

Matt Hancock MP
Department of Health & Social Care
Ministerial Correspondence and Public Enquiries Unit
39 Victoria Street
London
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24th November 2020

Covid-19 Vaccine Priority and Learning-Disabled Deaths

Dear Mr Hancock,

We are writing to you to urge you to consider who is prioritised for the Covid-19 vaccine when it becomes available.

The impact of Covid-19 on our community has been devastating. The people we support are in the highest risks groups when it comes to the virus, the majority are still shielding, with many falling into the clinically extremely vulnerable group – children, young people and adults.

Whilst we appreciate that information regarding who is prioritised for the vaccine has perhaps been given as an indication at this point, it is extremely alarming to our community that the majority will not be prioritised. Many of them will fall into group 6 which is for high risk adults under 65 but even more concerning is there is no mention here of children and young people with complex health needs. Pneumonia is already the most common cause of death in people with Rett syndrome and others in the learning-disabled community; the risk to children and young people is very significant.

Do we have your assurance that adults, children and young people with complex health needs at increased risk of mortality will be given higher priority than the first list would indicate?

Will carers (paid and unpaid) providing 24/7 care for children, young people and adults in their own homes get counted as 'health and social care workers'?

Last week we heard that Covid deaths for people with learning disability in England are six times the average. The Public Health England review found that those aged 18-34 with a learning disability were 30 times more likely to die with the virus than their counterparts in the general population. Yet where do they feature on the priority list?

Please also consider this in the context of a community where care and support for families fell away completely in March.

- Parents in their 80s caring for adult sons/daughter 24/7 at home without any carers going in.
- Young families at breaking point from trying to care for their child with such complex needs, home school other children and work.
- Parents who were not able to see their sons/daughters in residential settings for months in the first lockdown and are now facing continued separation with the visiting restrictions, creating serious mental health issues for people with learning disabilities and their families.

The learning-disabled community has been continually overlooked in this pandemic. With a vaccine on the horizon, now is the time to put that right and ensure that they are in the first groups do receive it as soon as it is available.

Yours sincerely

Mrs R Jenner, CEO, Rett UK,

Mrs R Stevenson, Executive Director, Reverse Rett

Mr R Kramer, CEO, Sense

Dr James Cusack, CEO of Autistica and Chair of Embracing Complexity

Mrs A Mortensen, CEO, Battens Disease Family Association

CC Helen Whately MP

