



INTERNATIONAL
LONG TERM CARE
POLICY NETWORK

The impact of COVID-19 on long-term care in Sweden

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Last updated 22 July 2020

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ltccovid.org

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Suggested citation

Szebehely M (2020) *The impact of COVID-19 on long-term care in Sweden*. LTCcovid.org, Long-Term Care Policy Network, CPEC-LSE, 22 July 2020.

1. Key points

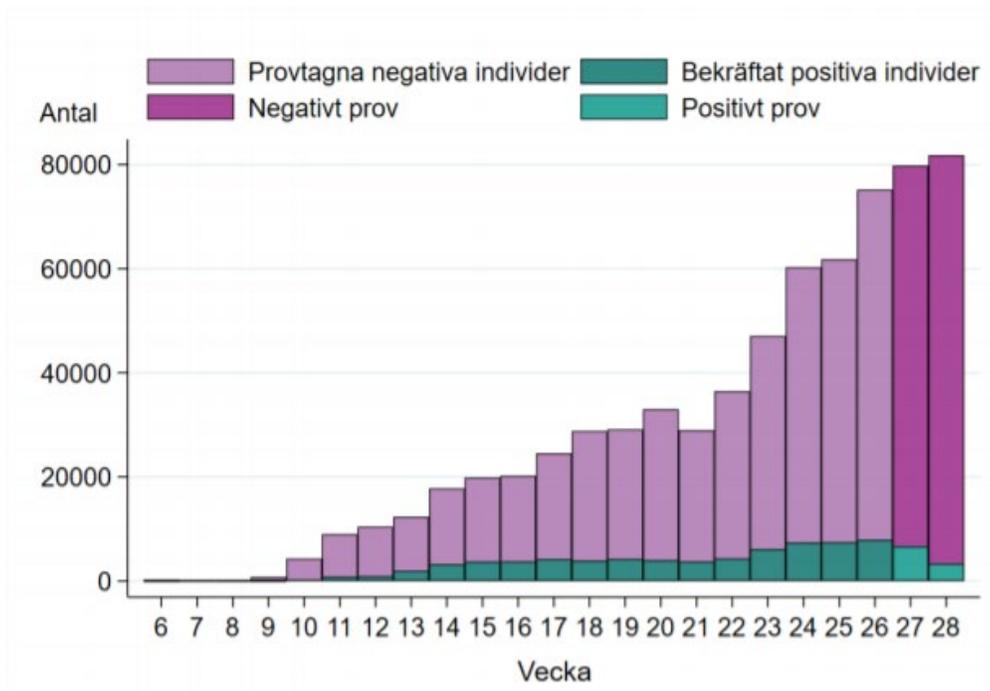
- Sweden has been badly hit by the COVID-19 pandemic. In mid-July, more than 5,500 individuals had died from the infection, corresponding to around 550 deaths per million inhabitants. While there was a clear excess mortality in April and May, since June the death rates in Sweden are back to normal.
- Of those who have died of COVID-19, 47 per cent were care home residents and 25 per cent were homecare users, corresponding to 3.1 per cent of all care home residents and 0.8 per cent of all homecare users.
- The regional differences are striking: in the Stockholm region, 7 per cent of the care home residents have died while there have been hardly any COVID-19 deaths in care homes in several other regions.
- Sweden has a tradition of voluntary measures on infection control based on recommendations, with an emphasis on individual responsibility. During the pandemic, the authorities' recommendations to stay at home when sick, to wash hands frequently, to keep physical distance and to limit travelling have largely been adhered to.
- To avoid people going to work when sick with mild symptoms, on March 11 the government introduced pay also for the first day of sick leave (normally in Sweden, sickness benefit is paid only from the second day).
- In the management of the pandemic in the LTC-sector, a combination of recommendations and legally binding rules have been applied including a ban on care home visits (from April 1).
- According to a survey of care home managers in mid-April, the infection probably entered care homes through residents returning from hospital, family visiting (before banning visits) and infected but asymptomatic staff.
- Once the infection got into a care home, the managers reported difficulties in restricting the spread because of staff shortages, a scarcity of testing equipment and Personal Protection Equipment and the physical layout of the homes with limited possibilities to stop infected residents with dementia from moving around and meeting with other residents.
- One quarter of the care workforce are employed by the hour, and in the beginning of the pandemic, staff shortages due to ordinary workers being on sick leave or in self-isolation, led to an even higher use of casual workers, with less or no formal training. As problems following hygiene routines were reported, a national e-training program focusing on hygiene was developed early on and has been completed by more than 140,000 care workers.
- The government has appointed a commission to investigate the Swedish COVID-19 strategy. One of the tasks for the commission is to investigate the recommendations and actual measures taken to limit the spread of infection in eldercare services and to evaluate whether problems in work organisation, working environment and employment conditions, have contributed to the many cases of death in the sector.

