COVID-19 INSIGHT

Issue 11

June 2021

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STATE OF CARE

COVID INSIGHT

FOCUS ON OUR WORK TO SUPPORT PEOPLE WITH A LEARNING DISABILITY

Introduction

Support and services for people with a learning disability are often not good enough. For too long, people and their families have faced significant and ongoing challenges in getting care at the right time that meets their individual needs.

We have seen how this can lead to people staying for long periods in inappropriate environments, being cared for by people who do not know them and who do not have the skills or knowledge to support them well.

To further explore people's experiences and how services have worked together for people with a learning disability during the COVID-19 (coronavirus) pandemic, we have carried out a provider collaboration review across seven local areas in England.

Our provider collaboration review on people with a learning disability

Our provider collaboration reviews aim to show the best of innovation across systems under pressure, and to drive system, regional and national learning and improvement.

Through our latest review we have sought to find out more about the care for people with a learning disability who live in the community, and what impact the COVID-19 pandemic has had on them and the services they receive. To do this, we have looked at:

- Whether people with a learning disability still had access to the right care and support when they needed it during the pandemic. This includes how services have collaborated to keep people safe.
- What the impact of the pandemic has been for people living independently in the community. This includes how well services have been planned and delivered to ensure continuity of care.
- How providers have balanced the need to keep staff safe with continuing to provide people with a learning disability with the support they need.
- How digital technology has supported or prevented services from being able to provide people with the care and support they need.

As well as speaking with providers about what they have been doing to meet the needs of people with a learning disability, we wanted to get to the heart of people's experiences.

To do this, we have looked in depth at the experiences of 34 individuals across the seven areas that were the focus of our review. We are also continuing to engage with and hear from people with lived experience and the organisations that represent them.

We are currently reviewing all the evidence we have gathered from our fieldwork. We will publish the findings of our review in July.

What do we know so far?

Many of the issues emerging from our provider collaboration review are not new. In a lot of cases, the pandemic has simply served to shine a light on pre-existing challenges, gaps and poor-quality care.

We have been, and continue to be, clear that there is no one-size fits all to care and support for people with a learning disability – what works for one person does not work for everyone.

But we know that there are some approaches to care delivery that can provide people with the care that they need, in a way that enables them to lead their best lives. For example:

- **Giving people choice, control and independence.** This includes supporting people to live independently or being cared for in the community close to friends, family and support networks, not being isolated in a hospital setting far from home.
- **Access to the right care and support at the right time.** This includes having access to the right health care and support services, including in emergencies and crisis.
- **Collaboration between services, and with the person and their families.** This includes appropriately sharing information about the person such as their likes, dislikes, interests and preferences, as well as information about their health and wellbeing.

Previously, we have voiced our concerns about how well services have worked together, or collaborated, to share information and ensure that people receive the right care at the right time.

In particular, we have highlighted issues with transitioning from the support of children's services to adult services, and how, when things go wrong, people can end up in inappropriate environments.

These continue to be concerns emerging from our provider collaboration review.

But the pandemic has also introduced some new challenges. For example, we know that people with a learning disability have an increased risk of respiratory illnesses and a higher prevalence of asthma, among other health concerns. All of these, amongst other factors, can make them more vulnerable to COVID-19.

In particular, during the pandemic, figures suggest that there has been an increase in deaths of people using services with a learning disability as a result of COVID-19.

In our national report we will be looking to explore what the impact of COVID-19 has been on people with a learning disability living in the community. For example:

- How has the introduction of lockdowns and social distancing affected people's ability to access the care they need, including GPs, dentists, day care and respite care?
- How have people continued to be supported? What impact has this had on their health, wellbeing and safety?
- What impact has the sudden shift to reliance on technology, including video calling, had on people with a learning disability. For example, have they been able and supported to use this? What effect has it had on how providers work together?
- How were people's needs prioritised? For example, were they given access to vaccinations? If so, how were they supported to get vaccinated?

Where possible, we will seek to highlight examples of good practice where partnership working with people and between health and social care has made a difference and improved outcomes for people.

