to one care 24 hrs a day and this is delivered by a council approved private charity provider. However it does not fall under Independent Living and is classified as residential care thus placing him under the same restrictions as a care home even though it is only a small bungalow and is for younger people. David's epilepsy is severe, he can often have up to 20 tonic clonic seizures a month and is also at risk of status epilepticus and has been under the care of a neurologist at the Walton Centre in Liverpool for his epilepsy treatment and review for the last 20 years.

David is extremely close to all members of his family and always has been, and before lockdown met with myself at my home and with our Mum at her home several times a week and for sleep overs at my home regularly. David has a very social lifestyle going out for meals, walks and to attend music concerts etc with his nominated keyworkers and home visits for sensory activities such as aromatherapy and massages. The main reason for David's social lifestyle in addition to enjoyment is that years of experience has shown us that David's general health and epilepsy control is greatly influenced by the amount of contact he has with his immediate family as he has a very touch sensitive and emotive relationship with us. When David has had to be away from his family even for a week such as holidays or work commitments, he rapidly gets depressed and withdraws from interacting which is known in David's circumstance to result in declining health and increasing seizures.

During this unprecedented pandemic and subsequent lockdown, we have been unable to visit David and vice versa and he is only allowed out to be pushed around the block surrounding his bungalow in his wheelchair once a day with a carer. We as a family have provided David with a tablet so that technology led communication apps can be used to video call him regularly but unfortunately whilst the initial response to this was good it has not been enough and now is not effective as he does not have the understanding that whilst he can see our faces and hear our voice that we are not there in person and subsequently his health is deteriorating and his epilepsy is significantly worsening. David is also unable to comprehend that this will eventually change or even what a virus is and whilst there has been guidance from the government regarding Covid-19 and people with learning disabilities I do not feel that it considers the often complex and unique situation of each individual concerned and subsequent medical and social needs.

As a family we are getting very mixed messages on what is permissible and what is not as we hear of some people being allowed to travel short distances to spend time with family members with learning disabilities whilst maintain safe social distancing measures whilst we have been told that it is not an option based on the same guidance.

We understand as a family the immense pressure the country is under and have all maintained to the restrictions completely but we also realise the impact this is having on our loved ones and in David's particular circumstance the impact on his health that is close to resulting in him requiring increased medical input and potential hospitalisation thus putting unnecessary pressure on our health system and actually placing him in further danger from the virus if he ends up going into hospital.

April 2020