2. Impact of COVID19 on long-term care users so far

2.1. Number of positive cases in population and deaths

Until the last month, comparatively few individuals have been tested in Sweden (see figure 1). Up until week 28, in total 680,000 individuals have been tested and of these there have been 75 488 positive cases in Sweden.

Figure 1. Testing for COVID-19. Number of tests per week, negative and confirmed positive.¹

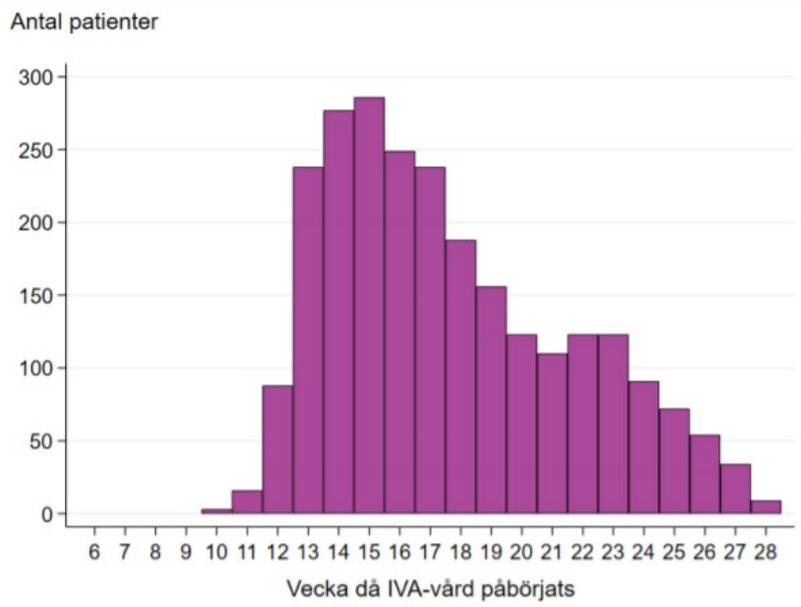


Purple: Tested individuals, negative (week 6-26); number of tests, negative (week 27-28). Green: Tested individuals, positive (week 6-26); number of tests, positive (week 27-28).

Of the confirmed positive cases, the proportion seriously ill has declined considerably as has the number of patients in intensive care, see Figure 2.

¹ [Weekly report](#) week 28 on covid19 from the Public Health Agency, published July 17.

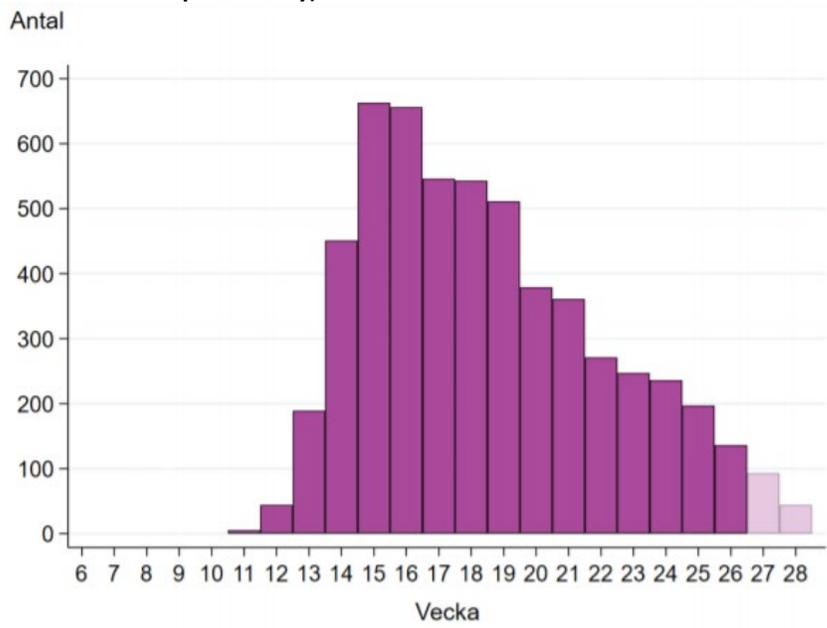
Figure 2. Number of patients with COVID-19 in intensive care, new cases per week. ¹



In total, 2,478 individuals with COVID-19 have been in cared for in intensive care (until end of week 28).