Improving our regulation of services

The findings of this provider collaboration review support our wider ambitions to improve our regulation of services for people with a learning disability and autistic people.

As an organisation, we know that how we regulate the services that care for people with a learning disability and autistic people needs to improve. In response to this, we are carrying out a year-long programme of work to transform the way we regulate services for people with a learning disability and autistic people.

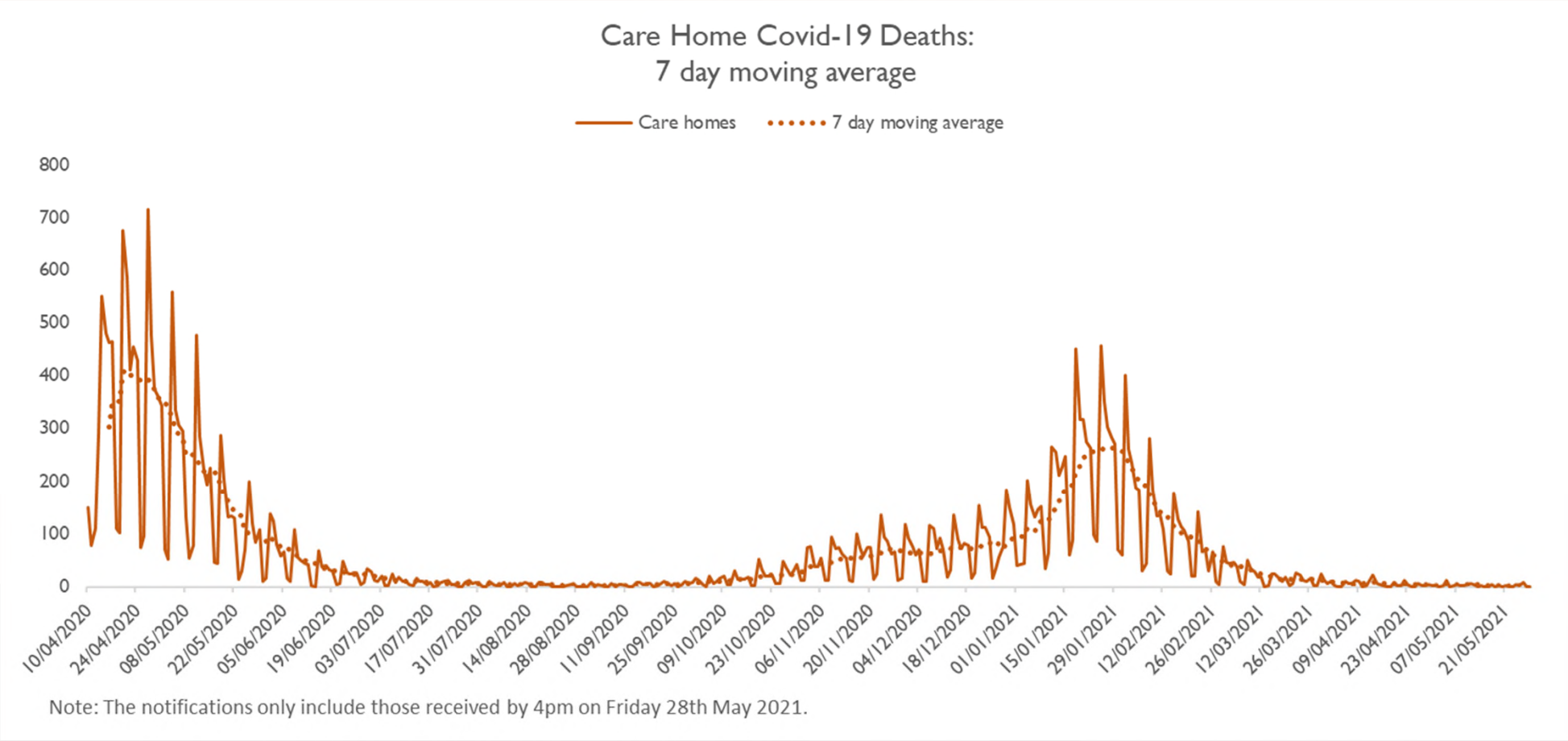
Above all else, we want to make sure that services for people with learning a disability and autistic people are good. To do this, we are focusing on three key areas:

