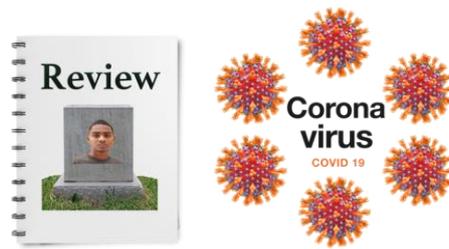


Learning from death during Covid-19



A summary of work so far and recommendations to the Kent and Medway Health and Social Care Systems July 2020



LeDeR stands for Learning Disability Mortality Review.

It is a programme of work that looks at people's whole life after they have died.



We can learn a lot from people, and we want to use the learning to make health and social care better in Kent and Medway.

This report is for everyone so that we all do what we can to make sure people with learning disabilities are treated equally.



At the end of March 2020 Kent and Medway paused Full LeDeR Reviews because of the Covid-19 Pandemic

The Kent and Medway LeDeR did rapid reviews for everyone whose death was reported to the LeDeR Programme.



The Kent and Medway LeDeR Team, people from the Partnership Board, health and social care services looked at what the rapid reviews said and made recommendations in May 2020.



At the start of June 2020, one of the reports was shared publicly by Learning Disability England (LDE)

This was good because it meant that the learning was available to everyone in the country.



Kent Learning Disability Partnership Board

We also shared it with the Learning Disability Partnership Board. You can see the meeting here: https://kentldpb.org.uk/calendar/view_event.php?eid=522



In July Bemix invited self-advocates and people from social care providers to a workshop where we thought about what the report said.

There is a [video](#), and this paper has been made to help people keep something that is written down.



At the workshop we asked three questions. These were:

What you think about what we have found and done so far?

What is helping you now?

What else do you think needs to happen?



Here are the answers from our workshop:

What you think about what we have found out so far?



A person with learning disabilities said:
“It is shocking, felt like people had already decided whether we should live or die. For some people it might feel like it pointless to live.”



Testing is still an issue, especially for people living in supported living.



Support workers are going above and beyond their role to make sure people are cared for and kept safe.

They are also delivering more healthcare assistant tasks to support the NHS to assess clinical need



What is helping you now?

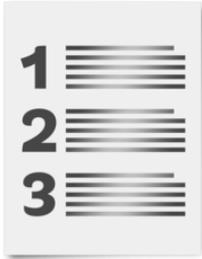


Kent police have been really supportive and have had really good attitudes toward people with learning disabilities and autism during the pandemic.



Paramedics have also been enormously supportive.

We wondered what GPs could learn from the Paramedic model to deliver Primary Care services better.



We said that we think there is a lot to address but we want to use this report to thank everyone for the really great work that they have done.



What else do you think needs to happen?



We need proactive contact that can link clinical support to people who live alone, especially people with learning disability, Autism, and “low level MH need”



An Inquiry

We think an inquiry is needed to look into preparedness, how the pandemic was handled, and look at some of the big decisions that discriminated against people with learning disabilities.



We know this is much bigger than our work but think our local findings should be fed into it. People would like to understand how this works and what information will go toward this.



Commissioning

There needs to be consideration about how we commission as a system to make sure social care providers and clinical staff are equals. This will mean they can work together better to make sure people are protected and supported.



Flu vaccination

We are worried about a 2nd wave of Covid-19 and seasonal flu at the same time. Vaccinations for people with learning disabilities and Care Staff teams needs to be 100%.



GPs need to work with, and trust Social Care providers of residential and supported living to give the vaccination.

System Trust

We think healthcare professionals need to trust people, parents and social care provision and work together so people with learning disabilities get better access to primary care.



This will mean that we can pick up serious health conditions sooner.



This should start with annual health checks and flu vaccinations, with virtual support and clinical partnership from community teams so that people most at risk of illness are seen first if needed.



Track & trace

The reality of how people behave when they are tired and need connection.

We are worried that Support workers might need to isolate for 2 weeks.



We are also worried that people might come into contact with people who are positive and people they support.

This is also worrying because there are still issues in accessing testing for people with learning disabilities in supported living.

Sharing PPE

We talked about a stockpile of uncertificated PPE that has been made available to Kent County Council.



We asked how this can be given to people with learning disabilities and autism who might not have enough money to buy face coverings, and who may experience, or be anxious about experiencing shame if they are not wearing a face covering.

Oximetry

Oximetry is a test that looks at how much Oxygen is in your blood. This shows how well your heart is pumping blood around your body.

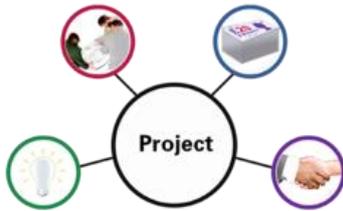


*<https://www.medisave.co.uk/md300d-finger-pulse-oximeter-p-6895.html>

Easy Read information about Oximetry, how to do it, what it means, and what to do is needed, especially for people who live independently.



If this was available we think it could be shared easily through Social Media and by Community and Voluntary sector partners and advocacy groups.



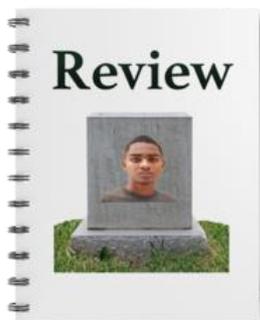
Social care Providers need access to clinical support and a process about who to call and what support there is to understand the readings, Clinical staff need to understand the clues they see and what they might mean about health.

We need to understand how Care Homes are dealing with talking to people with learning disabilities and other people so we can share the good practice



Aloneness

Theme of Aloneness carries on after death as people have been restricted as to how they can access saying goodbye. We think this needs more work.



LeDeR Reviews

People with learning disabilities and Social Care Providers should be involved in making the recommendations and knowing what is learned from these when the project starts.

The LeDeR Reviews need to start again as soon as possible.