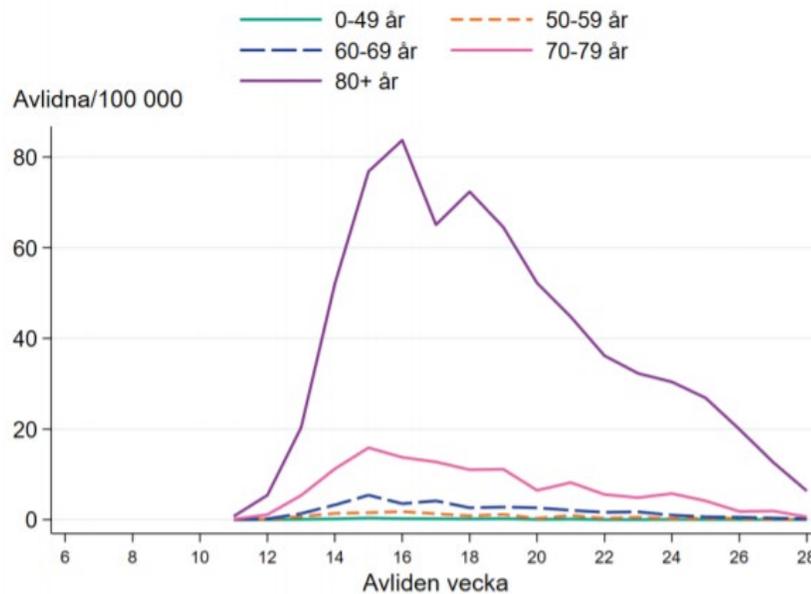
There is a similar declining pattern in the COVID-19 related death statistics, see Figure 3.

Figure 3. Number of deceased individuals with a positive COVID-19 test. Per week (note that the statistics for the last two weeks are preliminary).¹



As in most countries, the oldest age groups are most affected, see Figure 4.

Figure 4. Number of deceased individuals with a positive COVID-19 test per 100,000 in population. Per week, by age.¹



There are two sources for information on COVID-19 related death in Sweden. One source, used by the Public Health Agency, reports all individuals who have died within 30 days after a laboratory-confirmed test of COVID-19 (PCR test). This is the source for Figures 3 and 4. The other source, used by the National Board of Health and Welfare, reports all individuals where death has been caused by COVID-19 according to the death certificate. There is more than a 90 per cent overlap between the two sources, but some individuals with a positive test may have died of other causes, and some individuals where the death certificate reports COVID-19 as cause of death, may not have been tested or may have shown a negative test result.

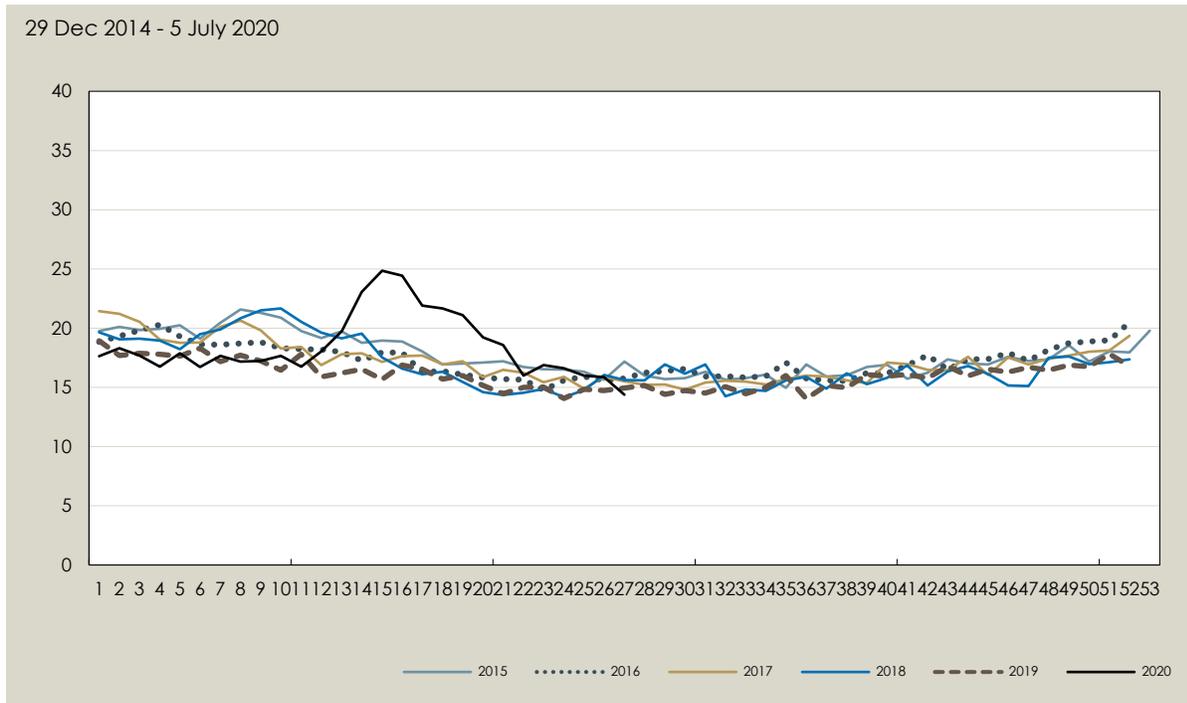
Up to July 13, the Public Health Agency reported the death of in total 5,572 individuals with a positive Covid-19 test² and on the same date, the National Board of Health and Welfare reported 5,428 individuals³. Both sources report that around 90% of those who have died were 70 years+. In relation to the population in Sweden (10,102,000), the total incidence is 551 cases per million inhabitants.