- **Registering the right services** – *I use services that support me in the way I want to live and where I want to live.*
- **Supporting providers to improve** – *I will not be asked to move to a service that isn't safe, I won't be expected to continue to live in a service that doesn't meet my needs.*
- **Influencing the improvement of care pathways and ensuring that people are receiving the right care at the right time** – *I can access local services that meet my needs and get the right healthcare when I need it.*

COVID INSIGHT

DATA APPENDIX

Deaths notified by care homes

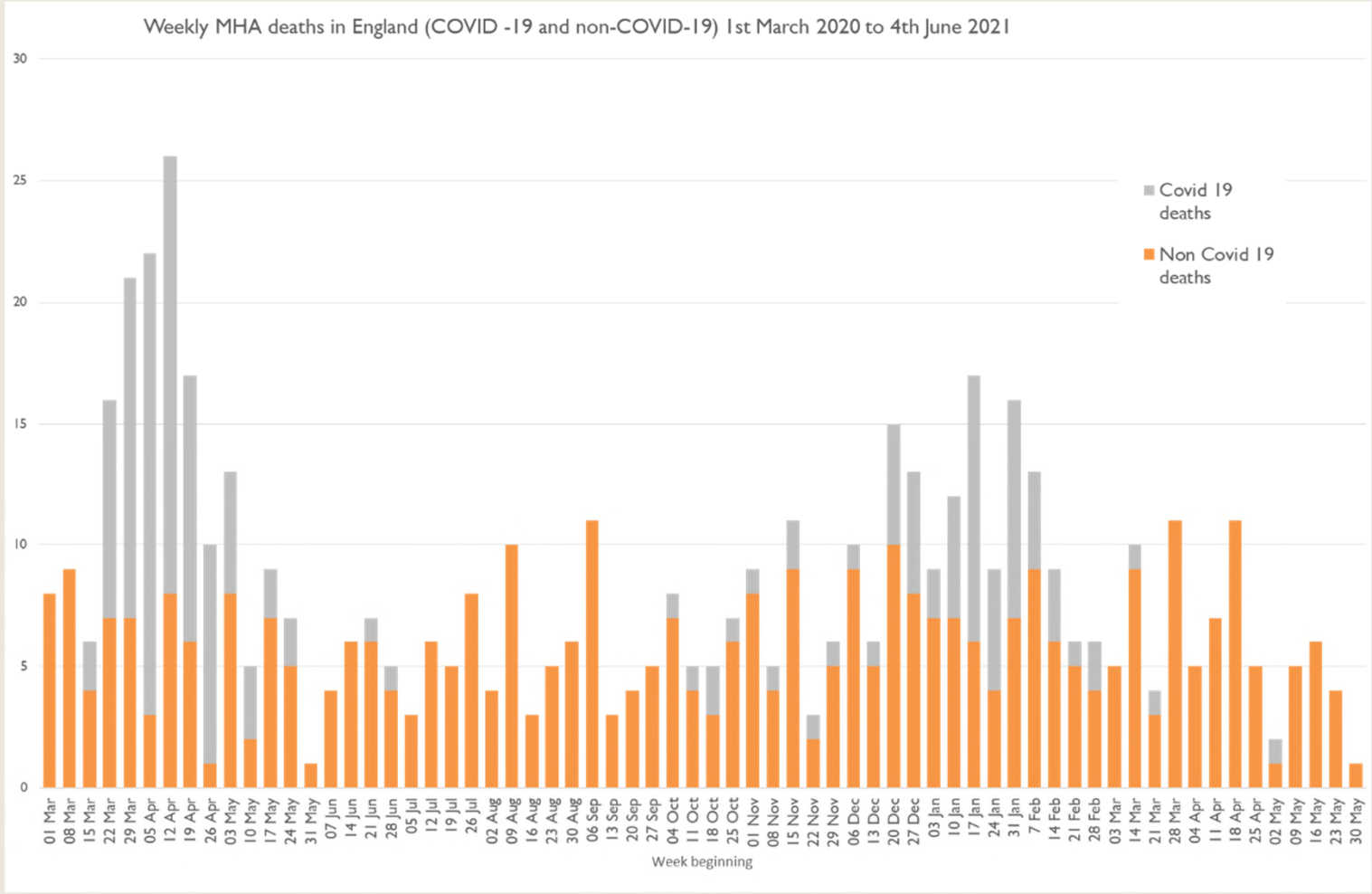


Source: CQC death notifications submitted 10/04/2020 to 28/05/2021

The chart shows the number of death notifications of people in care homes flagged with COVID-19 submitted each day up to 28 May 2021, with a seven-day moving average line showing the smoothed trend. The numbers of deaths appear to have peaked in mid-January and have been steadily falling since then.

Deaths of people detained under the Mental Health Act

All providers registered with CQC must notify us about deaths of people who are detained, or liable to be detained, under the Mental Health Act (MHA).* From 1 March 2020 to 4 June 2021, we have been notified of 166 deaths that mental health providers indicated were suspected or confirmed to be related to COVID-19 (an increase of one since we reported in May). A further eight COVID-19 related deaths of detained patients were reported by other (non-mental health) providers (no further recorded deaths since we last reported).**



* Includes detained patients on leave of absence, or absent without leave, from hospital, and conditionally discharged patients. 'Detained patients' also includes patients subject to holding powers such as s. 4, 5, 135 or 136, and patients recalled to hospital from CTO. These counts may also include notifications about the deaths of people subject to the MHA who are in the community and not in hospital.