A third source of information reports the excess mortality (all-cause mortality) per week in 2020 compared to the years 2015-2019, see Figure 5. While there was a clear excess mortality in April and May, since June the death rates in Sweden are back to normal.

² <https://experience.arcgis.com/experience/09f821667ce64bf7be6f9f87457ed9aa> (visited July 17)

³ <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-over-antal-avlidna-i-covid-19/> (published July 14, visited July 17)

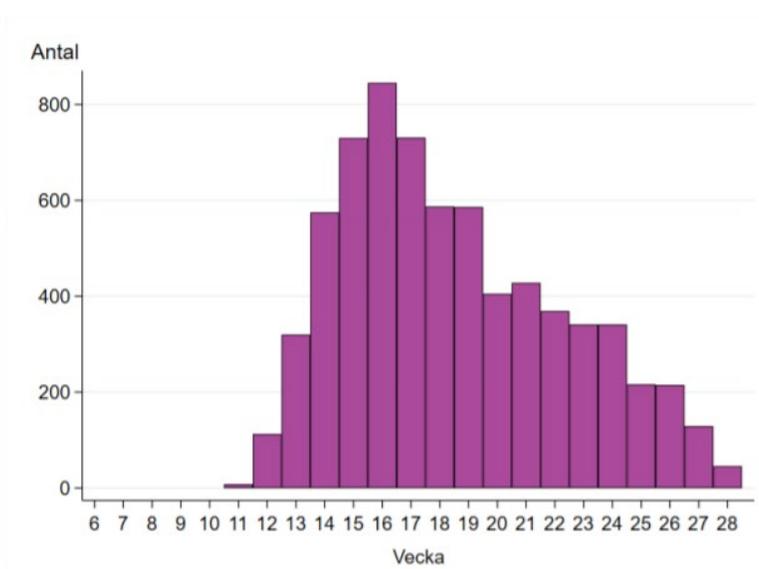
Figure 5. All-cause mortality per week 2015-2020, cases per 100,000 in population⁴



2.2. Rates of infection and mortality among long-term care users and staff

Care homes in Sweden have been badly affected by the pandemic.

Figure 6. Care home residents, number of cases with positive test.¹



⁴ <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-relaterad-till-covid-19/> (visited July 17)

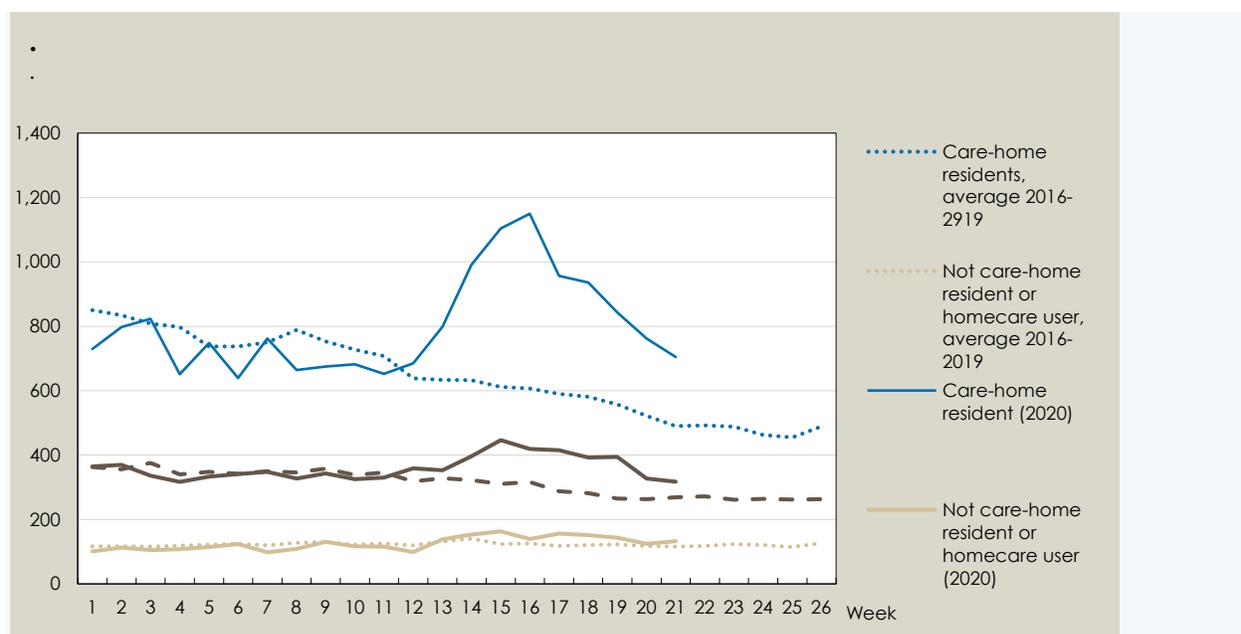
In total, there have been 6,985 residents with confirmed COVID-19 infection in Swedish care homes, corresponding to 9 per cent of all confirmed cases.¹