** Data on notifications may be updated over time and therefore successive extracts may lead to changes in overall numbers unrelated to new cases. The chart shows the number of deaths by week of death.

Deaths of people detained under the Mental Health Act (cont.)

Of the 557 notifications from mental health providers in the 2020/21 period (covering all causes of death from 1 March 2020 to 4 June 2021), 448 were from NHS organisations, of which 125 deaths were indicated as being COVID-19-related, and 109 were from independent providers, of which 41 deaths were COVID-19-related.

We have identified 33 detained patients whose deaths have been notified to us from 1 March to 4 June 2021 who had a learning disability and/or were autistic: the majority (22) were not identified as related to confirmed or suspected COVID-19. Of these people, most also had a mental health diagnosis. Please note that these patients were identified both from a specific box being ticked on the notification form and a review of diagnoses in the free text of the form.

The table below shows all deaths of detained patients from 1 March to 4 June 2021, by age band and COVID-19 status.

Age band	16-17	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Unknown	Total
Suspected or confirmed COVID-19		1	4	8	11	29	39	48	22	12	174
Not COVID-19	4	18	42	37	50	66	68	62	19	51	417
Total	**4**	**19**	**46**	**45**	**61**	**95**	**107**	**110**	**41**	**63**	**591**

Deaths of people detained under the Mental Health Act (cont.)

The table below shows all deaths of detained patients from 1 March 2020 to 4 June 2021, by gender and COVID-19 status.

Gender	Female	Male	Transgender	Unknown or unspecified	Total
Suspected or confirmed COVID-19	55	105		14	174
Not COVID-19	128	235	1	53	417
Total	**183**	**340**	**1**	**67**	**591**

Deaths of people detained under the Mental Health Act (cont.)

The table below shows all deaths of detained patients from 1 March 2020 to 4 June 2021, by ethnicity and COVID-19 status.