As care-home residents are much frailer than the general population, a much higher proportion of the residents with an infection have died. Of the 5,500 individuals who, according to the death certificate, had died of COVID-19 by July 20, 47 per cent (2,584 individuals) were care-home residents.⁵

Comparing this to the number of care-home residents in Sweden (82,217)⁶, suggests that 3.1 per cent of the residents have died of COVID-19. Another 25 per cent of all COVID-19 deaths have occurred among homecare recipients (1,399 individuals), corresponding to 0.8 per cent of all homecare recipients (172,790).⁷

The excess mortality among the population 70 years and older with and without eldercare services until week 21 (May 24) is reported in Figure 7.

Figure 7. All-cause mortality per week, cases per 100,000 (70 years+) among care-home residents, homecare recipients, respectively. The year 2020 compared to the average 2016-2019. Age- and sex-standardised figures.⁸



⁵ <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-over-antal-avlidna-i-covid-19/> (published July 21, visited July 22).

⁶ Bilaga – Tabeller – Socialtjänstinsatser till äldre 2019 <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistikamnen/socialtjanstinsatser-till-aldre/> (published April 28, visited July 17).

⁷ Calculated from the sources in footnote 5 and 6.

⁸ From Figure 8, in Statistik över dödlighet bland äldre med särskilt boende eller hemtjänst, <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-relaterad-till-covid-19/> (Published July 15, visited July 20)

As the graph shows, mortality is clearly higher among care home residents than among homecare recipients, which in turn is higher than among older people in the same age group living at home and not receiving home care. This is the case both under normal circumstances and during the pandemic, but as the graph shows, care-home residents have been particularly badly affected during the pandemic.

There is no national (publicly available) information on infection rates or death in particular care homes, but in mid-April, Dagens Nyheter, the biggest newspaper in Sweden, administered a survey to the regions in Sweden. Of the 21 regions, 15 responded to the survey. Altogether, infections were reported in 510 out of 2,040 care homes in these regions. In the Stockholm Region, two thirds of the long-term care homes had infected residents, compared to 18 per cent in the rest of Sweden.⁹ As of the July 20 fewer homes have infected residents, for example the Stockholm Region reported that less than 5 per cent of the homes had resident(s) with an infection.¹⁰

National statistics on infections and death rates in specific care homes is still missing, but there is information on the situation in municipalities and regions. The pandemic has hit different parts of Sweden very unevenly, both in the general population and in care homes. The Stockholm region was most affected in the beginning, at least partly because the region had a school holiday in week 9, and very large numbers of people were travelling abroad in that week. The population in the region corresponds to 23 per cent of the population in Sweden, but 41 per cent of the COVID-19 deaths have occurred in the region. There is a similar but even stronger pattern regarding death in care homes: while 18 per cent of the care home beds in Sweden are located in the Stockholm region, 41 per cent of care home residents who have died in COVID-19 are from the region. In relation to the care home population, 7.0 per cent of the care home residents in the Stockholm region have died in COVID-19 compared to 2.2 per cent of the care home residents in the rest of the country. In some regions, hardly any care home residents have died of COVID-19.¹¹

2.3. Population level measures to contain spread of COVID-19

The overall strategy to combat COVID-19 in Sweden has been to minimise mortality and morbidity in the entire population and to mitigate other health threats caused by the measures to combat the pandemic. Swedish public health work is based on a strong tradition of voluntary measures with an emphasis on individual responsibility, and in the management of the pandemic, a combination of legally binding rules and recommendations is applied.¹²

⁹ Dagens Nyheter, May 3, <https://www.dn.se/nyheter/sverige/coronasmitta-pa-over-500-av-landets-aldreboenden/>

¹⁰ <https://www.sll.se/verksamhet/halsa-och-varld/nyheter-halsa-och-varld/2020/07/20-juli-lagesrapport-om-arbetet-med-det-nya-coronaviruset/> (published July 20, visited July 22).

¹¹ Calculated from the references in footnote 5 and 6 plus population statistics.

¹² For the recommendations in English, see <https://www.folkhalsomyndigheten.se/the-public-health-agency-of-sweden/communicable-disease-control/protect-yourself-and-others-from-spread-of-infection/> and for information on the Swedish approach to the pandemic, see <https://www.folkhalsomyndigheten.se/the-public-health-agency-of-sweden/communicable-disease-control/the-public-health-agency-of-swedens-work-with-covid-19/> and

From the very beginning the same recommendations focusing on physical distancing and hygiene routines have been stressed: to stay at home when ill, even with the slightest symptom of an infection and for two more days; to work from home if possible; to avoid unnecessary traveling; to keep physical distance both outdoors and indoors and to wash hands frequently for at least 20 seconds. Specific risk groups, including those aged 70 and over, have been told to avoid all close contacts and not to visit places where many people gather like shops, cafés and public transport. The recommendations have largely been adhered to, which is reflected in the seasonal influenza and winter vomiting disease ending much earlier than normal.

Examples of legally binding rules include a ban on public gatherings with more than 50 participants, a shift to distance learning in secondary education and universities and a ban of visiting care homes. Pre-schools and primary schools have been open all the time. Cafés and restaurants have also stayed open but only serving at the table is allowed, and there has to be at least one meter between tables. The cafés and restaurants are regularly inspected and closed if distance is not being kept between customers.

Normally in Sweden, sickness benefit is paid from the second day of a period of illness. In order to facilitate for people to stay at home (without loss of income) when potentially having COVID-19, the government decided on March 11 that the state covers pay for the first day.¹³

3. Brief background to the long-term care system

Of the 2 million inhabitants aged over 65 years in Sweden, 82,217 (4 per cent) live in a care home. There has been a sharp decline in care home coverage, from 20 per cent of the population aged over 80 years in 2000 to 12 per cent in 2019. Consequently, care home residents are increasingly older and frailer. The average age of a person moving to a care home is 86 years, 78 per cent of the residents are 80 years or older, and at least 70 per cent have dementia. On average, a resident lives 22 months in a care home and 20 per cent die within six months of moving in.

There are approximately 200,000 care workers (assistant nurses and care aides) and 17,000 registered nurses in social care; around 60 per cent work in care homes. Approximately 25 per cent of LTC workers (in care homes and in homecare) are employed by the hour, and one in five care workers in care homes lack formal training. Staffing levels are comparatively high, but with fewer registered nurses and medical doctors than in some other countries. On average, there are three care workers and 0.4 registered nurses per ten residents in a care home.¹⁴

<https://www.folkhalsomyndigheten.se/the-public-health-agency-of-sweden/communicable-disease-control/covid-19--the-swedish-strategy/> (Published June 12; visited July 19).

¹³ <https://www.regeringen.se/regeringens-politik/socialforsakringar/atgarder-inom-sjukforsakringen-med-anledning-av-corona/>

¹⁴ Stranz A & Szebehely M (2018) Organizational trends impacting on everyday realities: the case of Swedish eldercare. In: Christensen K & Pilling D, Eds. *The Routledge Handbook of Social Care Work Around the World*. Routledge International Handbooks.

Care work is a demanding occupation around the world, and this is the case also in Sweden. Physical load injuries are three times more common in LTC than the average in the labour market. Occupational disease due to social and organisational causes have increased by over 70 per cent between 2010 and 2014 and female LTC workers have 50 per cent more sick days than women in the rest of the workforce (ibid.).

LTC in Sweden, as in many countries, has been affected by financial cutbacks and New Public Management inspired organisational changes. This has had negative consequences for care workers' working conditions and for their possibilities to meet the increasing needs of care users. Time pressure has increased, care workers are increasingly working in under-staffed conditions, and their job autonomy and time for support from colleagues and managers has decreased. Care workers find their jobs increasingly physically and mentally demanding and an increasing proportion want to quit their job.¹⁵

An inspection of more than 1,000 LTC units by the Swedish Work Environment Authority in 2017-2019 found health and safety deviations in almost 90 per cent of the cases.¹⁶

Regular inspections of how the mandatory hygiene routines are followed in health and social care show that the compliance with the routines is much lower in LTC than in hospitals. In one third of the situations inspected, there were deviations from the routines, especially among care workers with no or shorter formal training.¹⁷

4. Long-term care policy and practice measures

4.1. Whole sector measures

Since the beginning of the pandemic, Swedish authorities and politicians stressed the importance of protecting older people. However, no specific attention was paid to care home residents or homecare users; the initial focus was to limit the spread of the infection in the community and to ensure access to health care, especially intensive care.