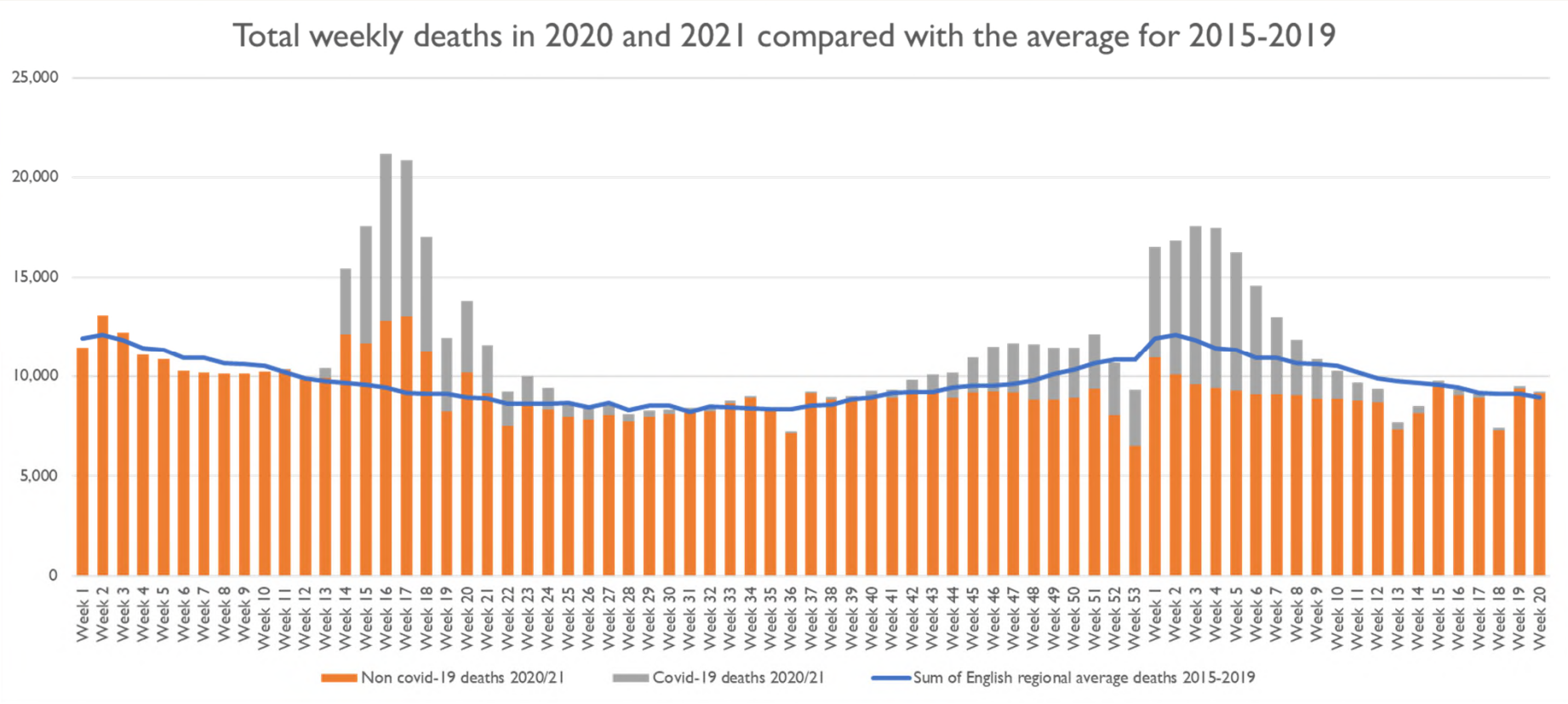
Ethnicity	Suspected or confirmed COVID-19	Not COVID-19
Asian	7	9
Black	21	30
Mixed	7	8
Other ethnic groups	1	3
White	98	235
Unknown	22	39
Not stated	18	93
Total	174	417

Deaths of people detained under the Mental Health Act (cont.)

The table below shows all deaths of detained patients from 1 March 2020 to 4 June 2021 by place of death and COVID-19 status.

Place of death	Suspected or confirmed COVID-19	Not COVID-19
Medical ward	119	132
Psychiatric ward	40	131
Hospital grounds	1	7
Patient's home	0	37
Public place	0	8
Other household	0	3
Other	3	52
Not stated	11	47
Total	174	417

ONS data on all weekly deaths in England (COVID and non-COVID) compared with the average for 2015-2019



Source: ONS COVID/non-COVID 2020 and 2021 death data:
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/datasets/deathregistrationsandoccurrencesbylocalauthorityandhealthboard
and 2015-2019 death data from:
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/11674fiveyearaverageweeklydeathsforenglishregionsandwalesdeathsthatoccurredbetween2015and2019
Week 20, 2021: week ending 28 May 2021