The responsibility to restrict spreading of any disease in care homes and other forms of social care services rests with the municipalities together with the regional infection control units (Smittskydd). During the entire pandemic, this local/regional responsibility has been stressed by the Public Health Agency and the National Board of Health and Welfare. The latter has mainly acted by providing recommendations and check-lists, and by presenting good examples. An e-training program focusing on hygiene was developed early on and has been followed by

¹⁵ Ibid.; Strandell R (2020) Care workers under pressure – A comparison of the work situation in Swedish home care 2005 and 2015, *Health and Social Care in the Community*, 28 (1) 137-147. <https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12848>

¹⁶ <https://www.av.se/globalassets/filer/publikationer/rapporter/2018-007023-projektrapport-aldreomsorgen-2017-2019.pdf>

¹⁷ <https://skr.se/halsasjukvard/patientsakerhet/matningavskadorivarden/matningbasalahygienerutiner/resultatmatningbkh.2277.html>

143,000 health and social care workers.¹⁸ The Board has also produced information material for staff in care homes and homecare services in several languages.¹⁹

As the large proportion of casual and untrained care workers in the eldercare sector has been seen as contributing to the spreading of the disease, the government also initiated a training program for 10,000 temporary employed care workers with limited or no formal training. The state will cover the expenses for the municipalities and the workers will keep their ordinary pay while they study to become care aides or assistant nurses. To be eligible for the state subsidy, the municipalities have to offer a permanent position to workers who successfully have finished the course.²⁰

During the first month, there was a scarcity of PPE in Sweden in general and in LTC in particular. Volunteers were producing shields of overhead sheets and aprons of plastic for eldercare workers and initially also for health care professionals.

The national authorities' main recommendation to avoid spreading the virus in LTC was to follow the legislation on basic hygiene routines (to wash hands and use sanitizer in all situations involving personal care); a responsibility that these routines are followed rests with the employer. The care workers' union Kommunal demanded proper facemasks for all care workers in care homes and homecare when providing personal care to care recipients with suspected or confirmed COVID-19 infection, but the authorities argued that this should be decided at the local level, depending on the situation.²¹

The Public Health Agency did not mention the use of facemasks and shields in eldercare services until May 7 when a document that gave some support for the use of masks and shields was published. However, the document stressed that it was most important to follow the legislation on basic hygiene, and whether to use masks and/or shields was still left to the local care home or home-care unit to decide together with the regional infection control units.²² Only much later, on June 25, the Public Health Agency recommended the use of shields and facemask in personal care of all care recipients with suspected or confirmed COVID-19.²³

There was also a scarcity of testing kits in the beginning of the pandemic. During the most critical period (April) care home residents, homecare users and eldercare staff were not

¹⁸ <https://www.socialstyrelsen.se/en/about-us/emergency-preparedness/the-role-of-the-national-board-of-health-and-welfare-during-the-covid-19-response-in-sweden/> (Director-general Olivia Wigzell presenting Swedish strategy to protect older people, published June 12, visited July 20).

¹⁹ The English version of the information leaflet for care-home workers: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/affisch-aldreboende-engelska-covid19.pdf>

²⁰ <https://www.regeringen.se/pressmeddelanden/2020/05/nya-atgarder-for-att-starka-aldreomsorgen-och-varden-under-coronakrisen/>

²¹ <https://ka.se/2020/04/17/kommunal-kraver-andningsskydd/>

²² <https://www.folkhalsomyndigheten.se/nyheter-och-press/nyhetsarkiv/2020/maj/grundlaggande-hygienerutiner-viktigast-for-att-sk-ydda-aldre-inom-omsorgen/>

²³ Since the beginning of the pandemic, Swedish authorities and politicians stressed the importance of protecting older people. However, no specific attention was paid to care-home residents or homecare users; the initial focus was to limit the spread of the infection and to ensure access to health care, especially intensive care.

prioritised for testing. More recently, when the capacity for testing has increased, residents and care workers are being tested without limitations.

When it became obvious in mid-April that the care homes were badly affected by the pandemic, the Government appointed the Health and Social Care Inspectorate (IVO) to conduct a large-scale inspection in care homes and other care units for older and disabled people. The aim of the inspections was to investigate the consequences of COVID-19 for quality and safety in the care services.²⁴

The following month, IVO inspected around 1,000 care units (of which 500 were care homes) and found deviances, particularly regarding hygiene routines, in 10 per cent of the units. These homes are now followed up with further inspections.²⁵

Partly as a result of these inspections, and partly as a result of complaints by staff and family members, IVO also initiated an inspection of 1,700 care homes with a focus on how medical assessments have been made under the pandemic. On July 7, a first report was published (ibid.) showing that in many cases, the homes had not have enough contact with medical doctors, and more than one third of the homes reported lacking preconditions to provide individual assessment and treatment for residents with COVID-19. According to media reports, in some homes palliative care had been initiated on a routine basis instead of considering admitting residents to hospital care. In 91 of the homes, the Inspectorate found more serious deviances and risks. These are now followed up by further interviews and document analysis (ibid.).

4.2. Care homes (including supported living, residential and nursing homes, skilled nursing facilities)

4.2.1. Prevention of COVID19 infections

The first national regulation for care homes were presented on April 1 when the government introduced a ban on visiting in care homes (the most affected Stockholm Region had introduced a similar ban two weeks earlier).

As the high proportion of casual workers in the eldercare sector was seen as posing a risk for spreading the infection, several municipalities decided to employ these workers on a more stable basis so that they could stay at home without loss of income when potentially infected (see also footnote 10).

According to a survey of care homes in the Stockholm Region conducted in April, the managers believed that the infection had entered the homes in several ways: by residents returning from hospital, by family visiting (before banning visits) and by infected but asymptomatic staff

²⁴ <https://www.regeringen.se/pressmeddelanden/2020/04/uppdrag-att-analysera-risker-inom-varld-och-omsorg-till-foljd-av-covid19/> Published April 17

²⁵ <https://www.ivo.se/globalassets/dokument/nyheter/2020/presskonferens-2020-07-07-presentation-ver-3.pdf>

working in the care homes. According to the survey, homes with residents with infection had more casual workers than homes without infection.²⁶

4.2.2. Controlling spread once infection is suspected or has entered a facility

Once the virus has entered the home, most managers in the survey mentioned above, reported difficulties in restricting the spread because of the physical layout of the homes, staff shortages due to workers being on sick leave and in self-isolation. This led to an increased use of casual workers, with less or no formal training. There have also been difficulties following hygiene routines, a shortage of PPE and difficulties stopping residents with dementia and mild symptoms moving around and meeting with other residents.²⁷ In a document based on the survey, published May 7, the Public Health Agency recommended that if possible, residents should be divided into infected and non-infected residents, and recommended that staff should not move between the two groups.²⁸

4.2.3. Managing staff availability and wellbeing

In the same document, the Public Health Agency stressed that care home managers are responsible to make sure that staff stay at home when sick, even with very mild symptoms and to ensure that staff have adequate knowledge and equipment to follow basic hygiene routines, to organise the work so that each member of staff cares for a limited number of residents and that staff keep distance away from each other.

More recently, the impact of psychological stress and the need for support for health care professionals has been acknowledged, and employers now offer additional support services for health care professionals. This has not generally been extended to care workers; the needs of care workers in care homes and other social care services have not been acknowledged or highlighted to the same extent.

5. Lessons learnt so far

Sweden has been comparatively badly hit by the pandemic and as in most other countries older people in care homes have been most affected. However, while Sweden has used more voluntary measures, the aim has been the same as in other countries: to slow down the spread of the infection and to protect those most at risk. There is a consensus in Sweden that this strategy has failed when it comes to the care-home residents.

The high number of COVID-19 deaths in Swedish care homes is one of the tasks to be investigated by a government commission that was appointed June 30. The commission is to evaluate the Swedish strategy in general and more specifically to analyze the situation in the

²⁶ <https://www.sll.se/globalassets/bilagor-till-nyheter/2020/05/kartlaggning-av-covid-19-pa-sabo-i-stockholms-lan.pdf> (published May 4)

²⁷ <https://www.sll.se/nyheter-stockholms-lans-landsting/2020/05/kunskaper-fran-enkat-ska-minska-smittspridning-pa-aldreboenden/>

²⁸ <https://www.folkhalsomyndigheten.se/nyheter-och-press/nyhetsarkiv/2020/maj/grundlaggande-hygienerutiner-viktigast-for-att-skydda-aldre-inom-omsorgen/>

eldercare sector. A first report on care homes and the homecare services is to be published November 30, 2020.

The commission has been asked to evaluate the recommendations and actual measures taken at national, regional and local level to limit the spread of infection in eldercare services. It is also asked to assess whether there are structural factors behind the situation and “to evaluate whether there are shortcomings in training level and skills, work organisation, working environment and employment conditions that may have hampered the ability to handle the spread of the infection” (from the instructions to the commission).²⁹

COVID-19 has exposed shortcomings in the care sector that care researchers have been stressing for several decades. The care workforce, with a high proportion of casual workers and increasingly arduous working conditions, is not well prepared to handle a pandemic. The fact that the authorities initially did not pay any attention to the eldercare sector exacerbated the situation. In recent months, both media and politicians have focused more on the eldercare sector than for many years, and at least at the rhetorical level there seems to be a consensus on the need for improved employment and working conditions for care workers. Whether this will lead to actual improvements is still to be seen, but it is a promising sign that the commission is to investigate structural factors behind the high number of COVID-19 deaths among care-home residents and homecare users.

²⁹ <https://www.regeringen.se/rattsliga-dokument/kommittedirektiv/2020/06/dir.-202074/>